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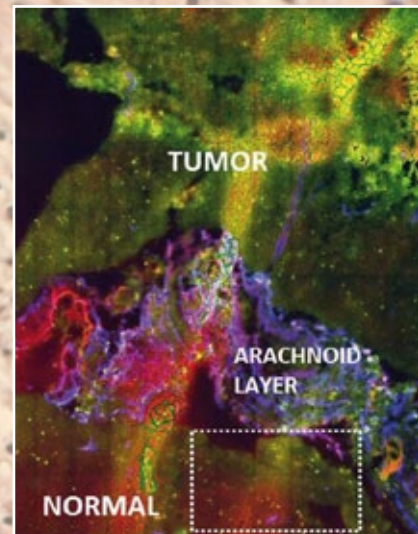
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**Greater Collaboration Leads to
Greater Knowledge and Hope. The
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Lafayette, California, Just Prior
to SNO/WFNO 2013**

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Greater Collaboration Leads to Greater Knowledge and Hope

The First World Summit of Brain Tumour Patient Advocates Takes Place in Lafayette, California, Just Prior to SNO/WFNO 2013

Kathy Oliver

The world of brain tumour patient advocacy had never seen anything like it.

From Argentina to Zimbabwe and Australia to the USA, 64 participants from 20 countries arrived in Lafayette, California, on November 18, 2013, to make history at a 2-day conference (November 19 and 20) aimed at increasing knowledge and collaborative efforts for the benefit of brain tumour patients and caregivers around the globe¹.

Nearly 2 years in the planning, the “First World Summit of Brain Tumour Patient Advocates” – organised by the International Brain Tumour Alliance (IBTA)² – provided a unique opportunity to meet like-minded people from different countries; exchange ideas on best practice, challenges, and advocacy experiences, and build new relationships between organisations and individuals in the advocacy arena.

Attendance at the Summit was by invitation. The countries represented were: Argentina, Australia, Belgium, Canada, Denmark, India, Ireland, Italy, Japan, Lithuania, Netherlands, New Zealand, Norway, Singapore, Spain, Sweden, Taiwan, United Kingdom, United States, and Zimbabwe.

■ Collaboration and Sharing

Just as the major international neuro-oncology and cancer scientific congresses strive to bring together global leaders in these fields so that they might interact with each other, learn from each other, and cooperate long-term, so the IBTA's Summit assembled the movers and shakers, the Board Chairs and CEOs of leading brain tumour advocacy organisations around the world.

The main theme of the Summit was “collaboration” and “sharing”. The 48-hour conference was professionally facilitated by a leading patient advocacy expert. The Summit was collegially designed so that nearly all of the participants either presented in a plenary session, spoke as part of a panel, ran a workshop or marketplace, acted as rapporteurs, or assisted in a practical way to ensure a smooth meeting.



Participants from around the world gather in Lafayette, California, to attend the IBTA's First World Summit of Brain Tumour Patient Advocates.

© Photo courtesy of SalcidoArts, www.salcidoarts.com

The IBTA's international team of 11 advisors provided advice, help, and support throughout the process of devising and holding the Summit.

■ Something for Everyone

The Summit featured different types of sessions so everyone had a chance to participate in a way in which they felt comfortable and confident about actively contributing to the programme.

A highlight of the Summit was the excellent introductory overview of current brain tumour treatments presented by neurosurgeon and past president of the Society for Neuro-Oncology (SNO), Dr Susan Chang.

Over the 2 days of the Summit, the 9 plenaries included a “Setting the Scene” session which introduced some of the issues faced by brain tumour patient advocates in their work such as: grappling with health technology assessment (HTA), accessing innovative therapies, caring for the caregiver, support and information provision, personalised medicine – the hype and the hope, challenges of paediatric brain tumours, and help for brain tumour patients in the developing countries.

Also featured in the plenaries were lectures on brain tumour statistics, country-specific challenges and solutions for brain tumour care and support, exploring some of the unmet needs of the brain tumour community, and sharing best practice.

¹ For the biographies of participants at the First World Summit of Brain Tumour Patient Advocates, see <http://www.theibta.org/BiosAndPhotos.pdf>

² International Brain Tumour Alliance – www.theibta.org

An innovative “Marketplace” session kept everyone literally on their toes. This part of the programme involved Summit participants moving in small groups between 6 different locations in the Summit hotel where facilitators conducted 30-minute “taster” sessions on various topics including fundraising in an era of austerity, how doctors can improve their communication with brain tumour patients, working with volunteers and the art of succession planning/sustainability of patient organisations, working with industry, social media and the IT revolution, and working with print and broadcast media (including public service broadcasts).

■ Workshops Ask Searching Questions

Five parallel workshops were also held at the Summit. These 75-minute sessions, led by Summit participants, addressed the following questions:

1. How can clinical trials be better organised for brain tumour patients?
2. What do brain tumour patients want from pharmaceutical companies in order for companies to be more ‘patient-centric’?
3. What do brain tumour patients want from the organisations that represent them?
4. What are the relationships like between brain tumour patient groups, cancer control organisations, and the neurological disease community?
5. How can we adequately support people with a low-grade or meningioma brain tumour?

Summaries were produced from all the plenaries, Marketplace sessions, and workshops with the aim of publishing a post-Summit report which will be released early in 2014.

■ A Remarkable, Historic Event

This historic Summit was remarkable in many ways. Collectively, the brain tumour advocacy leaders at the Summit represented over 500 years of experience in helping patients, their caregivers, and families on their journeys.

The large majority of brain tumour patient advocates at the Summit had never before met, yet the spirit of cooperation, determination, and teamwork permeated the 2 days of the Summit as if everyone had known each other for many years.

A deep camaraderie quickly developed among the Summit participants who all came from different cultural, socio-economic, geographic, and religious backgrounds. United for 2 days, these once-strangers from the 4 corners of the world seemed to find in each other a deep friendship and empathy, forged from their common desire to significantly improve the journey for brain tumour patients and their caregivers.

Indeed, 42 of the 64 participants were either brain tumour patients themselves, current brain tumour caregivers, or former brain tumour caregivers.

One participant at the Summit commented, “*It was great to be able to compare notes on running a brain tumour patient or-*

ganisation. But even more meaningful was to share our personal brain tumour journeys with others who really understood, from the depths of their souls, what it was like to see someone you love diagnosed with a brain tumour. This unique bond that we share is deep and powerful.”

Other participants at the Summit who had become involved in the brain tumour world, but not because of a personal connection to the disease, nevertheless brought to their roles in their organisations – and the Summit – a truly impressive commitment to improving the situation for our community through their determined and dedicated work.

■ Advocacy Challenges from Around the World

The Summit included not only advocates from developed countries, but also those from the less developed areas of the world such as Zimbabwe. The founders of the Zimbabwe Brain Tumour Association described how they have to work in a highly chaotic environment, greatly influenced by their country’s problems of rocketing inflation, political and economic instability, fuel and food shortages, and the collapse of the healthcare system.

Advocacy colleagues representing The Brain Tumour Foundation of India spoke compellingly of the challenges in their country: for example, the stigma of a brain tumour diagnosis, the numerous linguistic dialects, the very low level of public awareness about this disease, the limited surgical suites and imaging modalities, the overall health focus on communicable diseases, and the cultural bias toward superstition which affects the efficacy of healthcare.

A Lithuanian brain tumour colleague described the absence of information and organizational support as major barriers in his country.

Summit participants heard from colleagues in the USA, Europe, Japan, Australia, and Canada that even in the richest and most powerful countries on earth, patients can still be lost in a maze of uneven and inequitable care. In addition, brain tumour therapies do not easily fit into the regulatory systems and they certainly do not come cheap, causing challenges with their reimbursement and equitable access in countries with national health systems.

Representatives from Argentina, Singapore, New Zealand, and Taiwan described the situation for brain tumour patients and caregivers in their own countries and shared insights into what their particular challenges are.

An added value of holding the Summit in California in November was that participants, if they wished, could then attend the SNO/WFNO meeting in San Francisco after the Summit³. For some advocates, it was their first time at a high-level international scientific conference. SNO was extremely supportive

³ 4th Quadrennial Meeting of the World Federation of Neuro-Oncology in conjunction with the 18th Annual Meeting of the Society for Neuro-Oncology, see <http://www.soc-neuro-onc.org/2013-annual-meeting/>

of the Summit, demonstrating its commitment to the patient advocacy movement and its warm welcome of collaborative events of this nature.

■ Predicting the Future by Helping to Create It

The Summit examined, on many levels, what really matters to brain tumour patients and caregivers on their journeys. But it also looked at the road ahead.

One of the best ways to predict the future is to help create it. The Summit hopefully marked a turning point in the delivery of a better future for those whose lives are touched by this disease.

To achieve this, members of the international brain tumour advocacy community should push strongly for more support, more information, more research, and quality care for our patients. We should collaborate with others to help avoid duplication and waste of precious resources.

We should help, as much as we can, those brain tumour patients in the less developed countries of the world, too.

One Summit participant wrote after the meeting, *"Together our efforts for the brain tumour population will grow and not go unheard by government, healthcare workers, and our patients and families."*

Another participant added, *"It was an enlightening experience to listen to stories [from] across the globe. The challenges the brain tumour patient and caregiver face are truly universal. Everyone shared so many remarkable stories of faith, endurance, and hope. It was sad for all the loss, but amazing to hear how many people are making a difference for others ... [on] the brain tumour journey."*

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