



Report of the first Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) Planning Meeting

working together...improving outcomes...sustaining hope
for adult and pediatric brain tumour patients in
central, south, east and west Africa



18th - 20th October 2017

The Tower Hotel, London, United Kingdom

GREATER COLLABORATION ■ GREATER KNOWLEDGE ■ GREATER HOPE

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Variations in Spelling

Spelling in this publication varies according to country-specific practices and is thus variable throughout the report. For example, ‘tumor’ is spelled without a “u” in the United States but as ‘tumour’ in the United Kingdom and other countries. Sometimes the term ‘neuro-oncology’ is expressed with a hyphen and at other times without a hyphen. To preserve the international nature of this publication, the S-SANOC organisers have decided to vary the spelling accordingly.

Acknowledgements and Sponsors

The Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) Planning Meeting was held in association with:



in association with Mark Bernstein, Greg Wilkins-Barrick Chair in International Surgery, University Health Network, University of Toronto, Canada

With appreciation to the organizing committee for the S-SANOC meeting:

Kathy Oliver (United Kingdom), Christine Mungoshi (Zimbabwe), Gordon Oliver (United Kingdom)
Mark Bernstein (Canada), Gelareh Zadeh (Canada), Linda Greer (United States),
Chas Haynes (United States), Jason Huse (United States), Ken Aldape (Canada)

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In addition...

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Many thanks also to The Tower Hotel, for their help with our accommodation and conference arrangements.

The Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) Planning Meeting, a project of the International Brain Tumour Alliance (IBTA) in association with the Society for Neuro-Oncology (SNO) and the Zimbabwe Brain Tumour Association (ZBTA), was a wholly independent activity and was conceived, planned and carried out by the IBTA, SNO and ZBTA. The content of the S-SANOC meeting was not based on any specific treatment or therapy and full content and editorial control remained with the organisers. For details of the IBTA's sponsorship and transparency policies, please see www.theibta.org

Introduction

Dear Friends,

On 18th and 19th October 2017, we were delighted to welcome 33 participants from 16 countries to the first-ever Sub-Saharan Africa Neuro-Oncology Collaborative (“S-SANOC”) planning meeting in London, UK.

The vision for this innovative meeting was to bring together key stakeholders in sub-Saharan Africa to discuss the challenges and potential solutions for the treatment, care and support of brain tumour patients and their families in this part of the world.

The meeting was an opportunity to share knowledge and experience of sub-Saharan countries, and to identify key priorities and requirements for better outcomes for brain tumour patients.

The practical goals of the meeting were to:

- **organize a neuro-oncology educational course/conference in sub-Saharan Africa in 2018**
- **actively involve the sub-Saharan patient advocacy community in enhanced efforts to raise awareness of the challenges of brain tumours**
- **start building the foundations for a Sub-Saharan Africa multi-stakeholder neuro-oncology society.**

Within this comprehensive report are inspirational stories of efforts by healthcare professionals, patient advocates and others working tirelessly and selflessly in sub-Saharan Africa. It became apparent very quickly during the S-SANOC meeting that the challenges are, in many cases, monumental and the resources with which to meet them are few. The meeting also laid bare in moving testimonies from brain tumour patients and former caregivers the everyday significant struggles for people in this part of the world when diagnosed with a brain tumour.

And yet, despite the inequities and huge unmet need, the S-SANOC meeting pulsed with positivity, determination, hope and the promise of better things to come for brain tumour patients and their families in sub-Saharan Africa.

There is much to do, but the S-SANOC meeting was a vital start. Its overwhelming message was that, working collaboratively and with one voice, barriers can be broken down, the impossible may become the possible and dreams may turn into realities for those whose lives are touched by a brain tumour.

The S-SANOC day passed in a flash, with tremendous energy in the room as a result of the incredibly powerful presentations and testimonies. It was a great privilege to experience so much first-hand reality in so short a time. It was a powerful learning experience.

And so the work begins. We wish all of those who attended the first S-SANOC meeting the very best of luck in realising the ambitious plans discussed in London in October 2017.

*The S-SANOC Organising Committee **

*The S-SANOC Organising Committee consisted of: Kathy Oliver (Chair, International Brain Tumour Alliance (IBTA), Christine Mungoshi (Director, Zimbabwe Brain Tumour Association (ZBTA), Gordon Oliver (Director, International Brain Tumour Alliance), Mark Bernstein (Greg Wilkins-Barrick Chair in International Surgery, University Health Network, University of Toronto), Chas Haynes, (Executive Director, Society for Neuro-Oncology), Gelareh Zadeh (Co-Chair, Society for Neuro-Oncology International Outreach Committee), Jason Huse (Co-Chair, Society for Neuro-Oncology International Outreach Committee), Ken Aldape (Professor of Neuropathology, University Health Network, University of Toronto), Linda Greer (Manager, Member and Programme Services, Society for Neuro-Oncology)

About The International Brain Tumour Alliance (IBTA)



The International Brain Tumour Alliance (IBTA) is a global network founded in 2005 as a dynamic worldwide community for brain tumour patient organisations, patients, caregivers and others involved in the field of neuro-oncology.

THE IBTA brings together experience and expertise from a wide range of stakeholders including patient organisations, researchers, healthcare professionals, government agencies, regulators, medical societies, key opinion leaders and others.

Our vision is a world free from the fear of brain tumours.

Our mission is to advocate for the best treatments, information, support and quality of life for brain tumour patients, offering them, their families and caregivers hope – wherever they live in the world.

We work with Alliance supporters to:

ENCOURAGE

the establishment of brain tumour patient groups in countries where they don't yet exist;

PROMOTE

collaboration on programmes and projects to benefit the brain tumour community;

HIGHLIGHT

the challenges and needs of patients and caregivers;

DISSEMINATE

knowledge, information and best practice;

HELP

shape health and research policies at national and international levels;

HONOUR

the courage and achievements of brain tumour survivors and caregivers.

The IBTA's work is underpinned by the values of

SOLIDARITY EQUITY HONESTY INTEGRITY
TRANSPARENCY RESPECT HOPE

We are committed to strengthening the evidence base for patient-centred treatment and care, in particular through the telling of and promoting of peoples' experiences and perspectives.

About SNO and the Wilkins-Barrick Course in Neuro-Oncology



FOUNDED in 1995, the Society for Neuro-Oncology (SNO) is a dynamic force in neuro-oncology, providing a rich environment for its diverse worldwide membership through educational programs and forums. SNO's annual meeting regularly attracts over 2300 delegates from over 40 countries, and is widely regarded as the premier educational event in the field. SNO's flagship journal, *Neuro-Oncology*, is ranked among the top peer-reviewed cancer and neurology journals.

SNO welcomes professionals from all neuro-oncology subspecialties who are involved in the research, care and treatment of brain tumors to join the society. More information on the various levels of membership can be found on the SNO website, www.soc-neuro-onc.org.

The Wilkins Barrick Course in Neuro-Oncology is administered by the Society for Neuro-Oncology, and is made possible by the generous support of Mark Bernstein, the Greg Wilkins-Barrick Chair in International Surgery at the University Health Network, University of Toronto. Matching funds for the support of this initiative are provided by the SNO Foundation. The Wilkins-Barrick Course in Neuro-Oncology is intended to support the development of a symposium or educational event in the developing world.

To date, three Wilkins-Barrick International Outreach Courses have been organized: Malaysia (2016), Sri Lanka (2017) and Morocco (2017). Additional courses are in development for Peru and sub-Saharan Africa.

About the Zimbabwe Brain Tumour Association (ZBTA)



The Zimbabwe Brain Tumour Association (ZBTA) is registered in Zimbabwe as a private Voluntary Organisation (PVO 26/2005).

The ZBTA was established to raise awareness about brain tumours and to find ways of addressing the specific challenges posed by brain tumours in Zimbabwe.

Our work involves:

- awareness raising campaigns which include dissemination of information on brain tumours and other brain tumour resource material
- lobbying and advocacy to ensure that government creates policies that are favourable to the cause of brain tumour patients
- psychosocial support for patients and their families
- a supplementary feeding scheme where volunteers deliver food hampers during hospital and home visits to needy patients and their caregivers to help them with some of their immediate requirements such as high nutritional liquid foods and adults'/children's diapers.

Though based and operating in Zimbabwe, the ZBTA has deep concerns about the current brain tumour situation in the wider sub-Saharan Africa region and has joined forces with other regional and international stakeholders to bring meaningful, sustainable change. We believe that our collaborative advocacy efforts will make a real difference to our brain tumour communities in this region of the world.

Executive Summary

THE 2017 Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) planning meeting brought together a range of stakeholders focussing on the care and support of people with brain tumours and their families living south of the Sahara on the African continent.

Sub-Saharan Africa comprises the largest land area of the continent with those countries north of the Sahara making up North Africa and part of the League of Arab States. Sub-Saharan Africa consists of 46 countries. In 2016, the population was more than 995 million. Over 1,000 languages are spoken across sub-Saharan Africa.

National health systems and healthcare spending vary widely from country to country. Communicable diseases such as HIV/AIDS, lower respiratory tract infections, diarrhoeal diseases and malaria are among the top four killers in sub-Saharan Africa and generally command the main focus of attention in healthcare.

Recently, however, there has been an enhanced focus on non-communicable diseases due to the increasing incidence of such illnesses as stroke, asthma, diabetes, coronary heart disease, chronic hepatic and renal diseases, and cancer.

Amidst the many substantial challenges facing people in sub-Saharan Africa, brain tumours are low on the ladder of healthcare priorities. Additionally, brain tumours are rare and country-specific hospital and population-based registries, if they exist at all, are incomplete. So the accurate incidence and prevalence of brain tumours is largely unknown.

There is good news

But the good news for the sub-Saharan Africa brain tumour community is the emerging new focus of attention on it which is being led by highly dedicated and pioneering healthcare professionals with a determined and long-term commitment to improve the situation for people whose lives have been touched by this devastating disease.

The first-ever S-SANOC planning meeting was a coming together of some of these health professionals, along with brain tumour patient advocates, neuro-oncology nurses, members of neuro-oncology learned societies and other healthcare professionals with the aim of discussing the challenges and potential solutions for caring for people with brain tumours in sub-Saharan Africa.

On 18th and 19th October 2017, the IBTA was delighted to welcome 33 participants from 16 countries to the S-SANOC meeting in London, UK. The S-SANOC meeting was run in conjunction with the Zimbabwe Brain Tumour Association (ZBTA), the Society for Neuro-Oncology (SNO), Dr Mark Bernstein (the Greg Wilkins-Barrick Chair in International Surgery, University of Toronto, Canada) and the SNO Wilkins-Barrick Course in Neuro-Oncology.

The SNO Wilkins-Barrick Course in Neuro-Oncology was established in 2015 and provides seed funding for neuro-oncology symposia or courses in the developing world. As part of the 2017 round of funding, a specific call for applications from sub-Saharan Africa was made by SNO. During the period of the grant application process, SNO also became aware of the efforts of the IBTA and ZBTA in connection with brain tumour patients and advocacy communities in sub-Saharan Africa and the two organisations' desire to improve outcomes for brain tumor patients and their families in this part of the world.

Recognizing the congruent interests of SNO and the IBTA and ZBTA a decision was made to invite the SNO Wilkins-Barrick applicants and African patient advocates to London to examine the challenges and potential solutions for improving the care of brain tumor patients in sub-Saharan Africa. In addition, brain tumor patient advocates from Zimbabwe, Cameroon, South Africa and Uganda were given the opportunity to present their perspectives on the current situations for brain tumor patients in their countries.

The IBTA also presented on its current work in the international advocacy and awareness-raising field. In addition, representatives of the following neuro-oncology societies were present at the S-SANOC meeting: the European Association of Neuro-Oncology (EANO), the Indian Society of Neuro-Oncology (ISNO), and the Asian Society of Neuro-Oncology (ASNO). It was further hoped that bringing together key stakeholders from the region would be conducive to the development of a multi-stakeholder African neuro-oncology society that would take a leadership role in coordinating efforts to improve brain tumour patient care.

The challenges

Over the course of the S-SANOC meeting, the following challenges were identified (however, this list is not exhaustive):

- late and/or incorrect diagnosis or no diagnosis
- insufficient access to medical care on all levels from primary through to tertiary
- an acute shortage of healthcare professionals specializing in neuro-oncology
- a critical shortage of up-to-date and well-functioning medical equipment such as radiotherapy machines
- lack of specialist pathological expertise (especially in the increasingly-important arena of molecular profiling)
- systemic weaknesses, eg lack of funding for supporting staff development and educational training, procurement of equipment and facilities; weak management practices; lack of national and pan-sub-Saharan Africa guidelines for the treatment and care of brain tumour patients
- very few not-for-profit brain tumour patient and caregiver support, information and advocacy organisations. Those which already exist struggle significantly to provide much-needed services and fill gaps in support and information provision.
- the practice of traditional medicine as the main source of treatment and advice for a large number of patients
- substantial stigma attached to brain tumours and their symptoms, for example epilepsy, which is perceived by some as “being cursed”, “being possessed”, “being punished for a previous wrong committed”, etc.
- absence of a pan-sub-Saharan Africa neuro-oncology society
- the need for comprehensive palliative/supportive care and end-of-life care for brain tumour patients
- the necessity for all parts of sub-Saharan Africa (east, west, south and central) to collaborate, network and communicate with each other better

Recommendations

In response to the challenges above the following recommendations were made:

1. To organize a neuro-oncology educational course/conference for 2018 in sub-Saharan Africa, to be jointly funded by:

- the Society for Neuro-Oncology (SNO) Wilkins-Barrick International Outreach Course Grant in Neuro-Oncology
- the European Association of Neuro-Oncology (EANO)
- the International Brain Tumour Alliance (IBTA)
- other fundraising efforts

This course/conference - which would either be held as part of an already-existing international meeting planned for 2018 or as a stand-alone event - could address some of the challenges listed above and specifically disseminate the latest information on brain tumour treatments and care.

2. To establish a multi-stakeholder sub-Saharan Africa neuro-oncology society. For this, involvement of stakeholders in the region should broadly reflect the cultural and other needs of the brain tumour population within sub-Saharan Africa. Such a society could - provided it functions on a sustainable and relevant basis - help address the challenges listed above and help overcome some of the barriers which negatively affect outcomes for people with brain tumours in sub-Saharan Africa.

3. To involve brain tumour patient advocacy organisations in both the proposed 2018 and any future annual educational courses/conferences and also involve them in the proposed sub-Saharan Africa neuro-oncology society. Involvement of patient advocates in all aspects of the brain tumour journey is crucial in order that the patient and caregiver perspective is provided throughout.

Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) Planning Meeting

working together...improving outcomes...sustaining hope for adult and pediatric brain tumour patients in central, south, east and west Africa

The Tower Hotel, London, UK - 18 to 20 October 2017

S-SANOC Programme

Day 1 – WEDNESDAY, 18 OCTOBER 2017

13.00 to 18.00	REGISTRATION AND WELCOME DINNER Arrival at The Tower Hotel, London and registration for participants attending the Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) Planning Day meeting		Tower Hotel Front Lobby, Ground Floor IBTA Hospitality Desk
19.00 - 22.00	INFORMAL RECEPTION AND WELCOME DINNER FOR ALL PARTICIPANTS		Neville Room, upper foyer, The Tower Hotel

DAY 2 – THURSDAY, 19 OCTOBER 2017

	PLENARY SESSION 1		
08.30 to 09.00 30 mins	Welcome and brief introductions from all participants.	Chaired by Kathy Oliver, (Chair, International Brain Tumour Alliance – IBTA)	Discovery Room
	PLENARY SESSION 2		
09.00 to 11.00 120 mins	SETTING THE SCENE 1: Presentations for the SNO Wilkins-Barrick International Outreach Course by applicant groups: 09.00 to 09.10: Introduction by Co-chairs 09.10 to 09.25: Alan Davidson (Cape Town, South Africa Group) 09.25 to 09.40: Daniel Fulkerson (Eldoret, Kenya Group) 09.40 to 09.55: Nimrod Juniahs (Lome, Togo Group) 09.55 to 10.10: Thierry Muanza (Dar es Salaam, Tanzania Group 1) 10.10 to 10.25: Trish Scanlan (Dar es Salaam, Tanzania Group 2) 10.25 to 10.40: James Balogun (Abuja, Nigeria Group) 10.40 to 10.55: Teddy Totimeh (Accra, Ghana Group)	Co-chaired by Gelareh Zadeh ((Division of Neurosurgery, University of Toronto, Canada) and Jason Huse (Associate Professor, University of Texas MD Anderson Cancer Center Departments of Pathology, USA)	Discovery Room
11.00 to 11.30 30 mins	COFFEE/TEA/REFRESHMENT BREAK AND NETWORKING		Discovery Room

	PLENARY SESSION 3		
11.30 to 12.15 45 mins	Roundtable discussion on grant applicant group presentations with all participants	Co-chaired by Gelareh Zadeh ((Division of Neurosurgery, University of Toronto, Canada) and Jason Huse (Associate Professor, University of Texas MD Anderson Cancer Center Departments of Pathology, USA)	Discovery Room
12.15 to 13.15 60 mins	Group photograph LUNCH		Gallery Restaurant, upper foyer, The Tower Hotel
	PLENARY SESSION 4		
13.15 to 14.40 85 mins	SETTING THE SCENE 2: Presentations from the Sub-Saharan brain tumour patient and caregiver organisations and the IBTA 13.15 to 13.25: Introduction by Chair 13.25 to 13.40: Linda Longwe (Zimbabwe Brain Tumor Association) 13.40 to 13.55: Irene Azong-Wara (Jacob's Hope Foundation, Cameroon) 13.55 to 14.10: Bonita Suckling (Rainbows and Smiles, South Africa) 14.10 to 14.25: Wilson Mugarura (Uganda Brain Tumour Foundation) 14.25 to 14.40: Kathy Oliver (International Brain Tumour Alliance - IBTA)	Chaired by Christine Mungoshi (Founder and Director, Zimbabwe Brain Tumour Association - ZBTA)	Discovery Room
14.40 to 15.40 60 mins	Roundtable discussion with all participants		
15.45 to 16.15 30 mins	COFFEE/TEA/REFRESHMENT BREAK AND NETWORKING		Discovery Room
	PLENARY SESSION 5		
16.15 to 18.00 105 mins	PRACTICALITIES AND GOALS: roundtable discussion with all participants regarding the 2018 SNO Wilkins-Barrick Outreach Course in sub-Saharan Africa and the potential sub-Saharan Neuro-Oncology Society to include the following suggested topics: <ul style="list-style-type: none"> • Location - challenges and solutions • Faculty • Speakers • Additional funding required • Promotion and communications • Logistics (registration, venue, travel, etc) • Emergence of a sub-Saharan Africa Neuro-Oncology Society – challenges and solutions, membership, mentorship, SNO/Oxford University Press initiatives for 	Co-chaired by Chas Haynes (Executive Director, Society for Neuro-Oncology - SNO, USA) and Gordon Oliver (Director, IBTA)	Discovery Room

	<p>access in developing countries to <i>Neuro-Oncology</i> and <i>Neuro-Oncology Practice</i>; patient advocacy involvement</p> <ul style="list-style-type: none"> • Involvement of brain tumour patient and caregiver organisations (via a concurrent or consecutive patient conference in 2018?) and ongoing collaborative activities • Political challenges • Capacity-building (clinical groups and patient groups) • Involvement going forward of multidisciplinary team members; ie palliative care, specialist nurses, allied health care specialities (rehabilitation, psychosocial aspects, end-of-life care, etc) • The role of traditional healers • Next steps 		
18.00 to 18.15 15 mins	Meeting wrap-up	Chaired by Christine Mungoshi (Founder and Director, Zimbabwe Brain Tumour Association - ZBTA) and Kathy Oliver, (Chair, International Brain Tumour Alliance – IBTA)	
DAY 3 – FRIDAY, 20 OCTOBER 2017			
	Departures after breakfast		



Above: The first Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) planning meeting was held at The Tower Hotel, London, UK, located on the banks of the River Thames, just next to the iconic Tower Bridge, pictured above

Plenary Session 1

Welcome and brief introductions from all participants



Above: IBTA Chair and Co-Director Kathy Oliver welcomes delegates to the Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) planning meeting

KATHY Oliver, Chair and Co-Director of the International Brain Tumour Alliance (IBTA), opened proceedings with a warm welcome to all delegates at the first Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) Planning Meeting. The meeting was held in London, UK on 18th and 19th October 2017.

Speaking on behalf of the S-SANOC Organising Committee, Kathy Oliver thanked the many delegates who travelled great distances and overcame considerable logistical hurdles to attend. The S-SANOC meeting was the result of a joint effort by the IBTA, the Society for Neuro-Oncology (SNO), the Zimbabwe Brain Tumour Association (ZBTA), and the SNO Wilkins-Barrick International Outreach Course in Neuro-Oncology.

She explained that this was a historic meeting in the field of neuro-oncology because of the involvement of African patient advocacy organisations together

with so many other relevant stakeholders from the region and beyond to discuss improving outcomes for people with brain tumours. She thanked members of the S-SANOC Organising Committee, and supporting organisations, individuals and sponsors, without whom the event would not have been possible.

“I’m excited about the potential for constructive change in sub-Saharan Africa vis-à-vis brain tumours, and hope that the S-SANOC meeting will be foundational in the establishment of a strong and meaningful brain tumour collaboration,” Kathy said. “The region is vast and rich in diversity, with many unique needs and great challenges for the brain tumour community.”

There were two core aims for the S-SANOC planning meeting in London.

1. to make plans for a 2018 neuro-oncology educational course/conference in sub-Saharan Africa
2. to lay the groundwork for the establishment of a sub-Saharan Africa neuro-oncology society which would be truly multi-stakeholder in composition and include African brain tumour patient organisations.

All S-SANOC participants were invited to briefly introduce themselves to the meeting, stating where they were from and their role in their brain tumour community/organisation. Thirty-three participants representing 16

countries attended the S-SANOC meeting:

- South Africa
- Kenya
- Togo
- Ghana
- Cameroon
- Zimbabwe
- Nigeria
- Uganda
- Tanzania
- United States
- Canada
- United Kingdom
- France
- India
- Australia
- New Zealand

There was a striking cross-section of individuals from different specialities involved in brain tumour care: neurosurgeons, specialist neuro-oncology nurses, leaders of African patient advocacy groups and from other regions, researchers, representatives of industry, a radiation oncologist, palliative care specialist, a neuro-pathologist, two brain tumour survivors and current and former caregivers to brain tumour patients.

Plenary Session 2

Setting the scene: Presentations for the SNO Wilkins-Barrick International Outreach Course in Neuro-Oncology by applicant groups

Introduction by Chas Haynes, Executive Director of the Society for Neuro-Oncology (SNO)



CHARLES (Chas) Haynes, Executive Director of the Society for Neuro-Oncology (SNO), explained the background to the S-SANOC meeting and the SNO Wilkins-Barrick International Outreach Course in Neuro-Oncology.

SNO previously announced they were accepting proposals for neuro-oncology symposia or educational courses in the developing world, for which there would be a grant available up to a maximum of US\$20,000 for the provision of a multidisciplinary course, relevant to specific regional needs in the field

Left: SNO Executive Director, Chas Haynes, introduces the outreach course applicant groups at the S-SANOC planning meeting

of neuro-oncology. [This amount was subsequently increased to US\$30,000.] At the same time, IBTA Chair and Co-Director Kathy Oliver and the Director of the Zimbabwe Brain Tumour Association (ZBTA) Christine Mungoshi were endeavouring to create a multi-stakeholder brain tumour collaborative event in sub-Saharan Africa for 2018.

Discussions between the IBTA, ZBTA and SNO about the common goals they shared for neuro-oncology in sub-Saharan Africa resulted in the concept of the Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) planning meeting – a high-level gathering that would bring together stakeholders in brain tumour care from across the region and beyond. Dates were set for the S-SANOC meeting – 18th and 19th October 2017 – and a venue was secured: The Tower Hotel, London, United Kingdom.

An organising committee was established, consisting of individuals in the UK, USA, Canada, and Zimbabwe. The committee liaised and communicated via online messaging, telephone conferencing and, when possible, face-to-face when all attended medical conferences.

A decision was made to use the S-SANOC planning meeting as an opportunity for interested parties to make proposals for the SNO Wilkins-Barrick International Outreach award and to lay the foundations for the eventual establishment of a sub-Saharan Africa neuro-oncology society as the lasting legacy of the 2017 S-SANOC event. The desire was to facilitate a course/conference and neuro-oncology society that would integrate a multi-stakeholder team of people on the ground in sub-Saharan Africa who are committed to improving care in the region, rather than for SNO or the IBTA and ZBTA to define a prescriptive course/conference and society format.

Chas stressed that the S-SANOC planning meeting focused on the brain tumour patient and all those who look after the patient. An educational course/conference and pan-African collaboration (society) should be inclusive of all colleagues who play a role in a brain tumour patient's day-to-day life, and needed to include a wide scope of professionals and patient advocates. The emotional toll of brain tumours is considerable, he said, and so psychologists and other specialists should also be among the target audience.

There is a need to face up to the many challenges

in the sub-Saharan Africa region, and future efforts should deal with both primary brain tumours and other cancers that have metastasised (secondary tumours) to the brain. There is a considerable lack of neuro-oncology professionals in the region, and a sub-Saharan Africa collaboration will need to consider how best to manage with very limited resources. The field of neuro-oncology is evolving to a molecular-driven approach and resources and training will need to be prioritised.

Presentation 1

Dar es Salaam, Tanzania Group 1:

Dr Thierry Muanza and Dr Ekokobe Fonkem



Above: Dr Thierry Muanza (right) and Dr Ekokobe Fonkem (left) gave a joint presentation on their proposal for a neuro-oncology course in Tanzania

The first Wilkins-Barrick proposal applicant to speak was Dr Thierry Muanza, a radiation oncologist and clinical trials and translational researcher. He is a member of the Board of Directors for Brain Tumor Foundation of Canada, and Assistant Professor to the Department of Oncology and an Associate Member of the Departments of Experimental Medicine and Neurology & Neurosurgery of the Faculty of Medicine at McGill University, Canada. He also has experience working and training at various locations across North America.

“My goal is to give back to Africa. I have a great passion for the region and I have lectured for many years in countries such as South Africa, Ghana and Senegal. Organising and running an educational

course/conference is a continuation of my desire to improve the quality of care for brain tumour patients in sub-Saharan Africa," he said.

Both Thierry and his colleague neurosurgeon Ekokobe Fonkem said that the target audience for their team's proposed educational course/conference would be deliberately broad: brain tumour patients, caregivers, advocacy groups, medical doctors (including neurosurgeons, neurologists, oncologists, radiation oncologists, palliative care and primary care providers), nurses, ergotherapists (occupational health practitioners), physiotherapists and other rehabilitation specialists.

They explained that there needs to be a transfer of knowledge among professionals. The approach to brain tumour treatment is evolving from being based on a tumour's grade and type (its appearance under the microscope) toward analysis of its molecular and genetic features.

Education needs to address local cultures, each of which has its own societal and belief system. Patient advocacy groups would be key.

The proposed educational course/conference would:

- focus on ways to enhance the lives of those affected by brain tumours in the context of their society. In making progress, the importance of cultural beliefs must not be ignored.
- be designed to be relevant to the challenges faced in sub-Saharan Africa
- look at both primary and secondary brain tumour care

Cancer is increasingly becoming a major economic and social burden in sub-Saharan Africa due in part to better living standards and a longer lifespan. There is an increased incidence and prevalence of primary high-grade gliomas and meningiomas alongside increasing rates of secondary brain tumours that have spread from other cancers, such as lung, breast, cervical and prostate.

"The healthcare approach is not adequate in sub-Saharan Africa and there is a general lack of appropriate neuro-oncology education and training across the region. Add to this the lack of government support and the poor public awareness of brain tumours," Thierry Muanza said. "The ongoing challenge for the sub-Saharan Africa neuro-oncology group will be to try and address the lack of professionals and limited resources. There is also a pressing need to develop a brain tumour registry to assess the impact of brain tumours and the resources

that are needed. How do we know what is needed unless we know what it is like on the ground?"

Dar-es-Salaam, the largest city in Tanzania, is the proposed location for their group's educational course/conference. In addition to Thierry Muanza, the group consists of Dr Ekokobe Fonkem (neuro-oncologist and Associate Professor of Surgery, based in Texas, USA), Dr Gasper Kitange (Assistant Professor and neuro-oncology basic scientist at Mayo Clinic in Rochester, Minnesota, USA), Dr Hamisi K Shabani (Neurosurgeon Chief, Associate Lecturer, and a Trainer at the College of Surgeons of East, Central and Southern Africa, who is based in Dar-es-Salaam, Tanzania), Christine Mungoshi (Director, Zimbabwe Brain Tumour Association) and Kathy Oliver (IBTA's founding Co-Director and Chair, based in the UK). The Chairs for the proposed course/conference are: Dr Shabani, who works at Muhimbili University of Health and Allied Sciences, Tanzania; Dr Fonkem, who has worked in Cameroon, and Dr Muanza. Each member of the group had a role in designing the basic outline of the proposed educational course/conference.



Above: Ekokobe Fonkem (left) and Thierry Muanza (right) described their proposed neuro-oncology educational course

The vision for a symposium would be three-fold:

1. bridging the divide between patients, caregivers, medical professionals and traditional healers in neuro-oncology;
2. linking local/ domestic specialists with professionals from the developed world;
3. implementing modern technology

There will also be a Brain Tumour Patients' Advocacy Day immediately before the scientific programme.

On-going goals will be to optimise neuro-oncology standards of care in sub-Saharan Africa, and to improve the overall quality of brain tumour care. A 'community link' would be an important element of the running of the course/conference, with patients, caregivers, advocacy groups, and authorities as the main stakeholders with the neuro-oncology team.

The challenges and barriers are not to be underestimated, however. Thierry Muanza said that the three greatest challenges and barriers were the need to:

1. adapt to the local environment
2. address the intrinsic values of each member
3. accommodate cultural beliefs, especially the widespread reliance on traditional healers

Bringing together a grassroots sub-Saharan Africa neuro-oncology community, their mission will be to:

- create/increase awareness of brain tumours in sub-Saharan Africa
- provide an opportunity for multi-stakeholder collaboration between physicians and patients in sub-Saharan Africa
- address a variety of important topics, which includes common brain tumours, management, the potential role of telemedicine, and other advances
- consider the role of cultural beliefs,
- establish brain tumour registries
- assess quality of life for patients and their families
- analyse the role that patient advocacy plays, and
- evaluate brain tumour care and outcome in Africa.

Thierry then concluded by showing a provisional budget for the educational course/conference, a total estimated at US\$51,713, not including travel grants which he hoped they may be able to provide to delegates if their group's application is successful.

The presentation was followed by a short question and answer period from other S-SANOC participants. Responding to a request for more information about what the 'Advocacy Day' would involve, Thierry said: "The day would be a gathering, with networking and an opportunity for different groups to present and share their experiences."

A follow-up question from Jenny Baker (IBTA Senior Advisor, UK), asked about the group's vision for brain tumour patient advocacy groups in the region, and for those countries that presently have no brain tumour advocacy groups. "Networking will embolden and expand [the patient advocacy movement]," Thierry said, "and our



Above: IBTA Senior Advisor Jenny Baker (seated above right) and Sally Payne (seated above left) attended the S-SANOC planning meeting

Presentation 2

Eldoret, Kenya Group:
Dr Daniel Fulkerson



Above: neurosurgeon Dr Daniel Fulkerson (standing) has worked in Eldoret, Kenya and has an intimate knowledge of the challenges there in treating paediatric brain tumour patients.

Dr Daniel Fulkerson is Associate Professor of Neurological Surgery at Indiana University School of Medicine, USA and performs both adult and paediatric neurosurgery for Goodman Campbell Brain and Spine, Indianapolis, USA.

Daniel proposed a neuro-oncology course that would offer a "practical review of paediatric brain tumour management with hands-on demonstration of new technology to the area", to take place at Moi Teaching and Referral Hospital in Eldoret, Kenya. He has

performed neurosurgery at this hospital as part of the charity AMPATH's (Academic Model Providing Access to Healthcare) mission work for a number of years. His goal is to facilitate the few practicing neurosurgeons in Kenya who are tackling some very serious cases.

Eldoret, which literally means "stony river", is a city in the Rift Valley Province of Kenya, with a population of around 200,000 people (rising to around 800,000 including the surrounding lands). The large catchment area means that the city's hospital is very busy. With 800 beds, Moi Teaching and Referral Hospital treats approximately 8,000 oncology patients each year. However, as Eldoret is situated at an elevation of 7,000 to 9,000 feet (2,100 to 2,700m), the area has very limited access. The hospital was first opened in 1917 as a cottage hospital, but became a referral hospital with the establishment of Moi University in 1984.

Moi University School of Medicine was established in 1988, as Kenya's second medical school and its first students graduated in 1997. Indiana University Medical School (USA) has nurtured an important relationship with Moi University; its medical students and medical staff regularly visit Moi Hospital (over 500 Indiana University students having visited so far). Moi Teaching and Referral Hospital is the only hospital in the northern half of the country with neurosurgical capabilities. Daniel has built up a relationship with the institution and developed many friendships with the staff of whom Dr Florentius Koech was a visiting professor for the 2013 Frew Lecture in Indianapolis, Indiana and Dr Godfrey Wasike was hosted to observe neurosurgical practice and attend the 2017 American Association of Neurological Surgeons in Los Angeles, California. Through multiple trips to provide neurosurgical care, Daniel has gained an intimate working knowledge of the capabilities and needs of Moi Hospital.



The proposed 2018 educational course's target audience will be physicians at Moi Teaching and Referral Hospital, with an invitation to all neurosurgeons in training in Kenya to attend.

The course will specifically offer teaching, training and advice on:

- the latest **updates** for treating brain tumours
- **surgical safety** measures
- the use and application of **intraoperative ultrasound equipment** and
- the management and maintenance of **operating room equipment**

The goals of the proposed course are to create something that is durable and practical but also applicable and relevant to the people who are working in Kenya.

Daniel explained that skills transfer is crucial for the physicians there. For example, it is not routine to give brain tumour patients any prevention for deep vein blood clots after surgery. To implement simple preventative practices will have tremendous benefit for improving outcomes.

Through his work in the country Daniel had been able to successfully bring technologies and methods to medical professionals in Eldoret, demonstrating that good progress is achievable. A key goal of the proposed course will be to provide equipment, instruction on equipment maintenance, and training to improve efficiency of workflow.

The Chairs of the proposed course will be Daniel, Rebecca Dianne Seibold, a registered nurse who is chief of neurosurgery operating rooms at Riley Hospital for Children, Indianapolis, Indiana, USA, and Dr Florentius Koech, senior neurosurgeon at Moi Teaching and Referral Hospital.

Daniel included photos of patients with large skull growths, and images of MRI results displaying brain tumours. He stressed that many of the patients' conditions are not simple cases and are extremely challenging surgeries even in the most advanced operating suites. He told about one patient who survived major surgery but died two days later from a pulmonary embolism, which may have been preventable through what would be considered basic care in developed countries.

Photographs of the operating suite and available equipment showed that Moi Hospital had only very

Left: A key goal of the proposed course in Eldoret, Kenya, Dr Fulkerson explained, would be to provide equipment, instruction on equipment maintenance, and training to improve efficiency of workflow.

limited anaesthesia and ageing technology. "They need sustainable technology and skills transfer. Implementing what is the standard of care in the USA is not possible with technology there," he said.

An alternative to advanced technology is to use ultrasound as an adjuvant (additional aid) to surgery. Daniel showed a short video of an ultrasound machine being used to identify and locate a brain tumour. He explained that such relatively inexpensive technology can be used to locate a small target. However, accomplishing this requires knowledge, training, and tuition in troubleshooting and obtaining pictures. Daniel wants the hospital to receive a specialised ultrasound probe that will more effectively identify masses in the brain.

The rationale for the proposed seminar is to achieve the goal of transferring useful, durable knowledge and equipment to a hospital that provides the only brain tumour treatment in the northern half of Kenya. Daniel's existing and established relationship with the region allows for a realistic assessment of needs, and the hands-on knowledge and equipment that would be offered through the course will enhance the skills and capabilities of the neurosurgeons in Moi.

As well as improving the treatment of brain and spinal tumours, the neuro-oncology course will also have applications for brain abscesses and hydrocephalus (a build-up of fluid on the brain).

The need for such a course is very timely because with the retirement of Dr Leland Albright (in the town of Kijabe), there will be no dedicated paediatric neurosurgeon in Kenya. Furthermore, Moi Teaching and Referral Hospital has the capability to become a training centre for paediatric neurosurgery and a teaching hub for the wider area.

Daniel shared his vision for the emergence of a sub-Saharan Africa neuro-oncology society and proposed that they partner with the already-functioning oncology service at Moi, especially in neurosurgery. This event will be a first step in achieving improved brain tumour care in the northern half of Kenya. Future ideas include using telemedicine, offering material support, research, and helping orchestrate public health initiatives such as road safety programmes.

Head injuries from road traffic accidents are remarkably common in Kenya and a public health initiative that increased helmet use will have a dramatic effect on improving brain tumour care. This is because fewer head

injuries requiring surgery would mean less strain on the neurosurgical department, potentially freeing-up resources for brain tumour surgery.

Daniel presented a proposed budget for the neuro-oncology course/conference, which included travel and housing expenses of US\$5,000; administrative costs of US\$500, and costs of US\$4,500 to ship equipment from Indiana, USA, to Moi, Kenya. He proposed that equipment be secured from charitable donations from Indiana University and Riley Hospital for Children in Indiana and that resources be provided to free-up time and space for improved organisational purposes to help the administration team at Moi Teaching and Referral Hospital.

Presentation 3

Dar es Salaam, Tanzania Group 2: Dr Trish Scanlan



Above: Dr Trish Scanlan co-founded the Tanzanian children's cancer charity Tumaini la Maisha (Their Lives Matter) in 2011

Dr Trish Scanlan is an Irish paediatric oncologist who has lived and worked in Tanzania since 2006. Sharing some of her own personal story of twice being diagnosed with breast cancer, she spoke of how Dar-es-Salaam captured her heart during a visit in 2006, prompting her to join the paediatric oncology team at The Ocean Road Cancer Institute (ORCI) the following year.

At the S-SANOC planning meeting in London Trish presented the work of the non-profit children's cancer

charity 'Tumaini la Maisha' ('Their Lives Matter'), which she co-founded in 2011.

The charity's vision is that all children with cancer in Tanzania will have easy, free access to locally-based, high-quality, curative and palliative cancer treatment, leading to survival outcomes similar to resource-rich settings. Their plan is to reach every child with cancer in Tanzania in five years. Displaying a graph showing how lifespan is closely related to the wealth of the country, she quoted the words of the late statistician and public speaker Dr Hans Rosling: "There's really no reason why everyone can't move to the richer healthier corner of the graph."



Above: Dr Scanlan and her team have endeavoured to adopt international protocols and standards of care for children with cancer, including brain tumours, in Tanzania.

"There was a huge step forward in paediatric cancer care in Tanzania in 2004, when the government removed a lot of barriers to medical care which began to be offered at no cost, although the lack of resources meant that the cupboards were probably often bare." In 2005, childhood cancer had a survival rate of under 10% in Tanzania.

"One young Tanzanian girl who had terminal cancer and was left to die in the night without any pain medication or intravenous fluids had a profound effect on me," said Trish. "This represented everything that was needed.

"When I first arrived at Ocean Road Cancer Institute in Dar-es-Salaam, it was the only cancer care facility in the country, which has a population of 40 million, half of whom are children.

"Paediatric patients were left alone for hours on the cancer ward, unsupervised and untreated because

there was insufficient money to pay nurses to work night shifts. On the night the young girl died, in that moment I resolved that change absolutely had to happen. But how?

"Nelson Mandela said: 'It always seems impossible until it's done'. I had five thoughts as to how to achieve positive change:

1. Start with what is essential.
2. Prove that your efforts are having an effect.
3. Build up slowly as the service grows.
4. Give teaching from the very first day.
5. Engage with others both locally and internationally

Cost is an invisible border to care and so we have maintained the principle of free care. Palliative care also needs to be considered as an essential in Tanzania."

Since Trish started working to improve cancer care in Tanzania, children are now seen regularly by healthcare professionals, rather than being abandoned.

"When I first arrived, rudimentary oncology management - which is taken for granted in wealthy nations - was not being performed in Tanzania either. We have ensured that children receive basic tumour staging using the imaging technology (e.g. X-rays) to which they have access. We have also adopted international protocols and standards of care."



Above: Dr Trish Scanlan: "Ependymoma is the most common type of pediatric brain tumour seen in Tanzania, although a wide variety of brain tumours are diagnosed, ranging from craniopharyngioma to germ-cell tumours to DNETs (dysembryoplastic neuroepithelial tumours)."

In sub-Saharan African countries, it is essential that doctors provide accurate diagnosis information for children with suspected cancer. To overcome the lack of expertise and equipment in Tanzania, Trish's centre twinned with Our Lady's Children's Hospital in Dublin, Ireland. This allows Tanzanian doctors to send tissue sample packages to Ireland every week for a complete molecular analysis.

"We have received funding to give training that will establish a pathology service in Dar-es-Salaam, and this is intended to also serve the rest of the country."

Through a series of touching photographs, Trish highlighted some of the many achievements that Their Lives Matter has accomplished for improving paediatric cancer care, including that for brain tumours, in Tanzania.

"When I arrived there was no oxygen and the only laboratory services were in a shed which closed at 3pm. Now, children with cancer have access to free CT and MRI scanning equipment and there are no delays in accessing radiation therapy although presently there is only one cobalt radiation machine available. Children are now given psychosocial support, which includes playtime, compassionate care, fun activities, outings and good nutrition including 'magic porridge'. Care packs, which contain many basic essentials, are given to families and a skills room is available for parents."

Trish also described the 'Child Life Programme', which educates children about medical procedures with the use of dolls to show what will happen to them. This helps remove some of their apprehensions.

Education is important and it has therefore been one of the key activities at Their Lives Matter. They have access to 35 experts from around the world, and are training people locally.

They have helped establish an MSc course in paediatric oncology, which has already led to two homegrown graduates. Prior to this, there were no Tanzanian-trained paediatric oncologists in the country. The aim is to help train sufficient paediatric haematologist/oncologists for Tanzania and East Africa.

Additionally, Their Lives Matter has developed - in collaboration with MUHAS (Muhimbili University of Health and Allied Sciences) and the Tanzanian government - a Certificate Programme for Nursing in Paediatric Oncology and Haematology. They hope to run the course twice in 2018.

Through a community education programme, Their Lives Matter has been using local and national media platforms to deliver easy-to-understand messages to the general public about children's cancer, which includes early warning signs and how to access care. Importantly, they are not working in isolation but are working in collaboration with others, including traditional healers, to build relationships so that their message effectively reaches as wide an audience as possible.

"I believe it's important to continually review progress and ask 'Has this made any difference?' Prior to our interventions, a single ward bed would sleep three children, each of whom would have been receiving different therapies and treatments. Now, it is one child per bed despite the fact that the number of children coming to the hospital has increased dramatically in the time we have been in operation in Tanzania. In 2005, fewer than 150 children were receiving treatment for cancer and in 2016 approximately 600 children were treated," said Trish.

She added that outcomes have also improved. She showed a chart which listed rates of 'complete remission'/'on treatment' and that they had increased from approximately 42% in 2013 to nearly 50% in 2015. Citing a case study of a boy with a large Wilms' tumour (a type of kidney cancer), she said that in sub-Saharan Africa there is a wide variety of cancers and tumours, many of which are seen only when the disease is extensive. Thus, they present a complex medical and surgical challenge.

"When I arrived in Tanzania I found that, amazingly, the statistics showed that in 2005 there were no children with brain tumours seen at the hospital. I met with the team at the hospital and suggested that this fact should be publicised as it appeared that Tanzania was free of the problem of paediatric brain tumours! In reality, we all agreed that the problem did exist and it was quite literally that no children with paediatric brain tumours were being sent to the paediatric oncology centre."

Now Trish has a significant number of paediatric brain tumour patients. In 2015, 10.9% of conditions seen in the centre were brain tumours. Thanks to the partnership with the hospital in Dublin, they have access to accurate molecular information about these neoplasms. Ependymoma is the most common type of brain tumour seen although brain

tumours of a wide variety are diagnosed, ranging from craniopharyngioma to germ cell tumours to DNETs (dysembryoplastic neuroepithelial tumours).

“Our charity’s vision is to pool resources to create a hub and spoke paediatric cancer network in Tanzania. With Muhimbili National Hospital at the centre generating protocols and providing education in an open-source manner, the network would be a four-tier system of primary, secondary, tertiary and quaternary care. Primary and secondary centres across the country would act as spokes by provisionally diagnosing, stabilising and treating patients before transferring them to the tertiary hub.”

Trish showed a map of the proposed cancer network in Tanzania: “No one would be more than one day’s journey from a centre, and each centre would know what to do”.

A mobile money transfer system would be implemented, whereby individuals can be sent travel money directly via their mobile phone. In early 2016, Tanzania became the first country in the world to achieve full interoperability of mobile money services, allowing users of different mobile money services to transact directly with each other. Forty-three per cent of adults in Tanzania are already using these services to pay bills, make transfers to family and friends and conduct business transactions.

Trish also asked the S-SANOC participants to consider joining the ‘T. Pot’ (Tanzanian Paediatric Oncology Team), which is an international collaboration of organisations and universities supporting the goals of Their Lives Matter.

Trish insists that care must remain completely free for all children with cancer so Muhimbili National Hospital and Their Lives Matter presently share all costs, which amounts to just €320,000 (US\$377,000) per annum.

With this sum, they treat more than 500 children.

Put into context, that amount would cover the costs of care for just three children with childhood leukaemia in Europe.

“We are comparatively young in the field of neuro-oncology, and the SNO Wilkins-Barrick International Outreach Course award will help us to get up to speed in providing the most effective brain tumour care in Tanzania,” said Trish. “Our organisation has experience in hosting meetings and organising education, having hosted the International Society of Paediatric Oncology

(SIOP) Africa meeting in 2014, and the Annual East African Neuro-Trauma meeting.”

Tanzania is a suitable location for an international outreach course in neuro-oncology because it already has a comprehensive clinical service, excellent access to comprehensive pathology reports, an evolving paediatric neuro-oncology service, and an extensive panel of interested health professionals. The course could be combined with a planned 2018 neuro-trauma course, and their extensive pool of faculty staff from all over the world will help organise the event.



Above: S-SANOC participants had ample time to ask each presenter questions. Here IBTA Senior Advisor (and founder of Oscar’s Angels, France) Anita Granero puts a question to Dr Trish Scanlan.

Asked whether they were collaborating with any patient organisations, Trish replied: “Their Lives Matter has parents on board, and we consider it both patient- and parent-led. There is so much we want to do. Brain tumours have lagged behind and we want to bring together neuro-oncologists, surgeons, and other relevant professionals to develop training and research facilities, and then offer it across the region.”

Trish closed with a quote from Winston Churchill: “Success is the ability to go from failure to failure without losing your enthusiasm.”

Presentation 4

Cape Town, South Africa Group:

Prof Alan Davidson



Above: Prof Alan Davidson

Prof Alan Davidson is head of the Paediatric Haematology-Oncology Service at the Red Cross War Memorial Children's Hospital in Cape Town, South Africa.

He explained that he helps organise and run South Africa's annual Paediatric Brain Tumour Workshop (PBTW), and he has been co-chair of the event since 2008. His proposal was to rebrand this already-functioning and financially viable event into a meeting of the Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC). His colleagues have the necessary experience and the logistical infrastructure to upscale to a larger meeting while retaining quality and purpose. Furthermore, most of the available funds would be used for scholarships, with the aim of improving paediatric brain tumour multi-disciplinary teams (MDTs) throughout the region. This last point was the most important, he said, because "funding for scholarships has great need".

The existing PBTW course has established a strong agenda for advancing the cause of paediatric brain tumours in sub-Saharan Africa, thanks to the collaboration of the combined neuro-oncology service of the University of Cape Town and its affiliated teaching hospitals. It is co-hosted by leading experts Professor Anthony Figaji (Head of the Department of Paediatric Neurosurgery) and Professor Jeannette Parkes (Head of the Department of Radiation Oncology).

The PBTW originated as a satellite meeting of the International Society for Paediatric Neurosurgery (ISPN). The target audience is neurosurgeons, paediatric and radiation oncologists and colleagues from related disciplines, such as radiologists and pathologists. Attendees for the PBTW come from all over South Africa and beyond.

"Beyond" is limited by money," Alan said. "We have been trying to raise funds to support attendance of colleagues from more sub-Saharan countries. So far, we have had delegates from Angola, Kenya, Malawi, Nigeria, Sudan and Uganda."

The format of the proposed course would be in keeping with that of the annual PBTW, and will feature a prominent international speaker. Keynote lectures will be delivered by the international speaker, alongside talks from other invited specialists. Members of the local MDT will give presentations, and registrants would offer their clinical vignettes/case studies for the purpose of generating discussion.

Some key features of sub-Saharan Africa and the developing world are:

- Since 2000, global under-five mortality per annum has been declining – from 9.9 million in 2000 to 6.3 million in 2013.
- Ninety per cent of those deaths are taking place in low and middle-income countries (LMICs).
- Prematurity, intrapartum death, pneumonia, diarrhoea and malaria are some of the most common causes for these deaths.
- The fall in mortality rates is partly accounted for by declines in infectious disease deaths.
- At least 176,000 children under age 15 are diagnosed with cancer each year.
- Eighty per cent of these children live in LMICs.
- Cancer mortality is roughly twice as high in LMICs, compared to that of high-income countries.
- Deaths in these countries account for the majority of the world's 90,000 childhood cancer deaths each year.

Many childhood brain tumour patients are 'invisible patients' who are undetected in low and middle-income countries. Based on northern hemisphere data, about 20% of childhood cancers are paediatric brain tumours, but numbers in the developing world are quite different. Available data showed that in Ghana, paediatric brain tumours account for just 3.4% of cancers in a tertiary referral centre. In Namibia

this figure is 5.2%, and in Nigeria, 6.9% of childhood cancers are recorded as brain tumours.

Alan Davidson said: “These low numbers reflect an under-reporting of these invisible patients. But at least this is changing. Data from Bangladesh shows that the proportion of childhood cancers recorded as paediatric brain tumours has increased from virtually 0% in 2001 to 4.4% in 2014. These figures are estimates and we won’t know the actual figures without registries.”

The overarching goal of the proposed educational course in Cape Town is to increase knowledge of paediatric brain tumours and to address the challenges faced by teams treating these tumours in the low/middle-income country setting.

“Money solves problems and lack of resources is perhaps the greatest challenge faced in sub-Saharan African countries.”

Other challenges include the:

- low rate of diagnosis and referral of paediatric brain tumours
- general lack of functioning, multi-disciplinary teams
- absence of standardised treatment protocols
- widespread use of inappropriate therapies which have excessive toxicity
- absence of published data
- inaccurate media and parental expectations

“I would lead the coordinating team for the proposed course together with Jeannette Parkes and Tony Figaji,” Alan said. “We three have substantial experience and relationships in the region, having trained radiation oncology, neurosurgery, and oncology physicians from Botswana, Kenya, Ghana, Democratic Republic of the Congo, Nigeria, Malawi, and Ethiopia among other sub-Saharan Africa countries.

Moreover, we:

- are operating as a centre of excellence for patients from all over South Africa and the subcontinent
- have secured a large grant from the Cancer Association of South Africa (CANSA) for epidemiology and molecular biology
- run the established website, ‘Brainchild’
- have weekly telemedicine meetings on the Cure 4 Kids website
- are developing treatment protocols specifically tailored for LMICs (medulloblastoma and low grade

glioma have been completed so far)

- are an African partner of Varian Medical Systems’ ‘Access to Care’ radiotherapy education course
- have, between us, taught in international conferences in Tunisia, Stellenbosch (South Africa), Cape Town (South Africa), and Morocco”

Possible chairs and speakers for the proposed course would not be exclusively from Africa. The proposed chairs are: Lorna Renner (Ghana) who is the International Society of Paediatric Oncology (SIOP) Africa President; Peter Ssenyonga (Uganda) and Edwin Mogere (Kenya) who are both specialist neurosurgeons; and Moawia Elhassan (Sudan) who is a radiation oncologist with a paediatric interest.

Proposed international speakers are: Tom Merchant (Chair of the Radiation Oncology Department at St Jude Children’s Research Hospital, Tennessee, USA); Siddartha Laskar (professor of paediatric radiation oncology at Tata Memorial Hospital, India); and Simon Bailey (who established a childhood cancer charity in Malawi and is Head of the Paediatric Oncology Department at the Great North Children’s Hospital and University of Newcastle-upon-Tyne, UK).

“My wider vision for a sub-Saharan Africa neuro-oncology society is that there is a pressing need to encourage communication between surgeons and other healthcare professionals in these countries. We must not be left to work in isolation as is often the case now. North-to-south collaboration needs to be encouraged [referring to the richer, northern hemisphere nations]. But this communication must be two-way because wealthier countries in the north have a duty to understand the context of the sub-Saharan region, rather than trying to teach our region how to do things.”

Alan envisions a neuro-oncology society that would build teams of collaborators from across the sub-Saharan Africa region, which would perform various functions including:

- hosting an annual multi-disciplinary team meeting
- developing regional setting-specific protocols
- auditing and publishing the clinical outcomes of treatment protocols
- coordinating neuro-oncology education and training
- helping guide existing educational initiatives, such as SIOP-PODC (International Society of

Paediatric Oncology-Paediatric Oncology in Developing Countries) and PROS-LMIC (Paediatric Radiation Oncology Society - Low and Middle Income Countries), ESMO (European Society for Medical Oncology), ESTRO (European Society for Radiotherapy and Oncology), ASCO (American Society of Clinical Oncology), and IAEA (International Atomic Energy Agency).

Summing up, Alan Davidson described their proposal's strengths:

- their established PBTW meeting
- existing relationships throughout the region

- an experienced team
- an effective oncology department

“There are challenges and obstacles, such as the expense and great distances of travel in the subcontinent, the variety of settings across sub-Saharan Africa, and the difficulties and costs of translation. Money is the real issue and we have lost university funding for scholarships.”

The provisional budget for the proposed educational course will be an average cost per non-South African delegate of US\$1,350 (ZAR 17,500), with the total expense amounting to US\$17,300 (ZAR 225,000).

Presentation 5

Abuja Nigeria Group:

Dr James Balogun



Above: consultant neurosurgeon Dr James Balogun represented a clinical team from the Ibadan/Abuja region in Nigeria.

Dr James Balogun is a consultant neurosurgeon at University College Hospital (UCH) in Ibadan and faculty member at the Department of Surgery, College of Medicine, University of Ibadan, Nigeria. At the S-SANOC planning meeting, he represented a team from the Ibadan/Abuja region.

Nigeria faces significant challenge in brain tumour care. A country with a population of 193 million, which is expected to double by 2050, Nigeria is a nation of diverse ethnic and religious groups. Most



Above: Dr James Balogun: an important goal of the 2018 neuro-oncology course in sub-Saharan Africa would be to identify knowledge gaps and stimulate research

patients have to pay for their care, which is typically at great personal cost. Allocation for health spending varies between 6% and 15% of the national budget.

The target audience for James' group's proposed neuro-oncology course would be: neurosurgeons and neurosurgery trainees, adult and paediatric brain tumour physicians, radiation oncologists, neuroscience nurses, radiologists, family physicians and patient advocacy groups. The first goal of the course would be to improve the understanding of the basics of neuro-oncology.

Typically, there is a big lag-time between a doctor's referral and neurosurgery for brain tumour patients in Nigeria. Hence, improving communication and fostering collaboration is a key priority. There are 'islands of excellence' across sub-Saharan Africa but there is little communication between these centres.

Other goals of the course/conference would be to:

- facilitate an understanding of the need for multi-disciplinary care/tumour boards in neuro-oncology
- provide an opportunity for the identification and collaboration of the available brain tumour workforce

"There is minimal brain tumour research in Africa," James said. "Hence an important goal of the course would be to stimulate research through the identification of knowledge gaps. The final goal of the course will be to improve the understanding of palliative and end-of-life care in brain and spinal cord tumour patients. People do not die in dignity, and there is little support for the dying."

One of the key topics at a 2018 course will be "Africa and the 2016 WHO brain tumour classification".

There are few facilities for molecular analyses, which is a pivotal diagnostic feature in the latest classification. A topic for discussion among course delegates will be how to address this and to put Africa at the centre of the classification and make the most of resources and what is available.



Above: Now is the time to pool resources and pull people together rather than being 'islands', James Balogun said in his presentation at the S-SANOC planning meeting

The course content will also seek to stimulate neuro-oncology research in the sub-Saharan Africa region, and

will include content designed to start the process of forming tailored guidelines for brain tumour therapy.

"We need to bring people together and discuss how these goals can be achieved. We will invite delegates and speakers from different regions to get their different perspectives. The course would be part of the process of building a neuro-oncology consortium that involves west, east, central and southern Africa."

Finally, the proposed course will draw up best practice for using the technology that is affordable to sub-Saharan African nations, such as ultrasound and tele-pathology. This could help close existing gaps in brain tumour care.

James displayed a colour-labelled map of sub-Saharan Africa, showing the wide variety of pathology expertise across the continent. For example, Nigeria has 158 trained pathologists while Cameroon has 12, and Somalia has none. Treatment needs to be optimised in line with the resources available. He showed an example of treatment guidelines for medulloblastoma that had been adapted for low- and middle-income countries (as published in the journal *Pediatric Blood Cancer* and prepared by SIOP PODC). These treatment recommendations are given according to the level of facilities and resources available on a rating of 0 to 4.

The Chairs for the neuro-oncology course - which would be held in Abuja (Nigeria's capital city) - are Dr Mark Bernstein and Associate Prof Kate Drummond. Dr Bernstein is a neurosurgeon at Toronto Western Hospital and is the Greg Wilkins-Barrick Chair in International Surgery at the University of Toronto, Canada. Associate Prof Drummond is a neurosurgeon at The Royal Melbourne Hospital and Director of the Central Nervous System Tumour Stream at Victorian Cancer Centre, Australia and undertakes annual teaching visits to Zimbabwe.

James Balogun's team, which is based at University College Hospital in Ibadan, consists of neurosurgeons, pathologists, radiologists, radiation oncologists, neurologists and paediatric neurologists. They have a collaboration with the Nigerian Academy of Neurosurgeons and Nigerian Societies of Neurological Sciences. The neuro-oncology course could ideally take place coincidentally with the Continental Association of African Neurosurgical Societies (CAANS) conference in Abuja City in July 2018.

Summary points from the provisional budget include:

- air fares for two international speakers: US\$4,000
- two days' hotel accommodation and food for faculty members: US\$1,500
- website/internet portal/notification flyers: US\$1,000
- hall rental/PA system/multimedia: US\$1000
- full catering services: US\$1500;
- course pack, program and associated materials: US\$1,000

"In relation to a sub-Saharan Africa neuro-oncology society," said James, "now is the time to pool resources and pull people together rather than being islands. Promoting education and training in all aspects of neuro-oncology is a key function of the proposed society, and the group will address the peculiarities of neuro-oncology in sub-Saharan Africa. The society should facilitate synergy and engender collaboration. We can also leverage relationships with organisations, such as SNO (Society for Neuro-Oncology), EANO (European Association of Neuro-Oncology), ASNO (Asian Society for Neuro-Oncology) and ISPNO (International Symposium on Pediatric Neuro-Oncology). It will also provide a platform to engage with the pharmaceutical industry."

A clear, documented vision and scope would be core, and the building units of the group will be made of national societies. The new society will act as a team with an ethos of inclusivity and balanced multi-disciplinary representation. It may be skewed in disciplines at the beginning, but it will foster inclusion of all. It should run an annual meeting and will have established procedures for governance, structure, constitution, finances, and legal aspects.

James further explained that: "There are many challenges and possible barriers for the creation of such a society. There is a lack of neuro-oncology specialists across sub-Saharan Africa, and industry, health organisations and government support tend to be focused on infectious diseases, rather than cancers. Geographical divides and ideological differences are potential barriers, while previously-held inaccurate stereotyped beliefs must be done away with if we are to maximise the future prospects of brain tumour patients. We have not yet been able to engage patient advocacy. We have tried to engage advocacy groups but have not been successful thus far, after having made first contact."

Presentation 6

Accra, Ghana Group:

Dr Teddy Totimeh



Above: Consultant neurosurgeon Dr Teddy Totimeh said that, in Ghana, they have the opportunity to look at brain tumour care in new ways and increase awareness.

Dr Teddy Totimeh is a consultant neurosurgeon at the Greater Accra Regional Hospital in Ghana and runs nationwide symposia on head trauma and primary trauma care.

"Ghana is the gateway to Africa," he said, and added with an engaging smile that he also considers Ghana to be the centre of the world. "Ghana is on the Greenwich Meridian where it crosses the equator and so geographically qualifies as being the centre of the world. Accra, the capital of Ghana, is a place that is radiating regional change and increasingly is a city where learning, teaching, and mentorship take place, with the effect of the location representing a synergy of bright minds."

The three principal goals of the Ghana group's proposed brain tumour course/conference in Accra are that:

1. It will **focus** attention on regional brain tumour care.
2. It will **extend** regional networks of knowledge and practice.
3. It will **inspire** new momentum on publishing brain tumour research.

"We are competing with infectious diseases and other challenges in Africa, and we have the opportunity to look at brain tumour care in new ways and increase

awareness to give it a place on the government and public agenda.”

The Accra team’s proposed brain tumour course/conference Chairs are: Dr Mark Gilbert (Chief of the Neuro-Oncology Branch at the National Institutes of Health, USA), Dr Mitch Berger (Professor and Chairman, Department of Neurological Surgery, University of California, USA), Dr Abhik Ray-Chaudhury (neuropathologist and Associate Professor at Ohio State University College of Medicine, USA, and National Institutes of Health, Maryland, USA), Dr Lindsay Rowe (clinician and clinical researcher at the National Institutes of Health Clinical Center, USA), Dr Patrick Bankah (neurosurgeon at Korle Bu Teaching Hospital, Accra, Ghana), Dr Edjah Nduom (neurosurgical oncologist in the Surgical Neurology Branch of the National Institutes of Health, USA), and Jerome Boatey (neurosurgeon in Temple, Texas, USA, who received his medical degree from the University of Ghana Medical School). Teddy felt that the proposed team has a good mix of youth and experience, which would increase the course/conference’s appeal to a wide range of practitioners.

The team’s vision is three-fold;

1. **harnessing** the brain tumour community’s collective ability
2. **encouraging** a renewed focus on conducting and publishing brain tumour research
3. **creating** bridges with the wider world for training, equipment and patient support strategies

“Coming together allows these things to happen and the course/conference will help us to build bridges with teaching, training and patient support strategies – which currently aren’t working well in this area,” said Teddy.

Accra is well positioned to ride the new tide of health investment.

Teddy explained that Ghana is going through a phase where more money is going into private health so it may be a very different, more positive picture in the coming years.

Private investors are driving much of this change, although collaboration is needed to ensure that new privately financed cancer services are fully staffed and sustainable:

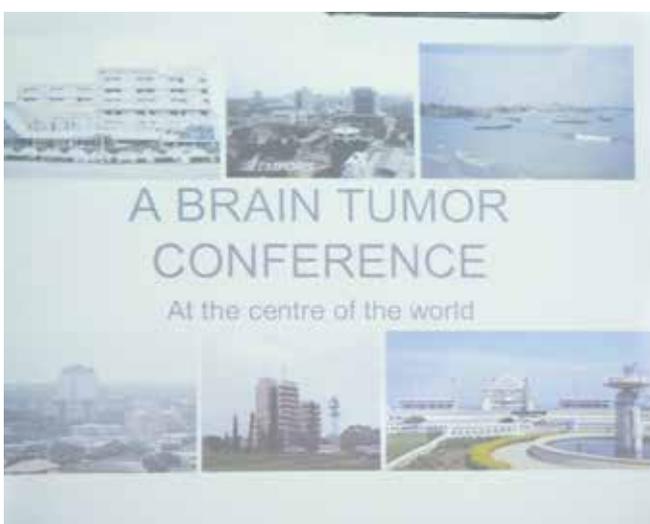
“Private initiatives are thinking ‘big’, although many investors are looking at buildings and physical infrastructure only – these conferences will give us the ability to bring people together to tackle these issues.”

One of the main challenges faced by the neuro-oncology community in sub-Saharan Africa is that brain tumours are not a high priority for funding. Rather, infectious diseases have the ultimate draw - a theme which was stressed by other speakers at the S-SANOC meeting.

The cost of travel between African nations is another significant challenge for a proposed course in sub-Saharan Africa. It can be cheaper to fly in and out of Europe. The lack of funding and resources not only limits the capacity to treat brain tumours, it also saps the motivation of those who want to bring about positive change.

A brief summary of the provisional budget for the educational course included conference facility fees, accommodation for visiting attendees, and travel for trainees, which came to US\$28,000. However, Teddy hoped that patient advocacy groups would be included in the final conference budget.

Below: Teddy Totimeh: “We can harness many voices across Africa.”



“We have secured significant discounts from the potential hosting hotel, the location has a developed information technology infrastructure, and is in easy reach of historical and international landmarks. The official language in Ghana is English. Infrastructure in Accra is also well-developed, safe, secure and welcoming, and direct flights are readily available.”

The proposed Ghana course/conference would feature plenaries, breakout discussions, and a day to give voice to patient advocacy groups. The target audience would be 100 local participants, 100 regional participants, and a wide range of disciplines including specialists, consultants, nurses, and paramedics.

Teddy closed with the words: “We can harness many voices across Africa to the centre of the world!”



Above: Dr Edjah Nduom - part of the Accra, Ghana consortium - discussed ideas for securing funding from other groups and forming relationships with other organisations.

Discussion

Christine Mungoshi (Zimbabwe Brain Tumour Association/ZBTA) asked about the Accra team’s ambitions for the number of patient advocates they hoped would attend the course/conference. Teddy replied: “The number of delegates is to include all disciplines. It is a big number so that patient advocates can come.”

Anita Granero (IBTA Senior Advisor and Oscar’s Angels, France) wondered what patient organisations they were able to build links with in the region. Teddy said that they had a connection with a paediatric cancer organisation and that strong relationships with patients would hopefully be a stepping stone for developing relationships with more patient groups.



Above: The Zimbabwe Brain Tumour Association’s Christine Mungoshi strongly recommended the inclusion of brain tumour patient advocacy organisations in any plans for a sub-Saharan Africa neuro-oncology course/conference

Presentation 7

Lome, Togo Group:

Prof Nimrod Juniahs

Mwakitawha Mwang’ombe



Above: Prof Nimrod Juniahs Mwakitawha Mwang’ombe is based in Nairobi, Kenya and is Director of the Neurosurgery Residency Training Program at Kenyatta National Hospital

[Editor’s note: Due to unforeseen circumstances, Prof Nimrod Juniahs was unable to attend the S-SANOC planning meeting at the last minute and so gave his presentation via a pre-recorded video.]

Prof Nimrod Juniahs Mwakitawha Mwang'ombe is Head of Surgery at the University of Nairobi and Program Director of the Neurosurgery Residency Training Program at Kenyatta National Hospital in Nairobi, Kenya. He is also President-elect of the Pan African Association of Neurological Sciences (PAANS).

Nimrod said: "It is generally known that brain tumours are responsible for 2% of all cancer deaths and are the most common solid tumour in young patients, representing 20% of childhood cancers. However, there is difficulty in gathering information in sub-Saharan Africa, resulting in underreporting and fragmented data. The increasing expectations on health services, despite limited funding, serves to further compound this problem."

Nimrod authored a research paper which sought to gain an accurate picture of brain tumours in Kenya and which reviewed and analysed all available existing brain tumour-related data from 1971 to 2005. The research was carried out at Kenyatta National Hospital tertiary referral centre in Nairobi, which has a total bed capacity of 1,800 and hosts a neurosurgical unit.

The research showed that the rate of new brain tumours in developed countries is approximately double that of developing countries. This is possibly due to under-diagnosis although it is thought that ethnic differences may alter the susceptibility to the development of brain tumours.

"We discovered that the majority (60%) of astrocytomas diagnosed in Kenya are in the under-30s, and nearly all ependymomas (99%) are found in under-10s. Astrocytomas are the most common tumour type (37.9%), followed by meningioma (34.4%). What is of significance are the very low numbers (2.8%) of metastatic brain tumours (those spread from other cancers) in Kenya, which is a common finding across Africa."

Nimrod said that studies comparing brain tumour incidence have consistently shown lower incidence in Africans compared to European populations. Several research papers conducted over many years have made this same observation in both malignant and so-called benign tumours. Research published in 2011 showed that young native-born Israelis of Ethiopian descent had a similar risk of brain tumours to those of Israeli children of non-Ethiopian descent. This study, therefore, suggests that the environment has a role to play.

"Further research," he added, "has since shown that there is a higher rate of brain tumours in black people

living in America than in those living in Africa. Rather than being solely due to genetic differences, tumour incidence among immigrants increases when they move to a richer nation and these differences are presumably due to changes in lifestyle or environmental risk factors."

In Africa, paediatric brain tumours represent the most common solid tumour of childhood. Occurring at a rate of three to five new cases per 100,000 children each year, medulloblastoma and low-grade glioma are the most common types, which is similar to elsewhere in the world. Specific data from Kenya show that the average age of diagnosis for brain tumours in the posterior fossa (the lower, rear brain regions) in children is 6.7 years. Brain tumours are more common in girls (a male-female ratio of 1:1.8).

The take-home message is that:

- **primary brain tumours are common in Africa**
- **they account for a large disease burden in a young population and**
- **rates of diagnosis are increasing - which will hopefully**

translate into improved outcomes in the future

Nimrod said that the way forward has two key elements.

1. Setting up a cancer registry in Kenya and other African countries will enhance the level of management of brain tumours in Africa and developing countries.

2. The formation of cross-country collaboration will play a major role in improving the healthcare management of brain tumours in this region.

There is a need to develop multi-disciplinary teams for brain tumour care across the entire sub-Saharan Africa region. There also needs to be a concerted effort to collect brain tumour data, especially now that diagnostic and surgical capacity is increasing.

A neuro-oncology educational course would take place in Lome, Togo, on 13-18 May 2018, during the biennial Pan African Association of Neurological Sciences (PAANS) Congress. The educational course's objectives will be to provide an update on the management of intrinsic and extrinsic tumours of the brain to physicians in developing countries and to create public awareness of brain tumours in sub-Saharan Africa.

The course co-chairs would be Nimrod and Prof Balogou A A Koffi (Professor of Neurology at Campus University Hospital of Lome, Togo). They had organised and run previous courses: the Comprehensive Clinical Neurosurgery Review Course ("The Management of Brain

Tumours in the African Patient”) in 2015 and the World Federation of Neurosurgical Societies (WFNS) Educational Course in 2011, both of which were held in Nairobi, Kenya.

A proposed new sub-Saharan Africa neuro-oncology society, said Nimrod, would have its head office in Nairobi, and the society would be a member of the Pan African Association of Neurological Sciences (PAANS). Membership of this neuro-oncology society will be broad and include all professions involved in brain tumour care, patients and relatives of those with brain tumours, and all those who support and advocate for the improvement of brain tumour care. Society meetings would be biennial and would continue to be held in conjunction with the PAANS Congress.

An association with PAANS would have benefits:

- PAANS is an organisation that spans all disciplines of the neurosciences, including neurology, neurosurgery, and neuroradiology.
- PAANS has membership in both English and French-speaking countries of Africa, which would further help with the membership drive.

Alongside PAANS, the new society would also work with its member countries to promote and facilitate the society’s activities. Officers and officials for the society will be elected at the PAANS Congress when it is launched. On an interim basis, Nairobi could offer facilities to coordinate the new society’s activities. The budget for the proposed neuro-oncology educational course had been submitted separately and also budgets for transporting participants from elsewhere in sub-Saharan Africa. The budget for the running of the proposed sub-Saharan Africa neuro-oncology society and the secretariat’s activities were to be prepared and submitted after the S-SANOC planning meeting in London.

Finally, Nimrod offered an invitation for S-SANOC delegates to attend the 23rd biennial PAANS Congress in Lome, Togo. PAANS is willing to partner with the Society for Neuro-Oncology (SNO) and the International Brain Tumour Alliance (IBTA) to promote awareness and management of brain tumours in sub-Saharan Africa where healthcare is suboptimal, he said.

Plenary Session 3

Roundtable discussion on grant applicant group presentations with all participants



Above: Dr Gelareh Zadeh (seated left) and Dr Jason Huse (seated right) co-chaired a discussion session at the S-SANOC planning meeting

AFTER a short break, a 45-minute open discussion was chaired by Dr Gelareh Zadeh (Division of Neurosurgery, University of Toronto, Canada) and Dr Jason Huse (Department of Pathology, University of Texas MD Anderson Cancer Center, USA). The session offered an opportunity for S-SANOC participants to discuss pertinent issues arising from the morning’s presentations. In a lively and constructive session, a wide variety of views and opinions were expressed by representatives from all countries.

Gelareh Zadeh and Jason Huse said that there appear to be many divides within sub-Saharan African countries and communities. These are due to ideological differences, and have often existed for generations. Different regions have their own

healthcare approaches and there are challenges unique to each region.

Talking with S-SANOC delegates had confirmed that many mission efforts are sent to east Africa; but these isolated ventures need greater involvement with other people to be truly effective for improving the lives of those with brain tumours through breaking down divides and coming together. There are different professional organisations operating in sub-Saharan Africa that serve different specialities (e.g. neurological sciences, neuro-oncology, neurosurgery) yet they are not fully collaborating even though they are often treating the same patients.

Gelareh Zadeh asked the S-SANOC participants: “What do you see as the barriers and divides?”

Dr Edjah Nduom (Surgical Neurology Branch, National Institutes of Health, USA) added the follow-on question: “And what lessons can we learn?”

Christine Mungoshi (Zimbabwe Brain Tumour Association/ZBTA): “There seem to be divisions in brain tumour care in sub-Saharan Africa. Bringing different parties together may need someone who is an independent and who can use their moderating influence to bring cohesion. Specialist healthcare professionals struggle to cope with massive work load and responsibility. As such, patient advocates could become effective in the organization of other tasks as they have time at their disposal. Patient advocates could also be effective in bringing groups of professionals together because they do not have the time constraints that healthcare professionals do.”

Dr Teddy Totimeh (Greater Accra Regional Hospital, Ghana): “The health professional’s workload in sub-Saharan Africa is a significant barrier to improving collaboration. The absolute numbers of brain tumour patients are low, but there is so much other clinical work to deal with that you don’t have the time or resources to collaborate. Doctors regularly feel overwhelmed with work and so they lack capacity to look outwards. Training in brain tumour care should be extended for healthcare professionals, which will help to foster an attitude of learning and sharing with others. The more that people know about effective brain tumour care, and the more they know about others’ ways of treating brain tumour patients, the more likely they are to collaborate. Change does not come without concerted effort.”

Dr Trish Scanlan (Their Lives Matter, Dar-es-Salaam, Tanzania): “I agree – the amount of work is exponentially more than doctors can cope with. Collaboration should also be embraced on a smaller scale. Within departments, we need to hold hands also otherwise, the multi-disciplinary team approach will not work. I have seen some good and effective multi-disciplinary working in paediatric oncology.”

Dr Patrick Bankah (Korle Bu Teaching Hospital, Accra, Ghana): “We are a huge football nation. We have regional competitions and we also have a continental cup. Brain tumour collaborations could be structured in similar ways. It’s easier to use regionalisms first. We can strengthen them, and then



Above: Dr Teddy Totimeh said that the health professional’s workload is a significant barrier to improving collaboration in sub-Saharan Africa



Above: Dr Patrick Bankah (speaking above) from Accra, Ghana said that regional collaboration should be established first which can lead to stronger national efforts

these regional groups can talk to each other.”

Christine Mungoshi: “I have a concern that brain tumour care across sub-Saharan Africa could become fragmented. Each region can come together to build one voice but there is a danger that some areas could be left behind. How do you get all the regions to work together?”



Above: Session co-chair Gelareh Zadeh (Division of Neurosurgery, University of Toronto, Canada): “The regionalisation model proposed by Patrick Bankah could be effective.”



Above: Anita Granero (above centre): “Patient advocates can play a crucial role in bridging divides.”

Anita Granero (IBTA Senior Advisor and Oscar’s Angels, France): “Even in France and due to the many different disciplines involved in the care of paediatric brain tumour patients even in France communication can be fraught with difficulty. A volunteer can act as the link and as a member of the family to bring the different professionals together to care for the child. The

volunteer can stay alongside the family throughout their journey, all the way including palliative care and end-of-life. Even in a country like France, there is a huge problem with palliative care – talking about it is still a taboo; but we must not forget it.”

The discussion moved on to the topic of the educational course/conference supported by the SNO Wilkins-Barrick International Outreach Course in Neuro-Oncology grant.

Prof Alan Davidson (Red Cross War Memorial Children’s Hospital, Cape Town, South Africa): “We would support collegially and morally to pitch in and make it work. However, finances are typically a limiting factor. The problem is to get people together – and this takes money. ESMO [European Society for Medical Oncology] runs a three-day course in Africa, but there is a massive budget to get people there. It’s not about having the meeting, but about getting to the course the people who need to be there, otherwise the danger is of ‘preaching to the choir.’”



Above: Irene Azong-Wara established the patient advocacy organisation Jacob’s Hope Foundation in Cameroon when her father was diagnosed with a brain tumour

Irene Azong-Wara (Jacob’s Hope Foundation, Cameroon): “We have a big wall to break. Even within one country there are many different languages and different cultures. I am tired of ‘networking’ – we communicate for a while then nothing happens. A three-day course will not suffice. Rather than focus on just one event, a longer-lasting educational initiative should be considered. An effective project might be an online course or group that will get people to

work and participate together. There is a lot of talent but few opportunities and people who do undertake education and training must know that they are doing something worthwhile. Often this is not the case. If you do training, such as a three-day course, how do you follow-up to see what impact it has? People need to feel that they are 'adding value'. An initial enrolment fee could be refunded after completion, to serve as an additional incentive. We need money, but we also need value."



Above: Shungu Ushewokunze stressed that it was important not to start out in too complicated a way.

Shungu Ushewokunze (Sheffield Children's Hospital NHS foundation Trust, UK): "There are 46 countries in sub-Saharan Africa. But in this room, we are representing less than ten of them. We need to do something simple, not complicated. It is going to cost a lot of money to transport people and make an event accessible."

Teddy Totimeh (Greater Accra Regional Hospital, Ghana): "In support of a proposed course/conference, it should serve as a springboard for greater things. This is the first conference. But I hope that there are many more. I agree that webinars and online courses are a good idea and these could follow a first conference. I want to see a unified sub-Saharan patient body, and one for professionals, which communicate regularly with each other. I hope that the conference would be the seed. When created, it would validate brain tumour stakeholders, offering them the legitimacy and confidence to approach larger funding bodies for financial support. It should be the start of planning for something bigger."

Jason Huse: "What this hypothetical meeting would achieve is awareness-raising, information transfer, communicating best practice, networking, practical skills training, promoting research, and the bringing together of a society. Probably not all of these objectives can be accomplished practically in a two-day meeting. What, therefore, is the priority and what creative ways can be employed to achieve these goals?"

Gelareh Zadeh (Division of Neurosurgery, University of Toronto, Canada): "The diversity in sub-Saharan Africa is present due to geopolitical issues. But in North America, there is also great diversity and under-resourcing. The barriers in Africa need to be overcome, but diversity is not unique. Regionalisation is not necessarily a bad thing. Advocacy can be a binding force. Resources could be put into a web-based activity, which would help bind people together, but do we want this before we have a meeting? This should not be a one-time event. We could all make a commitment for five years or more."



Above: Dr Brian Nyatanga said a clear definition of what patient advocacy is in sub-Saharan Africa would be needed

Dr Brian Nyatanga (Centre for Palliative Care, University of Worcester, UK): "How strong are the bridges? We need a clear definition of what patient advocacy is. What is the interpretation of patient advocacy and how do people understand it? Advocacy suggests that people with a brain tumour cannot speak for themselves. Does this create dependence? Is it not better to create something that empowers brain tumour patients so that they can stand on their own two feet? We may not be able to provide



Above: Shade Adoh (originally from Nigeria) attended the S-SANOC planning meeting

Gordon Oliver (IBTA Co-Director, UK): “My view is that advocacy is an interim arrangement in some senses. It is about empowering people whose lives have been affected by brain tumours, especially those who are very busy with running their own lives and caring for others. Advocacy is to provide a source of information and take an active part in trying to give back to the patient the normality of the life that was taken away from them. The advocate’s role is to help and to protect.”

Anita Granero (IBTA Senior Advisor and Oscar’s Angels, France): “Advocacy is the empowering of patients and parents, but it is also empowering the medical community. Many times, the patient advocacy



Above: IBTA Co-Director Gordon Oliver defined patient advocacy as providing “a source of information and taking an active part in trying to give back to the patient the normality of the life that was taken away from them. The advocate’s role is to help and protect.”

organisation defends the hospital/centre that is treating the patient by getting resources and through lobbies and petitions. Advocacy is a partnership.”

Alan Davidson (Red Cross War Memorial Children’s Hospital, Cape Town, South Africa): “I urge caution about aiming to do too much too soon. We should start with small initiatives before attempting large schemes. In my experience, ‘twinning’ a hospital in a developing nation with one in a rich country for the explicit purpose of sharing training and advice can be very successful. I urge delegates to do what we do well – be it treating, teaching or caring – and then take others with us.”

Plenary Session 4

Setting the Scene: Presentations from the sub-Saharan brain tumour patient and caregiver organisations and the International Brain Tumour Alliance (IBTA)

Introduction by Chair - Christine Mungoshi (Zimbabwe Brain Tumour Association/ZBTA)



Above: Christine Mungoshi played a pivotal role in the genesis of the S-SANOC planning meeting

THE first session of the afternoon was chaired by Christine Mungoshi (Founder and Director of the Zimbabwe Brain Tumour Association), who was a member of the S-SANOC Organising Committee and played a foundation role in the genesis of the event.

Plenary Session 4 shifted the perspective of the day to brain tumour patient and caregiver advocacy organisations.

Christine said "Brain tumour patients in sub-Saharan Africa have been suffering for a long time and they need firm representation to improve on the current situation. Brain tumours are different from other cancers in that they can, depending on the tumour's location, cause someone to lose their ability to talk, move, and perform basic functions that we usually take for granted. The brain tumour patient will often rely on support from their caregivers, therefore, we



Above: Christine Mungoshi gave an impassioned address about the situation for brain tumour patients and caregivers in sub-Saharan Africa

work with patients and caregivers to be a strong support for them.

I understand the pain of having a loved one suffer from a brain tumour. This journey is personal to me. I lost my daughter Paida to a brain tumour. She was the pearl of my heart. No parent can ever think of burying their child, but when it happens it is very painful. It means you bury your dreams for them, the future you imagined for them, all the expectations - it is agonizing. I still follow my daughter's age mates and try to imagine her life alongside their milestones. I look at her peers, some of whom have now graduated from college, and I wonder how she could have been. I always feel my daughter's situation could have been different if she had access to proper medical care. The brain tumour journey is different for those who have proper medical care. What could have happened if she had access to such care? She went through unnecessary pain. Whilst it is not always easy to talk about it, I feel it is important to talk with someone, or with one another to share our stories."

Putting the sub-Saharan Africa brain tumour situation into a global context, Christine said that the region falls way below expected standards. According to the World Health Organisation: "the highest attainable standard of health is a fundamental right of every human being". And in sub-Saharan Africa the fundamental right to health is not being met by many countries, Christine added.

"Some people in sub-Saharan Africa have zero chance of survival after a brain tumour diagnosis. According to a World Federation of Neurosurgical Societies 2016 report, Sierra Leone, Central Africa Republic, Lesotho and South Sudan have no neurosurgeons. The Democratic Republic of Congo has four neurosurgeons with a population of 74.8 million, whilst the UK has 220 neurosurgeons with a population of 64.6 million people. We don't even know how many brain tumour patients there are in sub-Saharan Africa as the region does not have up-to-date brain tumour statistical data.

Christine shared the story of an eight-year-old Zimbabwean girl called Joyce who was diagnosed with a brain tumour.

"Joyce travelled to a hospital where they inserted a shunt. They then sent her back home and she was well, but couldn't afford more treatment. In 2010,

however, Joyce started to experience seizures. She had a scan, which showed the tumour had grown and she needed surgery as soon as possible. Since her parents were peasant farmers, they failed to raise money in time. When they finally raised the money required, Joyce eventually had surgery late in 2011 and surgery was followed by some radiotherapy sessions. But events then took a disastrous turn when the only radiotherapy machine in the country broke down while Joyce was due to undergo follow-up radiation therapy. Joyce sadly died in July 2012. We feel she would have had a chance of survival with adequate resources and timely treatment. We know we are not going to save everyone, but if everyone could have a chance of treatment then that would make a huge difference.

"We feel that a lack of resources and the system failed Joyce.

"We are all here at the S-SANOC meeting because we care. Each and every one of us is here because we want to make a change.

"I am making a call to you all, so that we can be strong and, together, we can reduce suffering in sub-Saharan Africa. Some will say it is an insurmountable challenge, but I want to remind you of the HIV/AIDS situation. People said there would never be a cure, but look at what happened – the successes and the differences made – when people came together. In communities, cultural attitudes towards HIV/AIDS are changing. Once, traditional physicians were recommending people not to use condoms, and that having sex with a young girl would cure you. Today, the situation is different as people have faith in their health systems' ability to treat HIV/AIDS. People's perceptions are changing and HIV/AIDS has been reduced to a chronic disease. Such a transformation could happen for brain tumours."

The Patient Advocacy Presentations

Irene Azong-Wara: Jacob's Hope Foundation, Cameroon



Above: Irene Azong-Wara (pictured above centre) has devoted her substantial energy and creativity to improving the situation for people in Cameroon with brain tumours and other cancers

IRENE Azong-Wara from Cameroon is the founder of Jacob's Hope Foundation, which became an established community-based organisation in 2016.

The idea for Jacob's Hope Foundation started in 2014 when her father (after whom the foundation is named) was diagnosed with a brain tumour. Describing their journey, she gave a moving account of how difficult it was to get treatment for him.

Surgery was not an option for Irene's father and there was only one radiotherapy machine in the country, which also serves other neighbouring nations. Health personnel were overloaded with the massive patient inflow and extremely long waits for radiotherapy were the norm. "You would arrive at 6am and wait until 6pm. Bribery and corruption were used to get a ticket for treatment," Irene said.

Her father received 36 radiation treatments over four months, but the radiotherapy machine was broken for two to three weeks at a time. Equipment would frequently break down, meaning that a day's wait

for therapy could result in non-treatment. Pain relief such as morphine was also in short supply and only available to patients in the Cameroonian cities of Douala, Yaoundé and Bamenda.

Irene showed photos of the overcrowded hospital waiting area and antiquated radiotherapy machine, which appeared to be held together with adhesive tape.

These challenges motivated her after the struggles she and her father faced.

"How can we make a change? How can we make waiting interesting?" These were two of the first questions Irene asked herself when she was establishing Jacob's Hope Foundation.

The three goals of Jacob's Hope Foundation are to:

1. raise **awareness**
2. create a **network** of brain tumour patients, medical experts and caregivers
3. provide patients and caregivers with **accurate and understandable information** about their brain tumour. This latter goal has presented one of the greatest struggles because test results are given in French – and the exact details are unclear.

Jacob's Hope Foundation is a not-for-profit organisation based in Cameroon's economic capital, Douala, where the only centre of care is located. Using communication technologies, such as the WhatsApp messaging smartphone app, Irene carries out the foundation's major activities from Douala. So far, these have included raising awareness, fundraising for painkillers, and offering psychological support. Social media platforms are useful in brain tumour awareness raising. Sales of t-shirts - which are handmade by brain tumour patients and carry the text 'Cancer does not have a face until it's yours or someone you know' - have helped fund pain relief provision.

Irene said: "I first got women involved – men are hard to recruit. I started an initiative called 'Beat Cancer Generously', where volunteers offer a hair and make-up service to members of the public. There is not a word for cancer in my language. It is a disease without a name."

A body art awareness-raising initiative in Cameroon used images of a naked woman painted head-to-toe with various words that are used to describe cancer in different languages. Professional photos were printed and taken to the radiotherapy waiting room.

Irene said that the photos prompted lots of debate.



Above: The full attention of S-SANOC participants was on Irene Azong-Wara of Jacob's Hope Foundation as she described the plight of brain tumour patients and caregivers in her country, Cameroon

Listing some of the achievements of Jacob's Hope Foundation, Irene said that they had also been able to procure pain relief medications through collaboration with the non-profit organisation Camfomedic eV, which was founded in Germany by Cameroonian healthcare students and Germany-based Dr Ivo Azeh. Irene was also inspired by a fund-raising concept she first saw in Ghana.

"Women make accessories, while waiting for treatment, which are sold to buy painkillers. Providing a constructive way to use the time spent in a waiting room, women are trained in how to hand craft items such as earrings and fans. A cancer awareness walk will take place in November 2017 and it is our desire to find ways to help the least educated people understand about cancer and brain tumours."

In Cameroon, families affected by brain tumours typically have many unhelpful perspectives about the condition – but these vary between classes and income.

No one talks about it and regardless of background, all families will keep a brain tumour diagnosis secret.

Irene said that middle-class, modern, educated families usually travel abroad to France or India for treatment, finances permitting, while families from a traditional/rural background with lower education and income tend to consider brain tumours as witchcraft.

"A brain tumour is 'death by headache', and is believed to mean you are paying back the evil you have done to the community, or someone has bewitched you. Belief in witchcraft affected my father's journey. Someone came to my father's house to say that an animal was protecting my father. But a dog was later found attacking animals and my father was then told that he would die as a result. It is devastating that people have these beliefs today."

Both rich and poor in Cameroon use traditional healing methods to try to cure cancer. Religiosity is also a strong influence on all sectors of society. Poorer, lower class families often turn to local 'Men of God' for 'deliverance', while the educated middle classes may travel abroad – often to South Africa – to seek healing at 'Churches of Deliverance'.

Irene explained that these people are hoping for a miracle, especially those who have low education and income. "Some people are able to raise funds from locals for medical treatment using Facebook as a call for donations, but many people with cancer get to hospital too late." To powerfully illustrate this point, Irene showed a photo of a woman who had arrived at hospital with breast cancer that had grown to such a size that it had broken through her skin.

The pressing challenges in Cameroon are:

- limited funds
 - limited access to information - what little is available is in French only
 - difficulties talking about cancer due to cultural norms
 - the conflict of modern versus traditional medicine
 - having access to hospital and doctor referrals – even those with financial means do not know where to go
 - bridging the gap between patients and doctors, the latter of whom are seen as ‘Gods’ and the last hope
 - in the rural communities, people do not even know the difference between doctors and nurses
- Looking towards the future, Irene shared her ‘wish list’ for a planned health fair project.

“I came up with an idea with friends to run health fairs for corporations. Organising and running these events may provide us with potential funding and a way of raising awareness of brain tumours in the middle classes who can afford to pay for healthcare.”

In addition to running health fairs, Jacob’s Hope Foundation’s goals include the creation of ‘health kiosks’, which Irene described as “information points in local areas so people know where to go for help.” Smart technology needs to be adopted to help brain tumour and cancer patients better understand their conditions - for example, a smartphone app that would give information about different types of cancer and what to do.

Longer term, Jacob’s Hope Foundation will be seeking the establishment of cancer care and palliative care centres, a chemotherapy centre, and real estate/homes for people affected by cancer.

“Through Jacob’s Hope Foundation, we hope we can create jobs, improve quality of life, and make the world a better place,” Irene said.

Bonita Suckling: Rainbows and Smiles, South Africa



Above: Bonita Suckling (Rainbows and Smiles, South Africa) lost her little boy, Jed, to a brain tumour and has since dedicated her life to helping children with this devastating disease

BONITA Suckling founded ‘Rainbows and Smiles’ in South Africa in 2009, in memory of her young son Jed who died from an anaplastic astrocytoma. Rainbows and Smiles is a charity dedicated to supporting those affected by childhood brain tumours.

“When Jed was on his deathbed, I made a promise that I would fight brain tumours for the rest of my life. I want to see the brain tumour community across sub-Saharan Africa collaborate and share knowledge.” She told S-SANOC participants that “Africa needs you!”

“Health advocacy is very different from ‘advocacy’. Whereas ‘advocacy’ means to ‘influence decisions within political, economic, and social systems and institutions’, ‘health advocacy’ is to ‘support and promote patients’ healthcare rights, and enhance community health’. At Rainbows and Smiles, we have adopted a human-rights based approach, which is a matter of social justice and gives a voice to the voiceless.”

Rainbows and Smiles exists to provide hope, fun and laughter to help families through the childhood cancer journey, while also seeking to give them the best possible treatment options, information and support.

“We do not discriminate on the basis of race, colour, culture, religion, financial status or any other factor.

“We have a team of passionate advocates and our organisation’s achievements to date include:

- becoming a member of the Cancer Alliance of South Africa
- presenting at the 2015 IBTA World Summit of Brain Tumour Patient Advocates in Barcelona, Spain
- attending the International Society of Paediatric Oncology (SIOP) 2016 Annual Congress
- full registration as a Public Benefit Organisation (PBO) in South Africa
- recognition as a Level 1 B-BBEE (Broad-Based Black Economic Empowerment) organisation which is an official government grading that indicates the highest standards of black workforce integration.”

So that Rainbows and Smiles could best focus its resources on meeting the specific needs of patients, their families and caregivers in South Africa, the organisation devised and sent a questionnaire to people who had been affected by brain tumours. An advocacy toolkit was then put together in response to questionnaire replies.

The priorities identified for improving the lives of those affected by brain tumours are:

- gaining access to treatment
- diagnosing and treating early (including education of early warning signs)
- upholding patients’ right to healthcare, and empowerment for them to voice their needs
- improved cancer training and education for healthcare workers, including challenging negative attitudes which make the situation worse
- addressing cancer’s stigma, because many people still think it is a curse
- educating traditional healers
- providing good psychosocial care of cancer patients and their families
- re-engineering the health system to ensure integrated cancer services instead of prolonged waiting in hospital for a specialist service
- addressing the negative impact of poverty on cancer services, which means some patients cannot even afford to travel for treatment
- lobbying for and implementing effective government and non-profit organisation collaboration.

Bonita quoted one questionnaire response in particular: “Where you live should not determine the outcome of your treatment”.

Inequalities in financial and social support for cancer patients, and inequality in cancer care itself, will require workplace policy reform. This is a hope to which everyone can aspire. However for many cancer patients from rural areas in sub-Saharan Africa, this inequality is a stark reality. The cost of cancer care can spiral for cancer patients and puts their families into poverty.

“We should not lose hope. We can turn the hopelessness that many face with their diagnosis into a realised hope with joint action and collaboration,” said Bonita.



Above: Bonita Suckling: “Never lose hope!”

Rainbows and Smiles’ branding includes the image of a bumblebee and Bonita explained why.

“We used a symbol of the bumblebee because, aerodynamically, they are not supposed to be able to fly. But - they do! We shouldn’t be able to survive after the death of our child, but we do. We fly and we soar.”

At the end of her presentation, Bonita showed a moving video - a photo montage of the many activities Rainbows and Smiles organises: individual play time with paediatric patients (called “Love Without Boundaries”), craft days at the hospital; fundraising events; brain tumour awareness activities in the community including sporting events/bike rides; awareness talks; generating newspaper/television coverage; and a ‘victory ceremony’ for children with brain tumours. (The video can be viewed online here: <https://youtu.be/1Nz6XLBqenw>)

Linda Longwe: Zimbabwe Brain Tumor Association (ZBTA)

[Editor's Note: Due to difficulties obtaining travel approval, Linda Longwe was unable to attend the S-SANOC meeting in person. A video link was arranged so she could give her presentation remotely. A delay in establishing a link with Linda meant that the order of the afternoon's presentations was altered.]



Above: Linda Longwe of the Zimbabwe Brain Tumour Association gave her presentation to the S-SANOC planning meeting by video-link

COMPANY owner and entrepreneur Linda Longwe is a board member of the Zimbabwe Brain Tumour Association (ZBTA) and the Cancer Association of Zimbabwe.

She said: "The ZBTA was born out of a brain tumour support group in Harare, the country's capital city, and was originally made up of mostly brain tumour survivors and parents of brain tumour patients. They came together to share experiences and discuss the challenges and problems faced by brain tumour patients and their families and caregivers. The members decided to form a body that would raise awareness of brain tumours and the ZBTA is now a registered welfare organisation that seeks to find ways to address the challenges posed by brain tumours in Zimbabwe."

There is widespread ignorance about brain tumours

in Zimbabwe. Like many other countries in sub-Saharan Africa, people live with brain tumours and do not seek medical attention until it's too late for treatment. Nevertheless, with adequate knowledge and early diagnosis it is possible for many lives to be saved.

Brain tumours are peripheral to other health challenges such as HIV/AIDS and malaria. So brain tumours are overshadowed by these conditions. Therefore, in addition to disseminating information about brain tumours one of the ZBTA's key activities is to lobby government to create policies that are favourable to the cause of brain tumour patients. Specifically, the ZBTA petitions the government to retain existing specialist neurosurgeons, as well as promote interest from local medical students to work in Zimbabwe after completion of their studies.

When the ZBTA has the funds to do so it provides counselling support services to patients, their loved ones and caregivers. It also supports patients receiving CT scans, catheters and shunts, and provides patients with toiletries.

Linda said: "We co-ordinate support groups and give psychosocial support and help with the cost of hospital visits which are particularly important for those living in rural regions because their families usually cannot afford to attend. We used to provide food for patients, but the government of Zimbabwe has now improved the quality and quantity of food served in hospitals."

Linda explained that as of now, there are only 15 neurosurgeons in Zimbabwe - one neurosurgeon per million people. They are hugely overworked because they are required to attend to patients in government hospitals in addition to running their own practices.

Eighty-five per cent of the population are unemployed and most people have no access to health insurance. Thousands of people have lost their jobs since September 2015 due to the prevailing economic downturn. General healthcare has a very high cost - a CT scan costs at least US\$350 and an MRI costs US\$450 - an expense most people cannot afford. A surgical procedure by a private practice neurosurgeon can cost up to US\$12,000.

Cancer drugs at government hospitals and subsidised pharmacies are a nominal US\$5, but there is a serious shortage of drugs. This means scheduled surgical procedures are unlikely to take place on time. There

is also a huge need for patient accommodation in Zimbabwe. A hostel in Harare that provided free lodgings for patients receiving radiotherapy was closed at the height of inflation in 2007, and remains closed.

However, there are glimmers of hope for radiotherapy treatment. Radiation equipment has recently been upgraded although it is only available in two cities, Harare and Bulawayo, which are 431km apart. There are very limited services for brain tumour patients. Surgical equipment remains antiquated. There are no sophisticated treatments, such as gamma knife.

The cancer statistics in Zimbabwe are not a true reflection of what is on the ground. Mostly based on those who go to government hospitals, they don't include those who leave the country for treatment (most often in South Africa or India).

The ZBTA is greatly limited by lack of finances and is only able to provide minimal support to patients. It relies on corporate and donor funding, but because the country is going through such a terrible economic crisis, corporate budgets have been slashed. Additionally, Zimbabwe is seen as a challenging place to send money which further limits sources of donations.

Linda explained that she still remains optimistic for the future: "I see hope in medical missions from overseas. Medical missions come to Zimbabwe to provide eye surgery, heart surgery and cleft lip surgery. Such visits represent an opportunity for brain tumours. One US anaesthetist coordinated a highly successful cleft lip surgery mission. He was a member of a Rotary Club in the USA (part of Rotary International, which provides humanitarian services worldwide). Other teams have come from as far afield as India. Brain tumours know no colour, creed or religion. Contrary to media reports, Zimbabwe is a safe country. Should any medical teams consider our plea, ZBTA is more than willing to liaise with Rotary and provide the contact numbers for the medical practitioners who have come to Zimbabwe on medical missions over the past few years. Ours is a beautiful and friendly country with spectacular scenery and sights! Come and help with medical missions!"

Wilson Mugarura: Uganda Brain Tumour Foundation (UBTUF)



Above: Pastor Wilson Mugarura was inspired to help establish a Ugandan brain tumour patient and caregiver organisation after he was diagnosed with a meningioma in July 2014

PASTOR Wilson Mugarura, a brain tumour survivor, is a founder member and vice chairperson of the Uganda Brain Tumour Foundation (UBTUF). He thanked the S-SANOC organisers for his invitation to the event in London and said that he was representing the youngest organisation in attendance.

"I offer life experience in brain tumours," Wilson said. "I was diagnosed with a meningioma in July 2014 and was evacuated to Yashoda Hospital in Hyderabad State, South India and I had a successful neurosurgery on August 14th that year. Since returning to Uganda, I have suffered backache, weakness in the right side of my body, pain in my right shoulder and blurred vision in my right eye. I take medication to prevent epileptic seizures. My symptoms can fluctuate dramatically - yesterday, I was unable to move one leg but thankfully, today I'm fully mobile. In July 2016, I wanted to launch a brain tumour organisation. The concept was completely new in my country, but there was a clear need given that Uganda has 26 million people with about five neurosurgeons."

The UBTUF was founded by nine members, among which three are brain tumour survivors. It was set up to be a Ugandan non-governmental, charity

organization, dedicated to providing support and tailored services to anyone affected by any type of brain tumour and their families and caregivers. Three further members have joined. In addition to the survivor's wives, the membership has a wide range of experience and expertise, and includes a pathologist, lawyer/advocate, public health consultant, neurosurgeon, and a senior military officer.

The foundation aims to help major hospitals in Uganda gain access to brain tumour coordinators, quality diagnostic facilities and quality treatment options. A CT scan costs UK£60 and the machine often malfunctions. By 2020 the UBTUF wants to have proper diagnostic centres. It aims to help organise care for brain tumour patients, their families and their caregivers, according to their needs and expectations.

Belief in witchcraft is another major problem, and the UBTUF is hoping to establish and maintain an information resource centre to raise awareness about brain tumours in Ugandan communities.



Above: Pastor Wilson Mugarura: a priority for the Uganda Brain Tumour Foundation is to strengthen community participation in the care of patients

Strengthening community participation in the care of brain tumour patients is a further priority for the UBTUF. The organisation seeks to encourage and empower brain tumour patients and survivors to participate in their own care to enable them to provide their own solutions and to participate in decision-making about their health and healthcare.

"We want to empower people, rather than let them live in self-pity."

Given the limited care available in Uganda, the UBTUF also liaises with clinicians, scientists and allied health professionals to undertake fact-finding, research, monitoring and evaluation of brain tumours and related diseases.

Wilson said: "Government intervention helped change attitudes to HIV/AIDS which is an example of positive progress that could be achieved in relation to brain tumours." The UBTUF has the further objective of seeking "to enter into any arrangements with any government or other institutions, or authority, that may seem conducive to the organisation's objectives, or any of them to obtain any such institutions, charters, contracts, decree, rights, grants, loans, privileges or concessions that are desirable to the organisation."

The UBTUF does not want to work in isolation, but to collaborate with multiple brain tumour stakeholders and members of the Ugandan community and international organisations around the world.

More than making sure that brain tumour patients receive treatment, UBTUF's goal is to help them live every remaining minute of their lives to the fullest possible.

UBTUF's other goals include:

- **eradicating** the stigma of brain tumours
- **training** brain tumour community caregivers
- **engaging** people who can give care ranging from health personnel, families, relatives caring for patients and any other interested people
- **educating** the next generation of brain tumour physicians by encouraging high school students to study medicine and creating interest in medical students to specialise in neurosurgery and neuro-oncology

Patients in Uganda do not get quick and efficient attention due to the lack of proper diagnosis. Knowledge of brain tumours is poor and they are diagnosed very late, damaging the prospects for the patient's survival. Very few health facilities perform neurosurgery with so few neurosurgical specialists in the country and treatment and diagnostic systems are inefficient.

Wilson Mugarura says he is a lucky man. "Thank God I am among those lucky few who managed to receive surgery. My treatment cost over US\$30,000 – for the care I received in Uganda and the surgery in India. I am able to stand before you today, because I was lucky to receive a donation that helped me get brain tumour surgery in 2014. I know of one person who recently

died in one of Uganda’s hospitals because he could not raise the money needed for treatment. Even the limited MRI and CT facilities are too expensive for most people and in addition to the cost of a CT scan the current cost of an MRI is GB£157.”

Wilson Mugarura’s personal story illustrates the many challenges UBTUF faces. He was taken to hospital - a 100 km journey - in the back of a pickup truck after collapsing. When he arrived at the hospital at 10am, no doctor was able to see him. On his second day in hospital, he received a basic CT head scan, but there was no one available for another day to interpret the

results. On day three, the surgeon arrived, but the staff failed to let the surgeon know about Wilson.

UBTUF receives no government grants or funding, and is wholly dependent on funds raised by its members and the generosity of members of the public.

“We appeal to all who can, to support us,” said Wilson, “so that we fully establish our foundation in Uganda and are able to support those affected by brain tumours in our country. I thank Kathy Oliver, the IBTA, Christine Mungoshi and the ZBTA for the advice and inspiration given to the UBTUF Executive Director during the foundation’s inception stages in 2016.”

Kathy Oliver: International Brain Tumour Alliance (IBTA)



Above: Kathy Oliver, IBTA Chair and founding Co-Director, speaking at the S-SANOC planning meeting

KATHY Oliver is Chair and Co-Director of the International Brain Tumour Alliance (IBTA). She described the history, evolution, and activities of her organisation, while also offering insights into how the S-SANOC planning meeting came into being.

Kathy opened by speaking about her family’s personal story.

“I am not a doctor, nurse, researcher, scientist or politician but I used to be a freelance journalist. My

life changed thirteen years ago when our son Colin, aged 24, was diagnosed with a grade 2 astrocytoma.

In the five seconds it took for the neurosurgeon to say to my husband and me: ‘I’m so very sorry, Mr and Mrs Oliver, but your son has a brain tumour’, I was catapulted from being a wife, a mother and a journalist to a role that I never dreamed I would play – that of a brain tumour patient caregiver. We found ourselves on a completely unknown road, filled with fear. It was

these experiences that led me to become a brain tumour patient advocate. I have learned more about brain tumours than I ever thought I'd have to know.

But it's been my great privilege to work in this field with people from all over the world - incredibly dedicated doctors, clever researchers, amazing specialist nurses, and of course, some of the most courageous people I've ever met – patients and caregivers who are living with a brain tumour diagnosis.”

Kathy described her initial meeting with Christine Mungoshi (Zimbabwe Brain Tumour Association). Christine's young daughter, Paida, lost her life to a brain tumour and when Kathy and Christine met face-to-face for the first time in 2006 in a coffee shop in Surrey (UK) they discussed how they could help brain tumour patients in sub-Saharan Africa. They both earnestly wanted for these people to no longer face the nightmares experienced by Christine and her family when her daughter was diagnosed with this disease.



Above: Kathy Oliver and Christine Mungoshi at their first face-to-face meeting in 2006 in the UK

They continued these conversations over the following years and the next pivotal step in moving towards their goal resulted from a meeting attended by Kathy which was organised by Bristol-Myers Squibb two years ago. At that meeting, Kathy Oliver met Pat Garcia-Gonzalez, Chief Executive of The Max Foundation, a not-for-profit organisation which helps increase access to treatment, care and support for people living with cancer in developing countries.

After a long and inspiring conversation with Pat at the BMS meeting, Kathy started talking with Christine



Above: Kathy Oliver said that the S-SANOC event was two years in the planning but had already been a twinkle in her and Christine Mungoshi's eyes since they first met in 2006

Mungoshi about how they might be able to take a leaf out of the Max Foundation's book and do something helpful for brain tumour patients in Africa.

Kathy and Christine then set to work trying to organise a multi-stakeholder, international meeting in which brain tumour patient representatives, healthcare professionals and other interested parties could sit down together in the same room at the same time to try to figure out how best to help patients and caregivers in sub-Saharan Africa.

“And here we are today,” Kathy said. “It has taken about two years to organise this specific meeting. Now, together, we can try to improve things, perhaps little by little. But at least we can now try.”

She quoted the stirring words from surgeon and public health researcher Atul Gawande: “Better is possible. It does not take genius. It takes diligence. It takes moral clarity. It takes ingenuity. And above all, it takes a willingness to try.”

Kathy thanked those who had been instrumental in the S-SANOC planning meeting preparations, including Chas Haynes, Executive Director at SNO; neurosurgeon Gelareh Zadeh and pathologist Jason Huse, the co-Chairs of the SNO International Outreach Committee; and Mark Bernstein, the Greg-Wilkins Barrick Chair in International Surgery at the University of Toronto, Canada.

She also thanked the seven companies that generously helped support the meeting: Bristol-Myers Squibb, Novocure, Pfizer, MagForce, NW Biotherapeutics, VBL Therapeutics and Photonamic.



Above: Support of the S-SANOC planning meeting from seven industry sponsors was gratefully acknowledged

Kathy explained that the IBTA is a UK-based, not-for-profit organisation that doesn't raise funds for research or provide formal support services. "Rather, we are primarily an advocacy and awareness-raising organisation whose central ethos includes supporting highly collaborative, multi-stakeholder approaches which address the challenges of brain tumours and other rare cancers."

The IBTA advocates for equitable access to brain tumour treatments and support. One of the IBTA's other priorities is to encourage the formation of brain tumour patient organisations in countries and regions where they don't yet exist. Although the IBTA has no specific funding available for such emerging groups, they can offer expertise, excellent networking opportunities, support and advice.

Some of the international brain tumour and cancer initiatives that the IBTA is involved in include having served on the European Commission Expert Group on Cancer Control; working with the EORTC (European Organisation for Research and Treatment of Cancer) on quality of life and patient-reported outcomes issues; serving on the SNO Guidelines Committee; working with EANO (European Association of Neuro-Oncology) to develop guidelines on palliative, supportive and end-of-life care; participating as a founding member in Rare Cancers Europe; and working with the European Reference Networks (ERNs) for rare and complex diseases.

Kathy described patient advocacy as "requiring a thick skin, having endless patience, an open mind and an ability to respond accurately and quickly to issues." Advocacy can be a hard road to travel. It's not glamorous and it's certainly not easy. Rather, it is incredibly demanding and requires

knowledge of government policy, politics, the subtleties of interpersonal relationships, psychology, medical and ethical issues, drug development, therapy approval, regulatory bodies and many other topics.

In-depth research is often needed and assertiveness frequently required, she added, when lobbying for policy change, especially when taking a moral stance that may not be very popular. Being a good listener is an important skill, and patient advocates should always respect what others have to say, although they may not agree with them.

Among the IBTA's core activities and services are:

- sending out its monthly 'e-News' electronically to nearly 7,000 members of the brain tumour community worldwide in 111 countries
- compiling, editing, publishing and distributing an annual, free magazine, *Brain Tumour*, which is one of the organisation's core offerings. This is a truly collaborative publication featuring articles written by brain tumour patients, caregivers, clinicians, researchers, nurses, allied healthcare professionals and professional societies from all over the globe. Around 13,000 to 14,000 copies are printed each year, freely distributed to recipients in 111 countries and provided gratis at major neuro-oncology and cancer conferences. The magazine is also available online as a digital edition.
- initiating and project-managing two international awareness-raising initiatives every year: the 'International Brain Tumour Awareness Week', and the 'Walk Around the World for Brain Tumours'.



Above: The covers from the last three editions of the IBTA's 'Brain Tumour' magazine. 13,000 to 14,000 copies are distributed annually for free to recipients in 111 countries and at major neuro-oncology and cancer conferences

Collaboration underpins everything the IBTA does. It is this strong collaborative spirit that led to the S-SANOC planning meeting.

She explained: "I've never been to Africa – so I must defer to the experts in the room for their knowledge on the ground about their specific challenges. This S-SANOC meeting represents lighting the torch and helping those on the ground carry it. We have a lot to learn from you all and we will do our best to help you. We can connect you to others who share your same goals. We can try and encourage more patient advocacy groups to form in Africa. We can provide our expertise on how to create a patient-centric approach to your work. We can provide the patient perspective, because most of us at the IBTA have had a close family relative affected by this devastating disease."

Hope on the brain tumour journey is vital said Kathy

quoting the American doctor and renowned cancer researcher Jerome Groopman, who wrote:

"Hope is the elevating feeling we experience when we see – in the mind's eye – a path to a better future. Hope acknowledges the significant obstacles and deep pitfalls along that path. True hope has no room for delusion. ...hope gives us the courage to confront our circumstances and the capacity to surmount them."

In summary, Kathy said: "When I was searching for hope after my son Colin was diagnosed, I was inspired by the philosophy of eminent head and neck cancer surgeon Professor Chris O'Brien from Australia, himself diagnosed with a glioblastoma. Chris said: 'Hope, not defeat, should always be the starting point, no matter someone's diagnosis.'"

Plenary Session 5

Roundtable discussion with all participants - "What is your vision?"



Above: Plenary session 5 co-chairs Chas Haynes (left) and Gordon Oliver (right)

SESSION co-chairs Chas Haynes, Executive Director of the Society for Neuro-Oncology (SNO), and Gordon Oliver, Co-Director of the IBTA, introduced the second period of open discussion at the S-SANOC meeting, giving delegates the opportunity to talk more about the challenges they face in their region and to consider plans for future collaboration.

Chas said he had been greatly inspired by the

stories he heard during the S-SANOC meeting. He was confident that funds could be raised for a future course/conference or collaborative initiative.

He then asked all of the S-SANOC participants: "What is your vision?"

Thierry Muanza (McGill University and Brain Tumour Foundation of Canada): "I am struck by the lack of resources for brain tumour treatments, including radiotherapy, and I will be happy to organise teaching in a sub-Saharan Africa country."

Christine Mungoshi (ZBTA, Zimbabwe): "Resources and expertise are vital. We believe there is a lot of expertise among organisations from other high-income countries and they could mentor brain tumour patient organisations in sub-Saharan Africa. Though the environment is different, we believe working with a mentor organization could also be helpful in forging donor trust to fund organisations in sub-Saharan Africa."

Neurosurgeon **Shungu Ushewokunze** (Sheffield Children's Hospital NHS foundation Trust, UK): "An expert is fine to help you. But what you really need is government involvement otherwise you will struggle, as they provide the funding. Core brain tumour services would only be met by the government's



Above: Neurosurgeon Shungu Ushewokunze said that it's crucial to have government involvement in patient advocacy work

involvement. Rather, it is the gaps where charities can make the difference – you need to find the gaps. Also, a World Health Organisation meeting was recently convened to discuss non-communicable diseases, which is timely, as governments are starting to recognise non-communicable diseases such as cancer in the developing world.”

Christine Mungoshi: “I have already witnessed positive change taking place in Zimbabwe for brain tumour care. In 2006, there were only three neurosurgeons. Now it is a different story altogether – a training centre for neurosurgeons has been announced in Zimbabwe. I believe that greater things can happen – slowly, but they will happen.”

Anita Granero (IBTA Senior Advisor and Oscar’s Angels, France): “Are there patient advocacy organisations in all the countries? If not, then it is a priority to build them. Attention should be paid to where there is the greatest need. We should focus on countries that have no advocates. It is very important that patient organisations are everywhere. Countries that have patient-based organisations have great potential to raise funds for research and support. A list of countries without patient organisations needs to be prepared so as to help guide future activities.”

Alan Davidson (Red Cross War Memorial Children’s Hospital, South Africa): “A Trust in South Africa raises lots of money for brain tumour causes, but there is an on-going need to work with the government, as their resources are much greater. Even for patients with the most limited prognosis, we need to offer them



Above: Prof Alan Davidson spoke about hope on the brain tumour journey

reasonable hope based on realistic expectations. We need open discourse with patients to explain what is and isn’t available, and why.”

Jenny Baker (IBTA Senior Advisor, UK): “What is the scale of our ambition? More accurate information is needed so that the scale of the problem can be known. This leads us on to the need for greater research and data and perhaps we can access research funding for this for a ‘top-down’ approach. One source of potential funding for research may be charitable foundations. This ‘top-down’ approach will mean that plans and priorities are based on an assessment of the entire picture. Conversely, a ‘bottom-up’ approach is one that is driven by the day-to-day experiences of patients and advocates.”

Daniel Fulkerson (Indiana University School of Medicine, USA): “Goals need to be realistic and investment is needed for sustainable outcomes. An educational course that discusses new technology will have limited value. One that has a low-tech approach that is practicable will improve what brain tumour treatments are there. This could then have a snowball effect – attracting new surgeons to the region.”

Edjah Nduom (National Institutes of Health, USA): “I don’t see any reason why you can’t invite advocates from different countries to a course/conference, who would serve to give advice. Bring them into the same room then give the advocates a toolkit for starting a group in their own country. This would be planting a seed that grows. A similar approach could be used for clinical teams, who would then use their learning to

disseminate good practice in their region. These courses/conferences could allow for sub-Saharan countries that have more resources to spread information to countries that are at a lower level of brain tumour treatment infrastructure, to help them understand how to fund new radiotherapy suites. This would help other countries move up to the next level, using their experience. We should aim at the small wins and low-hanging fruit. We should create a unified body that helps other countries get to the next place they need to go.”



Above: Edjah Nduom favoured the involvement of existing patient advocacy groups and encouraging new ones to form with the use of a “toolkit”

Plenary Session 6

Practicalities and Goals: roundtable discussion with all S-SANOC participants regarding the 2018 SNO Wilkins-Barrick Outreach Course in sub-Saharan Africa and a potential sub-Saharan Africa neuro-oncology society

AFTER a short break, session co-chairs Chas Haynes and Gordon Oliver reconvened the meeting for the third and final session of the day - to formulate more specific plans for a potential course/conference/society. Proposed topics for this session were:

- location - challenges and solutions
- faculty
- speakers
- additional funding required
- promotion and communications
- logistics (registration, venue, travel, etc)
- emergence of a sub-Saharan Africa neuro-oncology society - challenges and solutions, membership, mentorship, SNO/Oxford University Press initiatives for access in developing countries to Neuro-Oncology and Neuro-Oncology Practice; patient advocacy involvement
- involvement of brain tumour patient and caregiver organisations (via a concurrent or consecutive patient conference in 2018) and on-going collaborative activities
- political challenges

- capacity-building (clinical groups and patient groups)
- involvement going forward of multidisciplinary team members; i.e. palliative care, specialist nurses, allied health care specialities (rehabilitation, psychosocial aspects, end-of-life care, etc)
- the role of traditional healers
- next steps

Chas Haynes said that there isn't only one way to proceed. He described some of the other approaches taken by international neuro-oncology societies, including SNO and European organisations.

SNO uses “three factors” when considering whether a location is suitable for a course/conference which may or may not apply for the S-SANOC group.

The three criteria are:

1. accessibility, i.e. whether a location has good access for international travellers
2. infrastructure, i.e. the facilities in the hotel, including projection capabilities, hotel amenities, etc;
3. safety and appeal of the surrounding location,

which serves to motivate delegates from across the world to attend

Gordon Oliver (Co-Director, IBTA): “Irene Azong-Wara, in her presentation in Plenary Session 4 said that bribes are often required to secure radiotherapy treatment in Cameroon. This reminds me that there is a continuing need for vigilance in relation to sourcing funding used further down the line. It is important that the money to be used will be properly sourced, free from corruption.”



Above: Jenny Baker asked about the feasibility of holding a neuro-oncology course/conference in tandem with another event

Jenny Baker (IBTA Senior Advisor, UK): “Some of the proposals in Plenary Session 2 were to take place alongside another, pre-existing, conference. Is this appropriate?”

Chas Haynes: “Could ‘piggy-backing’ be a viable option for a sub-Saharan Africa educational conference in 2018? It makes economical sense due to economies of scale and the ability to share costs. It can help with availability of speakers, and faculty and programmatic challenges.”

Practicalities of forming a society

Geoff Pilkington (Brain Tumour Research Centre, University of Portsmouth, UK - Honorary Treasurer and Executive Board Member of the European Association of Neuro-Oncology-EANO): “I have experience in setting up a neuro-oncology society, in fact, the very first brain tumour society, the then British Glioma Association which has become the British Neuro-



Above: Geoff Pilkington has substantial experience in establishing a neuro-oncology society

Oncology Society (BNOS). I’m eager to help with the formation of a sub-Saharan Africa neuro-oncology society but I wonder what the practicalities would be. What role could EANO play?”

Chas Haynes: “We would welcome participation from other societies. EANO and other bodies could help financially by matching the funding of SNO, or underwriting one or more attendees. Other ways of giving valuable support would include encouraging others to attend by promoting the meeting. The EANO Charter document would be a better template for colleagues in sub-Saharan Africa to follow than SNO’s, given that EANO consists of many different countries. SNO, EANO and the Asian Society of Neuro-Oncology (ASNO) are members of the World Federation of Neuro-Oncology Societies (WFNOS).”

The practicalities of using this pre-existing EANO Charter as a template were discussed further. Edjah Nduom requested a copy of the document, saying that he thought it could be a starting point for a sub-Saharan Africa neuro-oncology society. Geoff Pilkington offered to share previous versions of the EANO Charter also, along with the current Charter, so that others could learn how it has evolved over time.

A stand-alone or ‘piggy back’ meeting?

Chas Haynes: “In addition to the 2017 SNO Wilkins-Barrick International Outreach Course in Neuro-Oncology grant, SNO could make a commitment for several years, subject to progress.”

Gelareh Zadeh (Division of Neurosurgery, University

of Toronto, Canada): “The pressing practical questions relevant to an educational course are:

- Will it be a scientific meeting?
- Will an aim of the course be to bring together a new society?
- Will it be a ‘tag-on’ to an existing meeting, or a stand-alone?

When these questions have been resolved, the next steps are to decide what the bylaws of a society and on-going plans and strategies would be.”



Above: Dr Rakesh Jalali shared his experience of helping to establish the Indian Society of Neuro-Oncology (ISNO)

Rakesh Jalali (Tata Memorial Hospital, India) shared his experiences of starting the Indian Society of Neuro-Oncology (ISNO): “I was founding General secretary of ISNO. In India, we had to register the society nationally, so needed a constitution and there was a legal requirement to have representatives from at least seven Indian states. In 2008, in a large tertiary cancer hospital, we held a pre-launch meeting where the organisation’s constitution and structure was decided, and positions of responsibility allocated, including physicians, surgeons, and patient representatives. Becoming firmly established is the most difficult time of an organisation’s journey. Sustainability is the key. To be sustainable for longer than two to three years is the hard part. You need a strong headquarters somewhere and if you already have any African neuro-oncology brain tumour societies, then it is important that they are involved also.”

Teddy Totimeh (Greater Accra Regional Hospital, Ghana): “It is not an option to have a scientific meeting

only. We must include patient advocacy – there is no way it can carry on without a societal base.”

James Balogun (University College Hospital, Ibadan, Nigeria): “An educational or training course in brain tumour care could be incorporated into a conference. A course could be key to the conference’s success. If it were annual and on-going, it would confirm the importance of the event and draw people to the meeting – at least for the first couple of years.”

Gelareh Zadeh: “Will all future such sub-Saharan Africa neuro-oncology events be ‘piggy-backed’ onto existing conferences?”

Rakesh Jalali: “I think not. After the first year, you should be on your own.”

Christine Mungoshi (ZBTA, Zimbabwe): “I have concerns for recruiting patient advocates to an event based solely around a scientific conference. How are you going to get people involved? Are patient advocacy groups included?”

Kathy Oliver (Chair, IBTA): “A patient advocacy day could take place immediately before or after the scientific event.”

Gordon Oliver (Co-Director, IBTA): “Regardless of the structure adopted, it would be a meeting at which all disciplines would be present.”

Teddy Totimeh (Greater Accra Regional Hospital, Ghana): “A newly formed sub-Saharan neuro-oncology society should remain distinct from other organisations. Ultimately, as we speak about tagging on we need to think about how to sustain a sense of culture and identity as a body. It may be convenient to tag-on, but we need to create our own identity.”

Patrick Bankah (Korle Bu Teaching Hospital, Ghana): “I have similar concerns about piggy-backing onto an existing meeting. I suggest that a three-day scientific event followed by a three-day educational course would be too long a time for delegates. As an alternative, if the sub-Saharan Africa neuro-oncology educational course could be incorporated within a scientific meeting itself, then that would be a good proposal.”

James Balogun (University College Hospital, Ibadan, Nigeria): “Two meetings immediately following one another would not necessarily mean that all delegates would need to stay for the entire duration. We are just leveraging the meeting and only the neurosurgeons would have to consider whether they will stay on for the following three days of a neuro-oncology educational course.”

Edjah Nduom (National Institutes of Health, USA): “I feel that concerns about the meeting’s duration are justified. Meeting fatigue is real and it is a big problem. At a lot of the conferences you lose a lot of people half way through. The second half of a conference is often seen as less appealing to delegates. The only costs being saved by ‘piggy-backing’ another meeting are the plane fares of the fifty or so neurosurgeons who chose to stay on. An existing scientific conference in Africa could be used to raise awareness, but a stand-alone meeting for the neuro-oncology course and the launch of a new sub-Saharan neuro-oncology society ought to be organised separately. Don’t be intimidated about putting on a new conference because it is sub-Saharan Africa. I think we can do it uniquely – and piggy-backing may hobble us by diluting the meeting and causing fatigue.”

Session co-chair **Chas Haynes** summarised: “From experience, you do lose focus from a shared meeting, but there are ‘under-the-hood’ economies of scale. For example, there will be one website, one registration; and no need to make badges or design a programme.”

Daniel Fulkerson (Indiana University School of Medicine, USA): “I agree with Chas’s summary. There are advantages to both – it is difficult to ignore the opportunity of having a third of the people in one place. It is hard to imagine that if it were a stand-alone event that you get the neurosurgeons to attend.”

Course/conference style and format

Gelareh Zadeh (Division of Neurosurgery, University of Toronto, Canada): “Participants need to share their thoughts about the organising committee for the course/conference, its structure, and who would be on it.”

Rakesh Jalali (Tata Memorial Hospital, India): “You need to have a vision – short-, medium- and long-term. You want to encourage students and trainees; but for them to attend there will need to be abstracts. Abstract submission to a course/conference would count as valuable experience. I suggest that the course/conference could present an opportunity for delivering Continuing Medical Education (CME) on brain tumour care topics.

Chas Haynes: “While some training content online could be chargeable, it would be best if CME were to be made available for free.”



Above: Rakesh Jalali shares his thoughts on the neuro-oncology course style and format

Rakesh Jalali: “What are the national or African brain tumour guidelines? In the absence of established treatment protocols, I suggest that the event be a springboard to develop such guidelines. In India, we have similar stories of poverty and poor quality of care. We drew up pragmatic guidelines. Three years ago at ISNO we chose medulloblastoma and drew up three levels of guidelines. We discussed these with a wide variety of stakeholders. The situation in sub-Saharan Africa could benefit from a similar approach and recommend guidelines that are national, regional and continental in scope.”

James Balogun (University College Hospital, Ibadan, Nigeria): “Should it be a course or a meeting? There are pros and cons of running the event as an educational course, rather than as a conference-style meeting. I suggest a course, with a steering group.”

Shungu Ushewokunze (University of Sheffield, UK): “An educational course may present challenges because it is a new initiative, and will need a lot of ‘buy-in’.”

Organisational structure of a new sub-Saharan Africa neuro-oncology society

Chas Haynes turned the discussion toward the organisational structure of a collaborative neuro-oncology society going forward. “When you draft your Charter, ensure that you have representation based on sub-specialty or region or both. Decision-making processes need to be democratic and pre-determined. You can’t move forward unless a majority of the organising committee votes in the affirmative for a

chosen location and topic for meetings. You can also codify how the group can move forward.”

Gordon Oliver (Co-Director, IBTA): “From my experience, voting on key decisions need not hamper planning. A managing body will emerge from the initial group meeting that would decide on venues, timings, etc; rather than needing to take a referendum on every issue.”



Above: Gelareh Zadeh emphasised the importance of inclusivity in creating a sub-Saharan neuro-oncology society

Gelareh Zadeh (Division of Neurosurgery, University of Toronto, Canada): “All delegates from sub-Saharan Africa present at the S-SANOC planning meeting in London should be on the organisational committee. Do any of you know of any other bodies or representatives from sub-Saharan regions that are critical for planning, but who are not present today? I note that there appears to be a lack of representatives from central Africa. In addition to the sub-Saharan members, oversight and help should be given by outside members, for example from SNO and/or EANO, who would provide an advisory and peer-review role.”

Chas Haynes: “Do any delegates present want to attempt a first draft of a sub-Saharan Africa neuro-oncology society constitution?”

Teddy Totimeh: “I would be happy to do so.”

A Society’s first steps: drawing up treatment guidelines?

Gelareh Zadeh returned to Rakesh Jalali’s earlier suggestion that the group could devise brain tumour

treatment guidelines appropriate for the region. She recommended sub-Saharan African colleagues to first decide which three areas are the highest priority which could then be presented at a meeting for discussion, and later form metrics for future research and data gathering.

Shungu Ushewokunze (University of Sheffield, UK): “Because brain tumours are low down in Africa for neurosurgery the idea is a good one. But maybe we need to conduct a survey to ask others about guidelines and opinions.”

Rakesh Jalali: “I endorse the suggestion of conducting a survey. The population is very heterogenous in Africa and India. There are many unknowns in sub-Saharan Africa and therefore, a survey will be an educational source document and something to present to the governments. Survey results can be used as a document to petition the case for improved brain tumour care funding with governments. It may be wise to give political consideration to the topic chosen, however. In India, we started with medulloblastoma because it involves children, it has a long-term survivorship issue, and treatment has a strong effect. These emotive and politically-convincing issues were successful in lobbying our case, but had we opted for glioblastoma first it wouldn’t have been as successful in securing funding.”

Patient advocacy involvement

Kathy Oliver (Chair, IBTA) emphasised that published treatment guidelines can also have an important role in patient advocacy. “When people are receiving substandard care, a copy of the official treatment guidelines can be sent to the patient so that they can insist on appropriate treatment as set out in the guidelines. It’s important to have a patient advocate on the guidelines creation group too.”

Edjah Nduom (National Institutes of Health, USA): “We should not forget the advocacy side. Looking toward the creation of a sub-Saharan Africa neuro-oncology society, would the society be for both professionals and brain tumour patient advocates?”

Gordon Oliver (Co-Director, IBTA): “Virtually all the presentations here at the S-SANOC meeting in relation to the proposed sub-Saharan Africa neuro-oncology society have stressed the multi-disciplinary aspect as being vitally important. To consider splitting that all-

inclusive proposed body into two separate societies, one for the medical professionals and one for the patient advocates and other non-medical stakeholders, surely runs contrary to what we have heard today.”

Rakesh Jalali: “This would be a first if advocacy were incorporated into the official society itself. Other official neuro-oncology societies were not conceived to incorporate both professionals and patients/patient advocates.”

Chas Haynes: “This is an important opportunity to create something that is unique.”

Rakesh Jalali: “Other oncology societies often contribute much to brain tumour care, and so it may be appropriate to invite other cancer charities (e.g. those representing childhood cancers) to all or part of a sub-Saharan Africa course/conference/event.”

The role of traditional healers

Discussion moved on to the role of traditional healers in brain tumour care in sub-Saharan Africa. **Gelareh Zadeh** asked: “Would traditional healers be involved in a course and in the proposed sub-Saharan neuro-oncology society?”



Above: Shade Adoh was keen for neuro-oncology structures in sub-Saharan Africa to be inclusive of all those involved in the field of brain tumours, including traditional healers

Shade Adoh (Healthwatch Buckinghamshire, UK): “I feel that participation should be fully inclusive of all those involved in the field of brain tumours, including all clinicians and allied professionals, service users and traditional healers.”

Christine Mungoshi: “The patient organisations should involve and engage with traditional healers because I

doubt whether traditional medicine practitioners would attend a formal meeting. The prevalence and impact of traditional medicine practices should be included so that we know what is happening on the ground. Having an understanding of the traditional healers’ role and the beliefs of people would give the sub-Saharan Africa neuro-oncology group an evidenced frame of reference for moving forward.”

Thierry Muanza (McGill University and Brain Tumour Foundation of Canada): “Patient advocacy groups might be best placed to survey their local area for information on the role and importance of traditional healers.”

Gelareh Zadeh: “Further funding would be needed for such a comprehensive survey to be performed adequately.”

Shade Adoh: “International societies of traditional medicine exist, and contacting such bodies may help encourage their involvement.”

Other S-SANOC planning meeting participants expressed caution about the involvement of traditional healers, who use unproven practices that are sometimes harmful.

James Balogun (University College Hospital, Ibadan, Nigeria): “There is a lot of controversy. We need to define the ethics of the course/meeting/event and/or society before worrying about who to include or not include. Nevertheless, I feel that involvement of traditional healers would be beneficial. We can leverage many beliefs rather than ignore everything that is not accepted medicine.”

Summing up

Session co-chair **Gordon Oliver** (Co-Director, IBTA) summarised that the consensus of the S-SANOC meeting participants was that people favoured a new sub-Saharan Africa neuro-oncology society, to be made up of both healthcare professionals and patient advocates, and that the proposed course/meeting/event in 2018 in sub-Saharan Africa should be multi-disciplinary, rather than neurosurgical only.

Edjah Nduom (National Institutes of Health, USA): “It was also agreed that the process of drafting brain tumour treatment guidelines for sub-Saharan Africa should begin. A standard protocol is not achievable in many sub-Saharan African countries due to lack of resources, so a continent-wide guideline may be problematic. Instead, the group should draw up



Above: S-SANOC participants Anita Granero (IBTA Senior Advisor and Oscar's Angels) and Jason Huse (MD Anderson Cancer Center, Texas, US) discuss the day's topics

guidelines with levels and tiers of treatment based on the infrastructure in different sub-Saharan African countries. This would also serve as a 'road map' to show what specific resources and personnel are needed to advance to the next level of treatment. As a practical point, there should be consultation with countries that have made improvements in brain

tumour care to aid in the drafting process."

Daniel Fulkerson (Indiana University School of Medicine, USA): "There is a previously-prepared protocol template, with levels of care (rated 0 – 4), based on the facilities and resources available i.e. whether radiotherapy is accessible, availability of surgical facilities, etc. All treatment guidelines need to be suitable for the resources and personnel available. You need the supportive care infrastructure to support the treatment, or else you can worsen patient outcomes, due to toxicity, lack of experience in dosing and procedures, etc. I offer my assistance with devising a tiered paediatric treatment protocol."

Gelareh Zadeh (Division of Neurosurgery, University of Toronto, Canada): "A survey to establish what current care is like should also be planned and initiated."

Chas Haynes (SNO) asked whether any delegates wanted to take the first steps in devising guidelines.

Dr James Balogun (Nigeria), **Dr Patrick Bankah** (Ghana) and **Dr Thierry Muanza** (Canada) volunteered to work together to formulate the first draft of an adult-based brain tumour guideline for the sub-Saharan Africa region.

Participants



Shade Adoh

I am a Registered Nurse (Continuing Healthcare Nurse Assessor) and a District Councillor representing the rural and diverse communities of Stokenchurch and Radnage in England. I served on the Improvement and Review Commission for two years. I am currently the Deputy Cabinet Member for Housing and a Member of the Personnel and Development Committee.

I was a Parliamentary candidate at the June 2017 elections in Doncaster North. I had the second highest vote, coming second to Ed Milliband and increased the votes too. It was my first time as a Parliamentary candidate and as Mr Milliband put it: a very good start!

I am a Board Director with Healthwatch Buckinghamshire where, with my colleagues, we set the strategy and direction for the organisation. I support in sharing and working with residents to signpost, advocate and influence health and social care providers so services are designed to meet local needs.

Access to care and support that is not dependent on 'how much' or location or gender or race or religion is what drives me to volunteer my time and share my knowledge and experience.

The knowledge, skills and experience of doing this work and having these responsibilities has made me realise just how important our public representatives are. The work is often challenging and requires much more listening than talking. It is important for representatives to take the time to hear what everyone has to say, so that they can genuinely represent the views of the people they serve.



Jean Arzbaecher

Jean Arzbaecher is an advanced practice nurse living in Chicago. She currently works as a clinical nurse specialist in neuro-oncology at the University of Illinois Brain Tumor Center. Jean has spent her entire career (32 years) in neuroscience nursing, and has worked exclusively in brain tumor care for 13 years.

Jean is active in the neuroscience nursing organization AANN (American Association of Neuroscience Nurses). She has served as the local chapter president, as well as the special focus group facilitator for the neuro-oncology group. She has presented numerous lectures on brain tumor topics both locally and nationally. She has published in peer-reviewed journals, contributed to the AANN core curriculum and written a book chapter for the Oncology Nursing Society.

Jean started a brain tumor support group seven years ago and currently facilitates a monthly meeting of survivors and caregivers. The group currently has over 100 members, and usually has between 30 and 50 participants at the monthly meetings.

Jean serves as a Senior Volunteer Advisor to the IBTA. She has written articles for the IBTA's *Brain Tumour* magazine, and also assists in distributing information about the organization annually at the ASCO (American Society of Clinical Oncology) meeting. She is excited to be participating in this very important S-SANOC meeting.



Irene Azong-Wara

Jacob’s Hope Foundation in Cameroon, sub-Saharan Africa, is a community-based organisation founded in 2016. We are a health development oriented organisation. We focus on advocating for patients while creating opportunities for them to have better access to health care and information. Our mission is to promote prevention, better health care, socio-economic development, discourage harmful traditional practices and adopt behavioural change communication. We are a small organisation making a difference in a very challenging environment. We are taking baby steps to make a change. Our strategies are advocacy/sensitisation, resource/information centres. Our target audiences are women, children, community-based organisations and policy makers.

people receiving the best possible treatment and care. Previously working for the National Trust for England, Wales and Northern Ireland, ultimately as its national lead on volunteering, community and diversity, in 2005 Jenny was awarded an OBE (Order of the British Empire) in recognition of her services to the heritage and environment.

Jenny currently assists IBTA as a Senior Volunteer Adviser and is an IBTA representative Trustee of the European Federation of Neurological Associations (EFNA). She is currently an appointed member of the National Committee of Healthwatch England, the statutory body established by the UK government in 2012 to help put people at the centre of health and social care by listening to patients’ views on their care and treatments and ensuring their views are heard by government and those running services. Jenny is also Chair of Healthwatch Bucks, one of 148 independent local Healthwatch organisations across England. Other past and ongoing national and local trusteeships continue to bring insights into the services of voluntary and community organisations and the difference they make to people’s health and wellbeing.



Jenny Baker

After a life-long career as a senior manager in the UK’s not-for-profit sector, Jenny recently retired after seven years as Chief Executive of Brain Tumour UK, a leading national charity supporting and speaking out for people affected by brain tumours and their families. With a keen interest in public health and patient engagement, Jenny is passionate about quality standards and



James Balogun

Born in Sokoto, Dr Balogun had his early education in Minna, and then proceeded to complete his medical education at the University of Ilorin. He did his rotational internship at the University of Ilorin Teaching Hospital before commencing the neurosurgery program at the University College Hospital, Ibadan. Upon completion of his neurosurgery residency training in 2011, he completed clinical fellowships in surgical neuro-oncology/skull base at the Toronto Western

Hospital, Toronto, Canada, and pediatric neurosurgery at the Hospital for Sick Children, Toronto.

He spent further time as a research fellow in anatomy of the skull base at the University of Pittsburgh Medical Center, Pittsburgh, USA. Dr Balogun worked briefly at the Federal Medical Center, Owo, Nigeria, where he pioneered the neurosurgery service. He returned to the medical center after his sub-specialty trainings before taking up appointment as a faculty member at the Department of Surgery, College of Medicine, University of Ibadan with a consultant neurosurgeon appointment at the University College Hospital (UCH), Ibadan. He is also a visiting consultant neurosurgeon at the University of Ilorin Teaching Hospital. His focus is on the epidemiology, science and surgery of adult and pediatric brain tumors particularly in Africans.

Dr Balogun's clinical practice also includes endonasal endoscopy, pituitary surgery and awake and ambulatory craniotomy. He also anchors the neuro-oncology tumor board in his institution, an uncommon facility in sub-Saharan Africa.



Patrick Bankah

Patrick Bankah, MBChB, received his medical degree from the University of Ghana and completed his residency in neurosurgery at the Korle Bu Teaching Hospital, Accra, Ghana.

He has completed fellowship training in pediatric neurosurgery at Johns Hopkins Hospital and is currently practising as a consultant neurosurgeon at Korle Bu Teaching Hospital.

He is involved with undergraduate teaching and postgraduate neurosurgery training for the School of

Medicine and Dentistry and the West African College of Surgeons respectively.

Dr Bankah has a keen interest in congenital malformations of the central nervous system and the improvement of surgical outcomes of pediatric brain tumour patients in resource-limited settings.



Alan Davidson

Associate Professor Alan Davidson graduated from the University of Cape Town (UCT) in 1992 and specialised in paediatrics and then paediatric oncology. He is currently the head of the Paediatric Haematology-Oncology Service at the Red Cross War Memorial Children's Hospital in Cape Town, South Africa. The service treats 130 new cases of childhood cancer each year with over 2000 admissions and over 5500 outpatient visits. The service also treats the full spectrum of blood disorders, acts as a regional haemophilia centre and advises a large network of shared carers across sub-Saharan Africa with the help of a telemedicine platform.

Professor Davidson is the past chair of the South African Children's Cancer Study Group, and was chair of the local organising committee for the SIOP (International Society of Paediatric Oncology) Cape Town conference in 2015. He also served as co-chair of SIOP's PODC Adapted Treatment Regimen Working Group which commissions and guides the publication of adapted treatment guidelines. His clinical and research interests include paediatric brain tumours, B-cell malignancy and other HIV-related cancers in children, genetic syndromes predisposing to childhood cancer, stem cell transplantation for primary immunodeficiency and adapted therapy regimens for low and middle income settings.

He has co-chaired South Africa’s annual Paediatric Brain Tumour Workshop since 2008, and currently serves as co-chair of SIOP’s Paediatric Oncology in Developing Countries Committee.



Stuart Farrimond

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Dr Stuart Farrimond is the IBTA’s Digital Technology Advisor. He helps coordinate e-newsletter stories, maintains website content, and oversees distribution of the IBTA monthly e-newsletter.

Stuart is a medical doctor but following the diagnosis of an astrocytoma in 2008, he was forced to leave the profession. He retrained and worked as a teacher in further education for three years before embarking on a freelance career. Stuart is now a science and health writer, presenter, and educator. He makes regular appearances on TV, on radio, and at public events, and his writing appears in national and international publications, including *The Independent*, the *Daily Mail*, and *New Scientist*. He also specialises in food science research and is author of the book *The Science of Cooking: Every Question Answered to Perfect Your Cooking*, which was recently published by Dorling Kindersley Books. He writes, edits, and provides web design and technical support for a variety of organisations and he founded an online ‘lifestyle-science’ magazine *Guru*, which was awarded funding by the Wellcome Trust, the world’s largest medical research charity.

Stuart volunteers as a STEM ambassador, offering teaching time to inspire the next generation of young people to be engaged in Science, Technology, Engineering and Maths; and is currently training as an independent advocate to help represent society’s most vulnerable people. Stuart is a keen cyclist and lives in Trowbridge, Wiltshire, United Kingdom, with his wife (and dog). His astrocytoma was treated surgically and he has had clear scans for eight years. And counting



Mario Ferraro

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Mario is the founder and Lead Photographer of MVF Studios, a business that was born out of his lifelong passion for photography. From his childhood years of learning to use manual cameras, and the related skills of developing hard-copy photographs in a darkroom, splicing movies together and adding soundtracks to 8mm films, Mario is now a professional photographer with full-fledged experience in corporate as well as personal assignments. Some of his noteworthy projects include the events organised by the Brain Tumour Society (Singapore), and his photographs of their signature Brainy Car Rally, some of which have been featured in the IBTA’s publications.

“The best of life. Captured” is Mario’s simple mission for his work. Ultimately, he wants to bring joy to individuals and pride to companies by capturing the best moments in the people, events and products that matter most. For Mario, “Photography from the heart” is a Code of Conduct that is reflected in the way he engages with his clients, in the intensity of his images and in his involvement in pro-bono work.

Although he is based in Singapore, Mario travels widely and his photographs celebrate the beauty and diversity of the world. He is excited to be part of the S-SANOC Planning Meeting, where his mission is to capture the diversity of the S-SANOC meeting’s representation, the intensity of engagement and cohesiveness of collaboration towards the common mission of brain tumour advocacy and support.



Ekokobe Fonkem

Dr Ekokobe Fonkem is currently the Director of the Baylor Scott and White Health System Neuro-Oncology Program in Texas, USA and an Associate Professor of Surgery at the Texas A & M University Health Science Center. He is involved in basic, translational and clinical research on both primary and metastatic brain cancers as well as their neurological complications.

He received a BS degree in biochemistry in 2002 from the University of Wisconsin-Madison, followed by his medical degree in 2007 at the Ohio University Heritage College of Osteopathic Medicine in Athens, Ohio. He completed neurology residency training at the Ohio State University Medical Center in Columbus, Ohio in 2011 followed by a neuro-oncology fellowship at Harvard University Beth Israel Deaconess Medical Boston, Massachusetts in 2012. He has published extensively in the area of general neurology and neuro-oncology. He has also lectured extensively in various universities in the USA, Asia and Africa. He is currently pursuing a year-long fellowship with the American Society of Clinical Oncology (ASCO) where his focus is on cancer leadership, cancer advocacy and global oncology outreach.

Dr Fonkem is also the CEO and founder of an NGO called "Healing Beyond our Horizon" which is dedicated to providing medical care, and clean drinking water in underprivileged communities in Cameroon, West Africa.



Daniel Fulkerson

Dr. Daniel Fulkerson is an Associate Professor of Neurological Surgery of the Indiana University School of Medicine, USA, and performs both adult and pediatric neurosurgery for Goodman Campbell Brain and Spine. Dr. Fulkerson cares for patients at Riley Hospital for Children, Peyton Manning Children's Hospital at St. Vincent's, and Methodist Hospital.

Dr. Fulkerson primarily cares for children with specialties in brain tumors, hydrocephalus, spine disorders, and spina bifida. He specializes in "minimally-invasive" surgery of the brain and spine, including endoscopic treatment of brain tumors and hydrocephalus.

Dr. Fulkerson received two undergraduate degrees from the University of Notre Dame. He graduated from the Indiana University School of Medicine in 1998. He did one year of residency training in general surgery at Wright State University (Dayton, Ohio), before serving in the United States Air Force as an emergency physician. He spent four years stationed in Misawa, Japan. He returned to residency training at Indiana University and graduated from the neurosurgery program in 2009. After residency, Dr. Fulkerson performed a one-year specialty training fellowship in pediatric neurosurgery at Texas Children's Hospital in Houston, Texas. He returned to the academic faculty in 2010.

Dr. Fulkerson is a "native Hoosier" from Warsaw, Indiana, as is his wife Amy. They have five children and are all enthusiastic fans of Notre Dame. Dr. Fulkerson has published over 50 peer-reviewed scientific journal articles and one book, *Nothing Good Happens at the Baby Hospital* (Archway Publishing, 2016). He enjoys golf, video games, speed chess, and spending time with his children.



Anita Granero

Anita GRANERO is Italian and lives in France. After a tragic personal experience she founded “Oscar’s Angels”, a charity based in France with projects in Italy and the United States, whose main objective is to provide care and support in the hospital to families of children and teenagers with brain and spinal cord tumors, severe neurological problems and to those in palliative care.

Oscar’s Angels established the first French Parents Advocate Program in Pediatric Neuro-Oncology in the Children’s Hospital of Toulouse. Their highly trained non-medical volunteers are part of the hospital teams where they represent the families, bring a different perspective to their care, and help healthcare staff to better understand the emotional stress and needs the families have to face. She holds a DU in Palliative Care.



Chas Haynes

Charles (Chas) Haynes, JD has over 20 years of experience in the leadership and operational management of non-profit medical associations, foundations and professional societies.

Throughout his career, his primary focus has been in the areas of neuro-oncology and acquired neuro-trauma. He has worked with or served on the board of a number of professional organizations including

the Collaborative Ependymoma Research Network Foundation, the International Brain Injury Association, the North American Brain Injury Society and the National Spinal Cord Injury Association.

Chas currently serves as the Executive Director of the Society for Neuro-Oncology, a position he has held since 2006. Chas earned a law degree from the South Texas College of Law, USA, in 1999.



Jason Huse

Dr Jason Huse is a neuropathologist who specializes in the diagnosis and molecular characterization of malignant brain tumors.

He is currently an Associate Professor in the Departments of Pathology and Translational Molecular Pathology at the University of Texas MD Anderson Cancer Center, USA, and has run an independent research laboratory since the autumn of 2009. His group focuses on the molecular pathogenesis of adult and pediatric gliomas with a major goal of translating their findings to the development of more effective therapies and diagnostic tools.



Rakesh Jalali

Dr Rakesh Jalali leads the Neuro-Oncology Group in Tata Memorial Hospital, the premier unit in India drawing patient referrals, training opportunities, observers and research project requests and funding. His research interests have focused on the evaluation of high-precision techniques of radiotherapy, late-term toxicities and quality of life, biological imaging, molecular prediction and evaluation of new agents in neuro-oncology. He has more than 200 publications to his credit.

Dr Jalali was the force behind establishing the Indian Society of Neuro-Oncology (ISNO) in 2008, serving as its founding general secretary. He recently completed his tenure as ISNO's President, and has been largely instrumental in putting ISNO on the international map. Under his leadership, two national expert panels on formulating ISNO guidelines for medulloblastomas (2015-16) and the 'WHO 2016 classification of CNS tumours and clinical impact' (2016-17) have been undertaken. Dr Jalali's honours include awards in Pediatric Clinical Research and Quality of Life Research at the SNO (Society for Neuro-Oncology) meetings and he has delivered countless lectures at various scientific and social forums. He is currently the Asian Society of Neuro-Oncology's (ASNO) co-editor of *Neuro-Oncology Practice* and webmaster of ASNO's website.

Dr Jalali also runs the Brain Tumour Foundation of India, a charity dedicated to the welfare of patients with brain tumours and their families. He also conceptualised and helped make an animation film for children with cancer, 'Bust That Noma', to alleviate anxieties suffered by children undergoing cancer treatment.



Nimrod Juniahs

Professor Nimrod Juniahs Mwakitawha Mwang'ombe, MBChB, MMED-SURG, PHD (LOND), FCS(ECSA)

Current position: Professor of Surgery, University of Nairobi & Program Director six-year Neurosurgery Residency Training Program, Kenyatta National Hospital, Nairobi, Kenya. Program has residents from Kenya, Rwanda, Botswana, Zambia, Uganda, Sierra Leone, Mauritius. Neurosurgery Specialist Reg. No A1181 Medical Practitioners and Dentists Board of Kenya.

Academic qualifications: MBChB (University of Nairobi, 1976), MMed Surgery (University of Nairobi, 1980), PhD (University of London, 1990). USA Educational Commission for Foreign Medical Graduates (ECFMG) Certificate No 261-767-8 (1976).

Clinical Training/Work experience: Pre-registration internship: Coast General Hospital, Mombasa, Kenya, 1976-1977 Residency in General Surgery, Kenyatta National Hospital, Nairobi, Kenya, 1977-1980 (MMed Surgery degree University of Nairobi). Specialist in General Surgery, Kisii County Hospital, 1980-1982. Neurosurgery Training: Kenyatta National Hospital, Nairobi, Kenya (1982-1984). Research Registrar, National Hospital for Neurology and Neurosurgery, Queen Square, London, (GMC Reg. No 84/1051, 1984-1988).

Awards: George Ablin International Fellow, Congress of Neurological Surgeons (USA) at McMaster University, Hamilton, Ontario, Canada.

Nominated as one of 100 most influential Africans in 2016 by *New African Magazine* (December 2016 issue).

Editorial board: *African Journal of Neurological Sciences*

Membership of societies: Kenya Medical Association, East African Association of Neurological Surgeons/



Wilson Mugarura

My name is Wilson Mugarura. I am aged 47 years. I am a trained theologian from Alpha-Omega Seminary, Jinja and Glad Tidings Bible College, Makerere, Kampala, Uganda. I am currently pastoring Rushere Full Gospel Church, in Kiruhura district, Uganda. I am married to Dr Bonitta Kafureka. We have a daughter, Ruth Bonitta Winfred Nkaikiriza.

On 26th July 2014, I had a seizure and lost consciousness. I regained consciousness and was put on drugs that relieved the pressure that the tumour was exerting on the brain. I had a successful surgery at Yashoda Hospital on 14th August 2014. I am well now, though with some numbness and paralysis on the right side of my body.

Though the situation has improved slightly with the training of more neurosurgeons, it is still a far cry from meeting the needs of brain tumour patients in Zimbabwe. The ZBTA continues to face a lot of challenges as it is operating in a country experiencing an economic downturn. Despite these difficulties, achievements have been realised through awareness campaigns and helping the brain tumour communities in Zimbabwe get support and access to brain tumour resource material. Most of the resource material was donated by brain tumour organisations around the world.

Christine is a brain tumour patient advocate, operating in a resource-strained part of the world; she understands the challenges that face the sub-Saharan brain tumour patient and their families.

Despite this challenge, she believes in the guiding principle: 'Every human life matters' and is working to bring change. She believes: "A tiny change today brings a dramatically different tomorrow" (Richard Bach).

Christine is a social worker by profession, and committee member of the International Committee of the British Association of Social Workers (BASW). She is about to complete her MSC Palliative Care Degree with De Montfort University (part time) in the United Kingdom.



Christine Mungoshi

Christine Mungoshi is the Director of the Zimbabwe Brain Tumour Association (ZBTA). She helped found the ZBTA after her daughter Paidamoyo was diagnosed with a brain tumour. In her efforts to seek treatment for her child she was confronted with many challenges as there was limited information on brain tumours, and no equipment available in the country to treat her daughter's tumour. With only three neurosurgeons serving fourteen million people at that time the situation was dire.



Luke Mungoshi

Luke Mungoshi is a committed volunteer with the Zimbabwe Brain Tumour Association (ZBTA), providing a lot of support first to the efforts to establish the ZBTA as a functional organisation; and then in continued work with the brain tumour community in Zimbabwe. Though his work experience is not congruent with the volunteering role that he is doing now, he has sought to gain the required skills through his experiences and interest in helping.

Luke is a retired aircraft armament technician. He retired from the Air Force of Zimbabwe after serving for twenty years. He has vast experience in fighter aircraft maintenance and training which saw him seek further training and thus served as a technical instructor for the ten years preceding his retirement from the Force. Luke is a qualified aircraft technician and he holds various certificates in structural techniques, aircraft safety precautions and a non-commissioned officers' senior management course.

Luke believes increased efforts will eventually bring change to the brain tumour situation in Zimbabwe and sub-saharan Africa.



Brian Nyatanga

Brian Nyatanga is a Senior Lecturer and Academic Lead for the Centre for Palliative Care at the University of Worcester, England, UK, where he also has an international teaching and training remit both in the UK and abroad. He has over 30 years of clinical and educational experience in palliative care. He has worked in hospices, hospitals and the community. He is passionate about delivering high quality palliative care for all patients but more so for those issues deemed important to the patient, as we only have one chance to get it right. Brian is aware of the emotional demands of caring for dying people and believes healthcare professionals deserve better social support in order to continue caring. His doctoral research thesis looked at caring and its relationship to death anxiety and burnout among palliative care nurses.

Since we all now live in multicultural societies, Brian is also interested in cultural aspects of care and how we can remain culturally competent while delivering care to a diverse patient group. Some of his arguments are outlined in his extensive publications, from editorials, commentaries and articles, to books including the classic text "Why is it so difficult to die?" now in its second edition. He has also just published his co-edited second edition book "Palliative and End of Life Care in Nursing - 2017".

He is an accredited facilitator for the Connected Advanced Communication Skills Training using professional actors. He also has had experience as accredited facilitator with the NHS Leadership Qualities Framework, and he is an experienced assessor/profiler for personal development/plans.

A family man who believes in work-life balance, he is often seen on a squash court and football refereeing at weekends.



Edjah Nduom

Edjah Nduom, MD is a neurosurgical oncologist in the Surgical Neurology Branch of the National Institutes of Health of the United States of America.

He studied biomechanical engineering at Stanford University and then attended medical school at the University of Pennsylvania. He pursued his primary neurosurgical training at Emory University School of Medicine in Atlanta, Georgia, during which he was awarded a clinical fellowship at the National Institutes of Health. After residency, he completed two years of further fellowship training in neurosurgical oncology and tumor immunology at UT MD Anderson Cancer Center in Houston, Texas.

His clinical specialty is the surgical management of benign and malignant brain tumors, and his research focuses on the study of immunosuppression in the glioma microenvironment as well as the use of non-coding RNAs as a novel immune therapeutic approach for glioblastomas.



Gordon Oliver

Gordon Oliver is a Co-Director of the International Brain Tumour Alliance (IBTA) and is married to Kathy Oliver. Their son, Colin, was diagnosed with a brain tumour in 2004 and tragically passed away in August 2011, age 32. The Olivers have a daughter, Miranda, who is a primary school teacher and is married to Keith Baxter-Russell.

Gordon has been a partner in the Central London law firm of Hamblins LLP from 1982 until May 2015. He now provides consultancy services including to that firm. Born and brought up in Wales, UK, Gordon was educated in England and graduated from King's London. Throughout his career he has specialized in commercial and company law, and latterly in anti-corruption systems and procedures for internationally-based groups of companies.

Family life is very important to him but he can occasionally be found working on an old car. Best thinking time.



Kathy Oliver

Kathy Oliver is Chair and a founding Co-Director of the International Brain Tumour Alliance (IBTA). She is married to the IBTA' Co-Director Gordon Oliver. Their son Colin, was

diagnosed with a brain tumor in 2004 at age 24 and passed away in 2011 at age 32.

Kathy advocates for equitable access to brain tumour therapies and support, encourages the establishment of brain tumour patient organizations in countries where they don't yet exist and raises awareness of the challenges associated with this devastating disease. She is a frequent plenary speaker at international neuro-oncology and cancer conferences having, to date, delivered nearly 75 presentations on various aspects of the brain tumour/cancer patient perspective. She has authored/co-authored papers published in *The Lancet Oncology*, *Journal of Cancer Policy*, *British Journal of Neuroscience Nursing*, *Parliament Magazine*, *EANO Magazine*, *WFNOS Magazine*, *The Oncologist* and *eCancer Medical Science*. She is the recipient of the NBTS Community Leader Award (2010), the EANO Award (2011), the 5th International Conference on Future Trends in the Treatment of Brain Tumours Award (2013) and the Healtheo360 Human Spirit Award (2017).

Other activities include: representing Rare Diseases Europe (EURORDIS) on the European Commission Expert Group on Cancer Control; member, steering committee for EURACAN (the European Reference Network/ERN for rare adult solid tumours) and the ERN for brain and CNS tumours; member, EANO Palliative, Supportive/End-of-Life Care Task Force; member, All.Can (improving efficiency in cancer care through focussing on patient outcomes); founding member, Rare Cancers Europe; Vice-Chair, ECCO Patient Advisory Committee; member, Society for Neuro-Oncology Guidelines Committee; member, ESMO Patient Advocacy Working Group; editor/publisher, *Brain Tumour* magazine; patient expert, European Medicines Agency (EMA); patient reviewer, EORTC; member, various industry patient advisory boards; founder member/former board member, Cancer52; member, NCI Brain Tumour Clinical Studies Group sub-group on Palliative and Supportive Care; consumer representative, Cochrane Neuro-Oncology Group; member, British Neuro-Oncology Society Council; European Patients' Academy on Therapeutic Innovation (EUPATI) Fellow and former Co-chair, Project Advisory Board, EUPATI; member, EORTC SISAQOL initiative ("Setting International Standards in Analysing Patient-Reported Outcomes and Quality of Life Endpoints Data").

World Federation of Neurosurgical Societies, Kenya National Academy of Sciences, Pan African Association of Neurological Sciences (President elect), Congress of Neurological Surgeons (USA), American Association of Neurological Surgeons, Society for Neuro-Oncology. **Research Interests:** Paediatric neurosurgery, neuro-oncology, CNS infections, neurocritical care. Married with one grown-up child.



Linda Longwe

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Born on Human Rights Day, December 10, Linda Longwe is passionate about humanity and supporting cancer causes. She is a board member of the Zimbabwe Brain Tumour Association (ZBTA), and the Cancer Association of Zimbabwe. Her efforts have seen the growth of ZBTA's community engagement and tangible patient assistance.

Linda Longwe, by profession, is a leadership development trainer and corporate reputation management consultant. She is based in Southern Africa and her company, Linda Longwe International P/L is registered in Malawi, Zambia and Zimbabwe.

Linda has won entrepreneurial awards, local and international service awards, including being voted Outstanding Rotary President of the Year: 2011; Winner: Rotary Assistant Governor of the Year: 2012 and is a Multiple Paul Harris Award Winner: Rotary International

She is a holder of a Business Administration Degree from the University of South Africa, a post graduate Marketing Diploma from the Chartered Institute of Marketing UK, and a Master of Business Administration Degree from Nottingham Trent University. She successfully completed a Doctoral Research Training Programme (PGC) with the University of Stellenbosch; she is a trained counsellor and recently completed The Spirituality and

Practice of Prayer course with Arrupe College.

Linda Longwe is a Council Member of the Manicaland State University of Applied Sciences and the founder of Ethics in Enterprise Africa. She thrives on challenges and is highly dependable. Linda is passionate about improving the lives of the disenfranchised.



Mary Lovely

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Mary Lovely PhD, RN, CNRN, is a volunteer Senior Advisor for the IBTA and lives in San Francisco, United States.

Dr. Lovely earned her PhD at the University of California San Francisco (UCSF) School of Nursing focusing on symptom management and brain tumor patient care.

During her Post Doctoral Fellowship she studied the effects of fatigue on brain tumor patients. Mary developed a program of research around long-term effects experienced by patients and families with brain tumors. She has numerous presentations and publications as Assistant Adjunct Professor in the UCSF School of Nursing.

Mary has held positions with the American Brain Tumor Association (ABTA) and the National Brain Tumor Society (NBTS). In these roles, she communicated with patients and families about clinical issues, nationally and internationally, and developed conferences for patients and healthcare professionals.

Dr. Lovely co-facilitates an active brain tumor support group in San Francisco, and reviews prospective articles for many journals. She is actively involved in the Milton Marks Brain Tumor Family Camp. She consults for patients and families dealing with cognitive issues following cancer.

She is a patient support consultant to biotech startup companies. Mary is a Patient Advocate representative on the NCI Brain Tumor Malignancies Committee.



Vincent Mbayo

Vincent Mbayo is an active volunteer with the Zimbabwe Brain Tumour Association (ZBTA). Vincent prides himself for being a volunteer in the role of field officer for the ZBTA which has given him the opportunity to work with the people directly or indirectly affected by brain tumours and says this has been a life transforming experience.

Vincent has argued that the greatest threat to our generation is not war, disease and pestilence but it is lack of knowledge, and the greatest needs for our generation are leaders and pioneers of world change. With the Zimbabwe Brain Tumour Association, his main thrust and drive is information dissemination on brain tumours for early detection, which may lead to better prognosis. Not only does he help patients and the community in general to acquire more knowledge about brain tumours, but he is also actively involved in caregiving as well as support for the patients.

In his journey as a ZBTA volunteer, Vincent endeavors to give hope by being a strong pillar in times of need so that brain tumour patients and their families may know that they are not alone. His wish is to bring change to the situation of brain tumour patients and their families.



Thierry Muanza

Thierry M. Muanza, B.A., M.Sc., M.D., FRCPC, is an Assistant Professor to the Departments of Oncology and an Associate Member of the Departments Experimental Medicine and Neurology & Neurosurgery of the Faculty of Medicine at McGill University. He is also the co-Medical Director of the Adolescent and Young Adult Oncology Program. Following a Bachelor's degree in biology at Suffolk University and a Master's degree in biomedical sciences from Northeastern University in Boston, MA, USA, Dr. Muanza obtained his Doctor of Medicine (MD) degree from the Université de Sherbrooke, Quebec, Canada.

He subsequently pursued his residency in radiation oncology at McGill University, as well as a Translational Research Fellowship, ASTRO-NCI, in radiation oncology at the National Institutes of Health in Bethesda, Maryland, USA.

Dr Muanza is also a member of the Board of Directors, Brain Tumor Foundation of Canada.

Dr. Muanza is a Fellow of the Royal College of Physicians of Canada.

Major Research Activities

Clinical:

Clinical trials in breast, lung, brain/central nervous system, adolescent and young adult cancers.

Laboratory:

Dr. Muanza's laboratory work focuses on translational research, radio-oncology, molecular targeted therapies, and biomarkers.



Sally Payne

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Sally Payne is the Associate Dean of Studies at a University Pathway College in Sydney, Australia. Sally's younger sister was diagnosed with an anaplastic astrocytoma in 2005 which prompted Sally to start researching the disease and the support available. Sally came across Denis Strangman and Kathy Oliver online in the early stages of the IBTA and was impressed with the international perspective and approach to patient advocacy.

Sally helped set up and continues to maintain the IBTA's unique brain tumour database of 11,000 contacts that is used to send monthly e-newsletters and the yearly IBTA magazine, *Brain Tumour*, to many countries around the world. Sally also assists the IBTA with planning and strategic direction. Sally's sister died in 2011 and the journey over those six years has given her an insight into the issues faced by a number of developed but small population countries with the lack of clinical trials and experienced neuro-oncology nurses and facilities.



Geoff Pilkington

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Geoff Pilkington, BSc PhD CBiol FRSB FRCPath, is Professor of Cellular and Molecular Neuro-oncology

and Head of the Brain Tumour Research Centre at the University of Portsmouth.

He is a Past-President of the British Neuro-Oncology Society and is currently Honorary Treasurer and Executive Board Member of the European Association of Neuro-Oncology. He also holds membership of the British Neuroscience Association, the British Neuropathological Society (formerly a committee member and Programme Secretary), the Society for Neuro-Oncology, and the European Association for Cancer Research.

Geoff has spent his entire career in brain tumour research, having started work on chemical neuro-carcinogenesis where he studied brain cancer stem cells and brain tumour development at the Middlesex Hospital Medical School in the early 1970s, and subsequently spent 23 years at the Institute of Psychiatry, King's College, London, latterly as Professor of Experimental Neuro-Oncology.

In 2003 he moved to the School of Pharmacy and Biomedical Sciences, University of Portsmouth, as Professor of Cellular & Molecular Neuro-Oncology and Director of Research. He now heads the largest laboratory-based, dedicated brain tumour research centre in the UK which is core-funded by the UK charity Brain Tumour Research. Over the years the research focus of his group has been development of models for the study of brain tumours, elucidation of the mechanisms underlying diffuse local invasive behaviour in glioma, delivery systems for passage of agents across the blood-brain barrier (BBB) and development of novel strategies for the use of mitochondrial pathways in treating glioma.



Trish Scanlan

Dr Trish Scanlan is an Irish paediatric oncologist who has lived and worked in Tanzania since 2006. Alongside her local colleagues and the NGO Tumaini la Maisha/Their Lives Matter (www.wearetlm.org) which she founded, she has helped create the national paediatric oncology service for Tanzania. The care is offered free of charge to all children and is now available at three centres across the country. She hopes to add more centres to the network until every child with cancer has a chance of cure.



Bonita Suckling

Bonita Suckling founded Rainbows and Smiles when her only son, Jed, was diagnosed with a high grade brain tumour: anaplastic astrocytoma.

Rainbows and Smiles Foundation is a charitable organization dedicated to providing assistance in the form of emotional, social and financial support to families and caregivers in need when a child or children of that family is/are diagnosed with cancer. This is achieved through coordination with the hospital facilities, social welfare and medical professionals. Bonita naturally has a special interest in brain tumours.

Rainbows and Smiles is a team of nine passionate

team members and a few volunteers who drive the fight against childhood cancer in South Africa. Four of the mothers who work with the Foundation have lost their children to cancer.

The assistance offered by Rainbows and Smiles is in the form of payment of medical bills, provision of toys, gifts and awareness items and grants directly to children, their families or caregivers. Rainbows and Smiles solicits funds through various events, from corporate companies and fundraising activities. The poverty rate in South Africa is heart breaking with many rural families sometimes skipping treatment due to a lack of funds for transportation to and from the hospital.

Rainbows and Smiles does not discriminate based on race, culture, religion, financial status or any other factor. We believe in providing hope and laughter as the family finds strength beyond the illness. We will strive to support children battling childhood cancer whilst advocating awareness initiatives through ongoing education of the early warning signs of childhood cancer.

The organisation also promotes the Gold Ribbon (a symbol for childhood cancer) in order to raise the profile of childhood cancer throughout South Africa.



Teddy Totimeh

Dr. Teddy Totimeh trained as a neurosurgeon at Ghana's premier medical teaching establishment and teaching hospital. He has spent additional time training in Israel, the US and Kenya.

He is currently a consultant neurosurgeon at the Greater Accra Regional Hospital and a part-time lecturer in neuro-anatomy. He also runs nationwide symposia on head trauma and primary trauma care.

He is a 2017 Joanna Brigg's Fellow conducting a

best practices implementation survey in Greater Accra Regional Hospital on head injury management.

A 2016 Eisenhower Fellow, Totimeh believes that empowering the private sector to handle critically ill patients is key to raising the profile of specialized healthcare in the country. He is collaborating with fellow doctors and entrepreneurs with a vision to build centres of excellence for acutely ill patients.

Mentoring, education and equipping of these centres is key to improving the outcomes for all acutely ill patients. Together with his group, Totimeh is committed to organizing high quality well resourced educational conferences that directly impact standards of care in Ghana and in the sub region for neuro-oncology patients.

A gifted writer, and a keen observer of the human heart and battles of being, Totimeh has published volumes of essays, short stories and a book of poetry. He blogs regularly on Linked In Pulse.

the Society for Neuro-Oncology (SNO) and the Asian Society of Neuro-Oncology (ASNO), and is a member of COGNO (Co-operative Trials Group for Neuro-Oncology, Australia). He is listed with the European Medicines Agency (EMA) as a patient expert in the field of CNS tumours and with the European Organization for Research and Treatment of Cancer (EORTC) for which he has reviewed patient information documentation and clinical trial protocols.

In his home country of New Zealand, Chris moderates two Facebook support groups for brain tumour patients and has written articles on brain tumours for the Cancer Society of New Zealand. Outside of the brain tumour world, Chris works as a marketing consultant specialising in doing business with Asia. Chris and Lynda live in the seaside suburb of Seatoun, in Wellington, New Zealand. They are the proud parents of Cassandra, age 24, and Nathan, age 21.



Chris Tse

Chris is an IBTA Senior Advisor based in New Zealand.

Chris became a brain tumour patient advocate through the inspiration of his wife Lynda, a long-term survivor of a glioblastoma. He has been a volunteer advisor to the IBTA since 2006, the year Lynda was first diagnosed. Currently he assists with managing the IBTA's social media channels, helping maintain the website and providing editorial assistance with the monthly e-News and *Brain Tumour* magazine.

The lack of effective brain tumour treatments available to Lynda motivated Chris to take a special interest in brain tumour research. He has represented the IBTA at several brain tumour conferences including



Shungu Ushewokunze

My name is Shungu Ushewokunze. I am from Zimbabwe and obtained my primary medical degree at the University of Zimbabwe in 1997. I moved to the United Kingdom in 1998 and completed my neurosurgery training in Birmingham. Following this I completed a fellowship in paediatric neurosurgery at the Royal Children's Hospital, Melbourne, Australia and developed an interest in epilepsy surgery.

I now work as Consultant Adult and Paediatric Neurosurgeon in Sheffield, United Kingdom. A large part of my work is the management of patients with brain tumours in the neuro-oncology service. I have a particular interest in the management of low-grade gliomas in children and young adults and regularly

perform surgery for these tumours including awake craniotomies with brain mapping.

I have been a member of the Society for Neuro-Oncology (SNO) for the last two years and am keen to collaborate with colleagues from around the world to help improve outcomes for patients with brain tumours.



Gelareh Zadeh

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Dr. Gelareh Zadeh, MD, PhD, FRCS(C), FAANS, is the Head of Surgical Oncology at University Health Network, Head of the Toronto Central Regional Cancer Program at Cancer Care Ontario, and also the Program Medical Director for the Krembil Neuroscience Centre at Toronto Western Hospital. She is a neurosurgeon-scientist at the Toronto Western Hospital and Princess Margaret Cancer Centre. She has a dedicated clinical and research program in neuro-oncology and neurosurgery. In addition, she is the Wilkins Family Chair for Brain Tumor Research, the co-Director of the Elizabeth Raab Neurofibromatosis Program, and the Director of the UHN Brain Tumor Biobank.

Dr. Zadeh has a dedicated neuro-oncology and skull base practice, which includes a number of multidisciplinary specialized programs such as skull base, brain metastases, pituitary tumors, Gamma Knife and neurofibromatosis clinics. In parallel, she has an active research laboratory focusing on integrated multi-platform molecular analysis of brain tumors, together with a focus on understanding molecular response to targeted therapies, such as anti-angiogenesis and metabolic inhibitors. She is also involved in a number of national and international organizations, like the WFNS, NASBS, and SNO.

S-SANOC Photo Album



At the S-SANOC welcome dinner (left to right): Ekokobe Fonkem, Patrick Bankah, Shungu Ushewokunze



Teddy Totimeh (third from right) and colleagues at the S-SANOC welcome dinner



Chas Haynes (second from right) greets a group of S-SANOC delegates



Pastor Wilson Mugarura (centre) and Daphine Kakura-Wilson (right) speaking with SNO Executive Director, Chas Haynes (left).



IBTA Senior Advisor Jean Arzbaeher handing out conference bags at the S-SANOC dinner. To her right is IBTA Senior Advisor Sally Payne. Bonita Suckling is also pictured (centre)



Left to right: Chas Haynes, Irene Azong-Wara, Chris Tse, Bonita Suckling



Kathy Oliver (left) with Brian Nyatanga (right) at the S-SANOC dinner



Edjah Nduom (left) and Jason Huse (right)



Seated left to right: Chas Haynes, Jenny Baker, Chris Tse. Standing, left to right: Above: Christine Mungoshi (left) and Brian Nyatanga (right) Sally Payne, Jan-Marc Lieskovsky (from MagForce AG), Bonita Suckling, Stuart Farrimond



Seated, left to right at the S-SANOC dinner: Anita Granero, Mary Lovely, Jean Arzbaecher, Shungu Ushewokunze. Standing, left to right: Edjah Nduom, Patrick Bankah, Jason Huse, Gordon Oliver, Teddy Totimeh



Left to right: Ekokobe Fonkem, Trish Scanlan, Thierry Muanza, Kathy Oliver and Luke Mungoshi



The S-SANOC welcome dinner, left to right: Daphine Kakura-Wilson, Irene Azong-Wara, Brian Nyatanga, Dimitri Pouradier, Melissa Lim



IBTA Senior Advisor Mary Lovely makes a point



Ekokobe Fonkem



Jean Arzbaecher, IBTA Senior Advisor, introduces herself



Bonita Suckling of Rainbows and Smiles, South Africa, addressing the S-SANOC meeting



Jason Huse speaks to the S-SANOC participants



Shade Adoh



During a break in the S-SANOC programme – left to right: Gordon Oliver, Chris Tse, Bonita Suckling



Christine Mungoshi (left) and Brian Nyatanga (right)



Shungu Ushewokunze (left) with Trish Scanlan (right)



Patrick Bankah addresses the S-SANOC participants



Drs Trish Scanlan (left) and Ekokobe Fonkem (right)



Dimitri Pouradier represented Bristol-Myers Squibb



IBTA Senior Advisor from New Zealand, Chris Tse



The 2017 S-SANOC meeting participants. Front row, left to right: James Balogun, Gelareh Zadeh, Thierry Muanza, Wilson Mugarura, Kathy Oliver, Jenny Baker, Mary Lovely, Irene Azong-Wara, Bonita Suckling, Christine Mungoshi, Dimitri Pouradier. Second row, left to right: Chas Haynes, Geoff Pilkington, Rakesh Jalali, Patrick Bankah, Stuart Farrimond, Anita Granero, Chris Tse, Shade Adoh. Third row, left to right: Teddy Totimeh, Jason Huse, Edjah Nduom, Gordon Oliver, Sally Payne, Daniel Fulkerson. Back row, left to right: Alan Davidson, Jean Arzbacher, Jan-Marc Lieskovsky, Luke Mungoshi



Left to right: Kathy Oliver (IBTA), Pastor Wilson Mugarura, Dr Rakesh Jalali, Dr James Balogun



Rakesh Jalali (far left) at the S-SANOC welcome dinner with Gordon Oliver (second from left), Christine Mungoshi (third from left) and Wilson Mugarura (right)



Left to right: A final photograph of some of the S-SANOC participants captures the exciting atmosphere of the meeting. Left to right: Pastor Wilson Mugarura, Prof Alan Davidson, Kathy Oliver (IBTA), Dr James Balogun, Dr Teddy Totimeh, Dr Thierry Muanza, Christine Mungoshi (ZBTA), Dr Edjah Nduom, Dr Patrick Bankah

Just some of the comments from the S-SANOC feedback forms

- "I feel major topics were tackled."
- "Great initial effort."
- "Everything important seems to have been covered...."
- "Networking, advice from older societies and opportunities for membership [was very valuable]."
- "[I enjoyed] the collaboration and multidisciplinary aspect."
- "Great sensitisation that Africa is important; great energy and enthusiasm and the need to harness this opportunity"
- "Joining tumour survivors/caregivers and the professionals was wonderful and educative."
- "Involvement of patient advocates in the same room with [medical] professionals and opportunities to learn from the parties and groups [was very valuable]."
- "Patient advocacy presentations were an eye-opener for many clinicians."
- "Every aspect was relevant."
- "The time was quite limited but a lot was achieved."

The important work of the S-SANOC project continues. If you have an interest in improving outcomes for brain tumour patients and their families in sub-Saharan Africa, please contact us. And watch our websites and social media for further information about advocacy activities in this part of the world.

"If you want to go fast, go alone. If you want to go far, go together."

(African proverb)

International Brain Tumour Alliance (IBTA)

www.theibta.org

kathy@theibta.org Twitter: @theibta, @KathyOliverIBTA

Society for Neuro-Oncology (SNO)

International Outreach Committee

www.soc-neuro-onc.org

linda@soc-neuro-onc.org Twitter: @NeuroOnc

Zimbabwe Brain Tumour Association (ZBTA)

<https://www.facebook.com/Zimbabwe-Brain-Tumor-Association-225796887464934/>

cmmungoshi@yahoo.co.uk

Twitter: @ZimBrainTumour

BRAIN TUMOURS

URGENTLY
NEEDED:

MORE
RESEARCH
AND SUPPORT