Bridging communities
Breaking barriers
Building progress

Highlights from the 5th Biennial World Summit of Brain Tumour Patient Advocates 2023

NZ Aotearoa Neuro-Oncology Society Annual Conference

Crowne Plaza Hotel, Queenstown, New Zealand, 26th August 2023

Chris Tse, Chair, Brain Tumour Support NZ

Disclosures

Personal disclosures: None

Brain Tumour Support NZ's participation in the 5th Biennial World Summit of Brain Tumour Patient Advocates was made possible by a travel grant from the International Brain Tumour Alliance

Bridging communities, breaking barriers, building hope

- The International Brain Tumour Alliance and the World Summit of Brain Tumour Patient Advocates
- Presentation Highlights
- Masterclass: Clinical trials – are we doing it right?
- Brain Tumour Support NZ Presentation
- Personal Highlights

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International Brain Tumour Alliance

- Founded in 2005 at the WFNO conference in Edinburgh, Denis Strangman (Australia) and Kathy Oliver (UK)
- Worldwide network of brain tumour patient organisations and others involved in the field of neuro-oncology
- Monthly e-news, annual Brain Tumour magazine, podcast series, virtual art exhibition
- IBTA Biennial World Summit of Brain Tumour Patient Advocates since 2013

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The IBTA and Global Advocacy

- International Brain Tumour Awareness Week and Walk Around The World For Brain Tumours
- Brain Tumour Patients' Charter of Rights
- Encourage the formation of patient organisations in countries where there are none
- Work in less developed countries, eg. SNOSSA
- Special projects, eg. Ukraine

Greater Collaboration – Greater Knowledge – Greater HOPE

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Strong connections

- Regional neuro-oncology societies, eg. SNO, EANO, BNOS, ASNO, WFNOS, SNOLA, SNOSSA
- Research, eg. NIH, NCI, CBTRUS, EORTC
- Advocacy, eg. ECO, ESMO, ASCO, EURORDIS, RCE
- Industry
- Around 200 patient organisations worldwide

“NOTHING ABOUT US WITHOUT US”

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IBTA World Summit of Brain Tumour Patient Advocates

Vienna, Austria, 26-28 June 2023

104

Participants

33

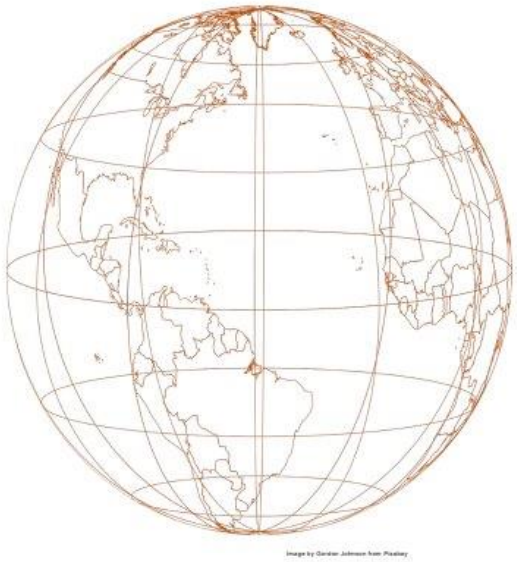
Countries

5

Continents

Countries represented at the 2023 IBTA World Summit of Brain Tumour Patient Advocates

Australia
Austria
Belgium
Cameroon
Canada
China
Croatia
Cyprus
Czech Republic
Finland
France
Germany
India
Ireland
Israel
Italy



Japan
Lithuania
Mexico
Mongolia
Netherlands
New Zealand
Nigeria
Pakistan
Poland
Portugal
Singapore
United Kingdom
United States
Ukraine
Zimbabwe

3

Past IBTA Summits

2013
California

2017
London

2015
Barcelona

2019
Bethesda, Maryland
(NIH)

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“I have found my people”

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International Speakers

Susan Chang

Matthias Preusser

Tracy Batchelor

Manmeet Ahluwalia

Also: Ather Enam, Georg Widhalm, Chas Haynes, Richard Price, Adelheid Woehrer, Ahmed Idbaih, Carola Lutgendorf-Causig, Christine Marosi, Friedrich Erhart, Gaetano Finocchiaro, Guy Buyens, Martin Glas, Minda Okemwa, Ulrike Leiss, Jack Letteur, Alexandra Diaz Alba, Andreia Capela Marques

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IBTA Summit Programme

Plenary Presentations

Workshops

Town Halls

Masterclasses

Brain Mets Symposium

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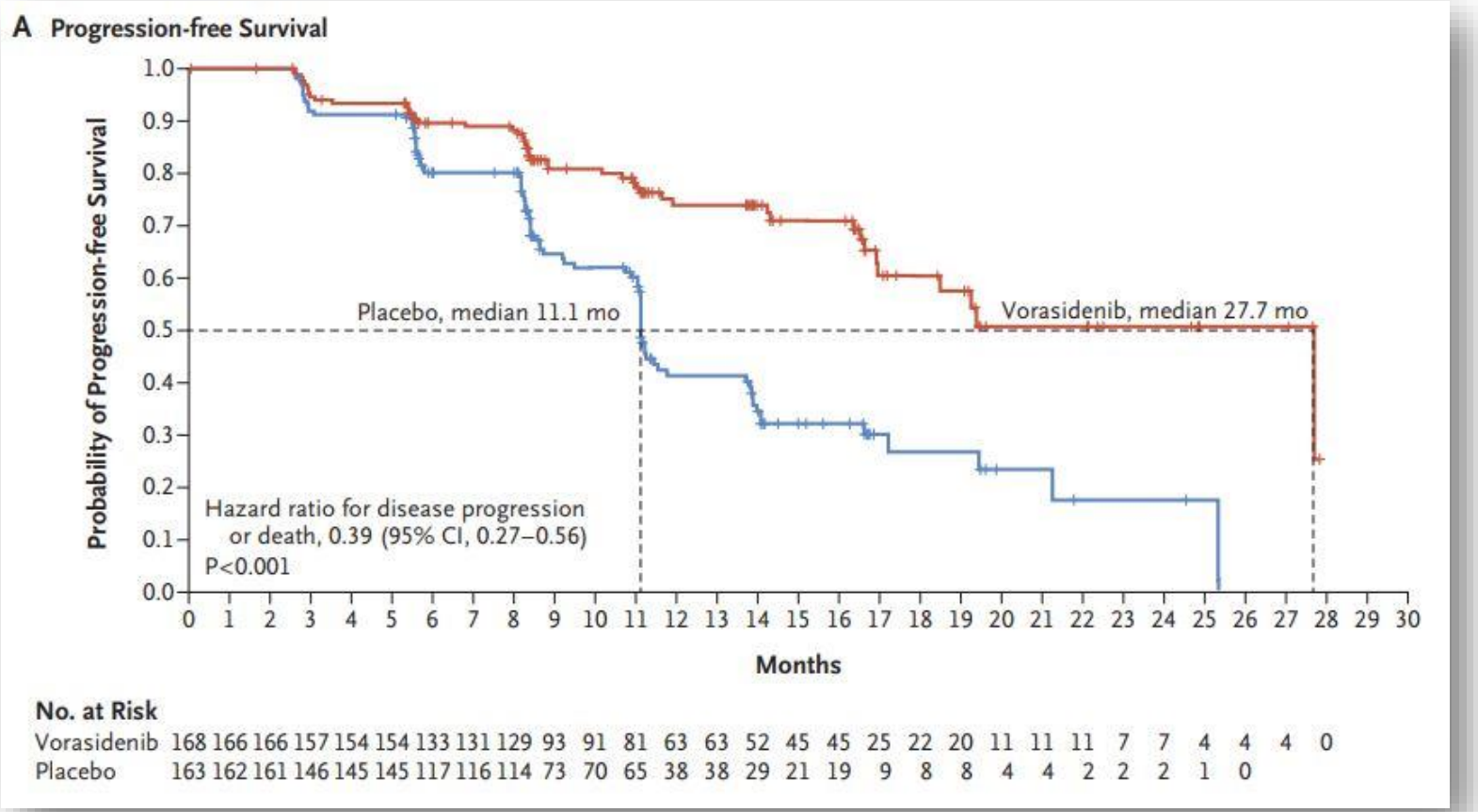
Vorasidenib – Phase 3 INDIGO Trial



Interim analysis at 135 events

Residual/recurrent grade 2 IDH-mutant glioma, surgery only. N = 331.

Median PFS 27.7 vs 11.1 mo
HR=0.39 (95% CI, 0.27-0.56)

TTNI at 18 mo 85.6% vs 47.4%
HR=0.26 (95% CI, 0.15-0.43)
TTNI at 24 mo 83.4% vs 27.0%

Mellinghoff et al, N Engl J Med 2023; 389:589-601

Vorasidenib – Questions and comments

- Does it work in patients who have previously been treated with radiotherapy and chemotherapy?
- Will it work in patients with grade 3 or 4 IDH-mutant gliomas?
- Is single-agent Vorasidenib the optimum treatment or will it work better in combination with other agents?
- We need more trials like this – targeted agent, double blinded, placebo controlled, etc.
- When will it be FDA approved?

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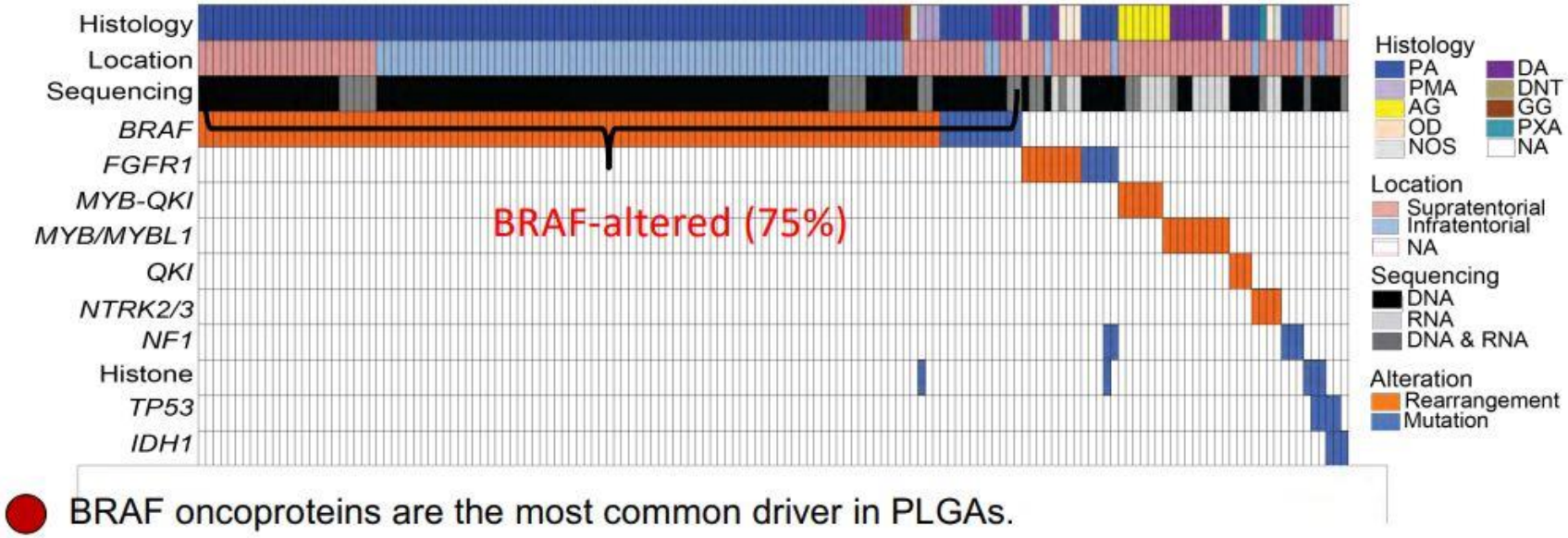
Pediatric Glioma
Targeting RAF/MEK



- BRAF oncoproteins are the most common driver in PLGAs.
- The majority of these oncoproteins are a truncation/fusion variant (orange bars). A minority are the V600E point mutation (purple bars) found in adult solid tumors
- Type 1 RAF inhibitors approved for V600E tumors are ineffective on truncation/fusion BRAF.
- During the current funding period, we have found a brain-penetrant type 2 RAF inhibitor that suppresses all forms of BRAF oncoprotein.

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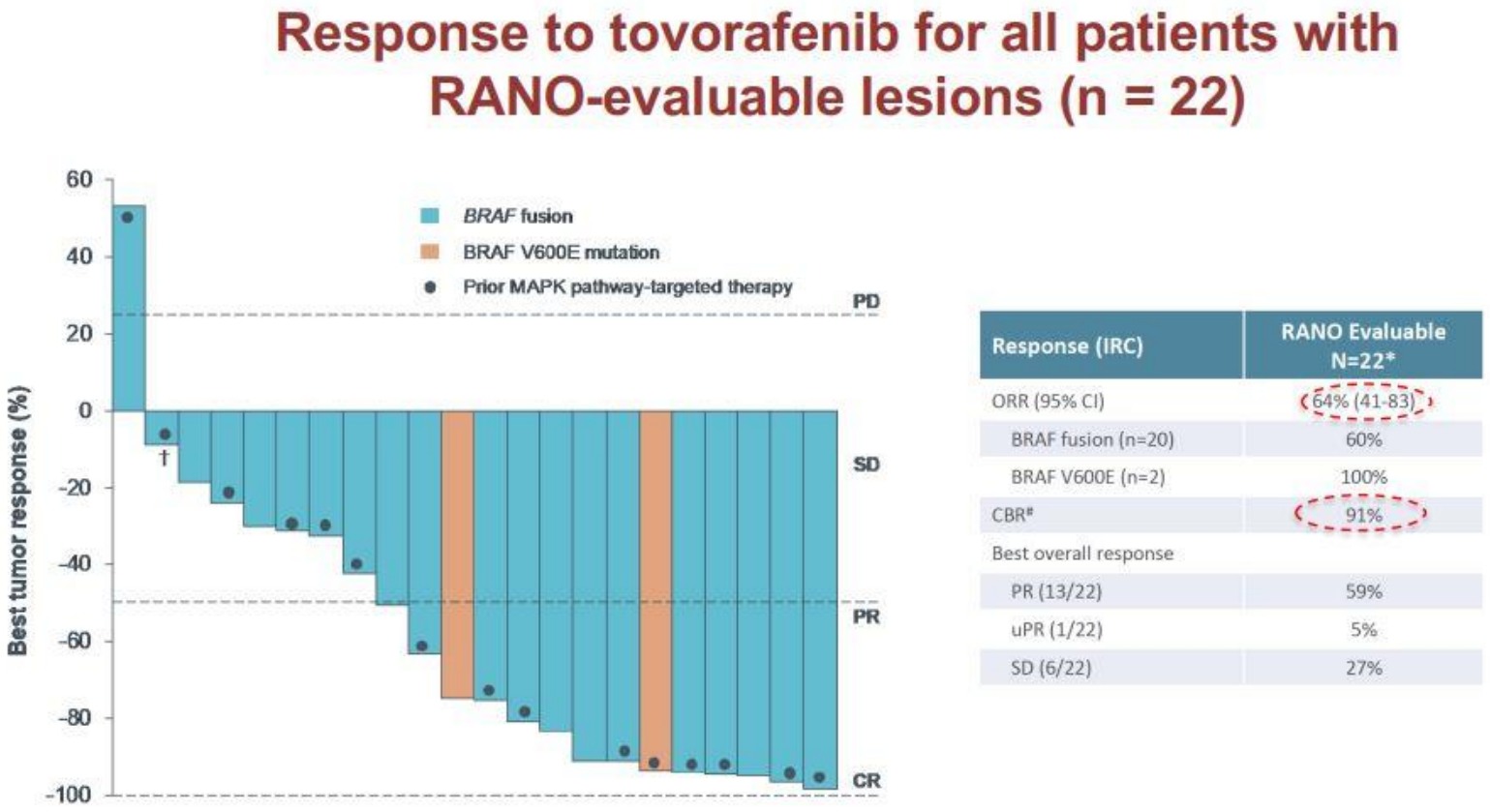
Tovorafenib (DAY101) – Phase 2 FIREFLY Trial



Response (IRC)	RANO Evaluable N=22*
ORR (95% CI)	64% (41-83)
BRAF fusion (n=20)	60%
BRAF V600E (n=2)	100%
CBR#	91%
Best overall response	
PR (13/22)	59%
uPR (1/22)	5%
SD (6/22)	27%

<u>2023 ASCO Meeting</u>

ORR (RANO) = 64%

Responses achieved in both BRAF fusions and V600E mutations

Hopeful for FDA approval!

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What else is on the horizon?

- Glutamate biosynthesis inhibitor – troriluzole [for high-grade glioma]
- Dendritic cell vaccine – DCVax-L [for glioblastoma]
- CAR T Cell – tisagenlecleucel [for PCNSL]
- DRD2 and ClpP inhibitor – ONC201 [for H3K27 mutant diffuse midline glioma]
- Guided Focused Ultrasound (FUS) [drug delivery, liquid biopsy, sonodynamic therapy]
- FDA-approved immunotherapies [for CNS tumours]

Agent (Target)	Indication
Dostarlimab (PD-1/PD-L1)	Tumors with DNA mismatch repair deficiency (dMMR)
Pembrolizumab (PD-1/PD-L1)	Tumors with High Microsatellite Instability, High Tumor Mutational Burden, or dMMR

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Masterclass: Clinical trials – are we doing it right?

How can we improve participation in clinical trials?

Only 10% of glioblastoma patients enrol in clinical trials – why?

- Their doctor did not recommend any clinical trials
- They were ineligible for any clinical trials
- They did not know where to find information about clinical trials

Why do so many phase 3 brain tumour clinical trials fail?

There is not one drug approved for recurrent GBM that has shown one day of survival benefit!

- Is the drug reaching the tumour?
- Did we do a good enough job in Phase 1 and 2?
- Selection bias, wrong targets

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Masterclass: Clinical trials – are we doing it right?

- Trial design
  - basket trials, external controls
  - eligibility criteria, age
- Convenience
  - telehealth
- Availability
  - international access
  - clinical trial networks
- Cost
  - money, technology (eg NGS)
  - infrastructure

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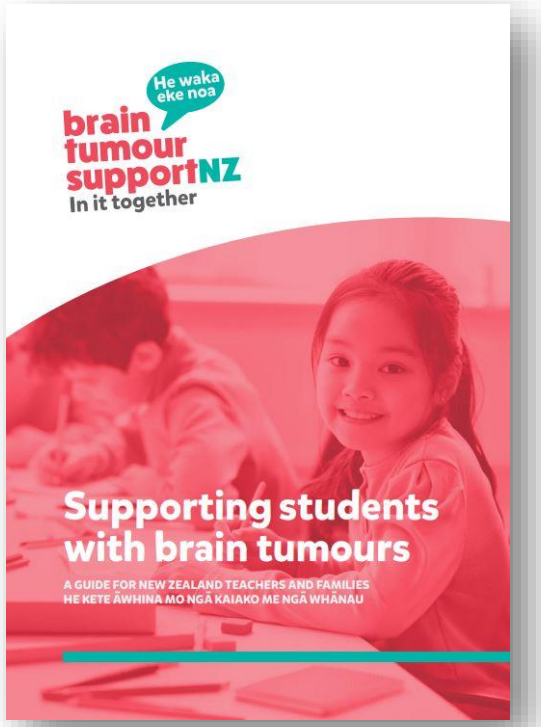
Back to school with a brain tumour

The Brain Tumour Support New Zealand experience



5th Biennial World Summit of Brain Tumour Patient Advocates
The Intercontinental Hotel, Vienna, Austria, 26th June 2023

Chris Tse, Chair, Brain Tumour Support NZ
Senior Advisor, International Brain Tumour Alliance

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Identifying the unmet need

Mid-2021 Held parent focus group

- Feeling dumbfounded, overwhelmed
- Gaps in support following clinical treatment, eg. back to school
- Existing information not specific to brain tumours or not made for New Zealand

Aug 2021 Appointed project lead

Sep 2021 Met with paediatric neuro-psychology team at Starship Children's Hospital

Moira Coatsworth

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Producing the guide

Oct 2021	Scope the document • Who is it for? • What age children should it cover? • New Zealand relevant
Oct-Dec 2021	Put advisory in place • Ministry of Education • Regional Health School • Starship paediatric neuro-psychologists • Paediatric neurosurgeon • Parents advisory group
Aug 2022	Launch!

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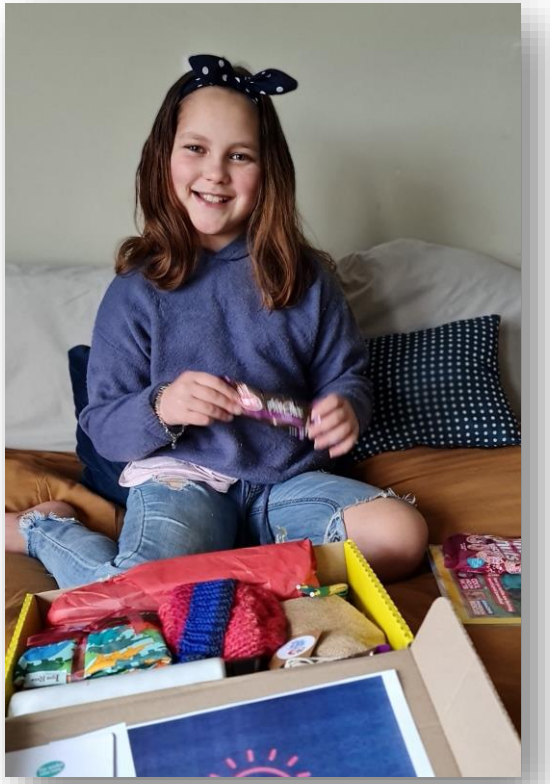
The finished product

- Family friendly
- Two copies in each Brain Box
- Distinctly New Zealand flavour
- Collaborative input
- Positive tone - strengths focused



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Lessons learned

- Do your research
- Don’t try and do everything at once
- Be targeted and focused
- Be realistic, play to your strengths
- Seek expert advice, collaborate

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Personal Highlights


Inspiration Fami
A Charity Foundation, which supports
adult cancer patients in Ukraine
Anna

Thank you!

BTSNZ's participation in the IBTA Summit was made possible by a travel grant from the International Brain Tumour Alliance www.theibta.org

Photos taken by Martin Hörmandinger www.mh-photography.at

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