



Brain tumours and COVID-19: a trio of surveys reflecting the patient and caregiver experience

Presented by:
Kathy Oliver, Chair and Co-Director, International Brain Tumour Alliance (IBTA)

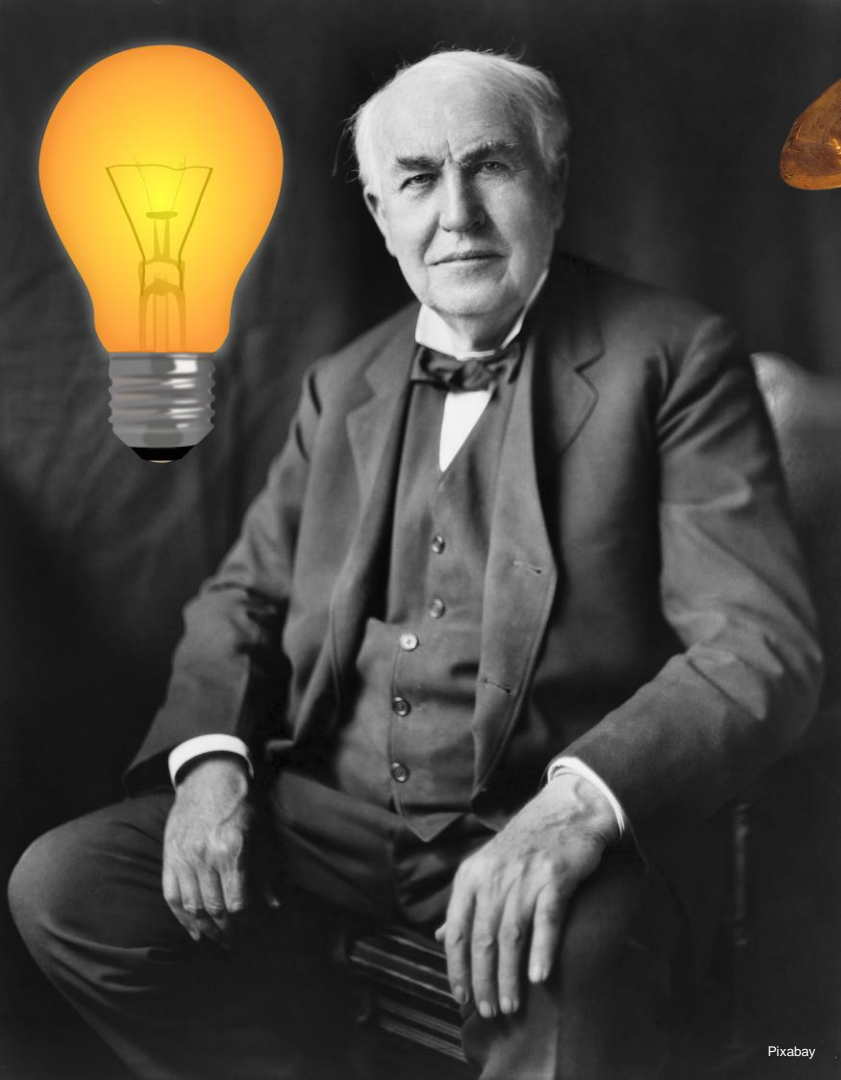
**RCE/ESMO/ESO Training course for rare cancer patient advocates
9th February 2022 - Virtual**



**I have no conflicts of interest
with regard to this presentation.**

**For full details of the IBTA's sponsorship policy,
and comprehensive details of our funding organisations,
please see our website at**

www.theibta.org



Pixabay



Bettman/Contributor/Getty Images

"I have not reached my conclusions through the study of traditions; I have reached them through the study of hard fact."

Thomas Alva Edison
1847-1931

Evidence-Based Advocacy (EBA): What does it achieve?



- Influences decision-makers
- Brings about change in healthcare policy
- Translates research into policy
- Shines a light on inequalities in cancer care
- Seizes healthcare challenges and defines them
- Catalyst to improve accessibility and quality of the essential elements of cancer care and support

Evidence-Based Advocacy (EBA): Objectives



- What are the research questions?
- What population are we interested in?
- What type of evidence do we want to generate?
- What impact should our research make?
- What is the strategy for analysing survey findings? Were there limitations regarding our survey population?
- What is the strategy for disseminating survey findings?

Survey #1 - Background

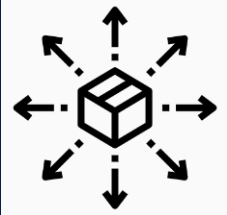
- During the early days of the pandemic, a measure was needed to understand the **effects of COVID-19 on brain tumour patients and their caregivers.**
- The International Brain Tumour Alliance (IBTA) approached the Society for Neuro-Oncology about our concerns. **SNO was very supportive.** We also approached the **University of Toronto** neurosurgical colleagues.
- The IBTA joined the **SNO COVID-19 Task Force** and then carried out our anonymous online survey on how COVID-19 was affecting the international brain tumour patient and caregiver community.

Survey #1 - Background



- An online **79-question survey** was developed by the IBTA in conjunction with the SNO COVID-19 Task Force.
- The survey was conducted over **39 days**, from April 22nd to May 30th 2020, inclusive.
- The survey was available in **7 languages** (French, Italian, German, Polish, Japanese, English and Spanish) and contained both categorical and open-ended questions.

Survey #1 - Background



- The survey was sent to **over 120 brain tumour charities and not-for-profits worldwide** to be disseminated to pediatric and adult brain tumour patients and their caregivers.
- The survey was also disseminated to an **international range of neuro-oncology professionals** around the world for forwarding to their patients and caregivers.

Survey #1 - Responses



- **1,989 unique surveys** were completed from **33** countries.
- We had **1,459 patient** responses
 - 1284 adult patients
 - 175 pediatric patients (with help from their parents/legal guardians).
- We had **530 caregiver** responses.
- **Over 30** different brain tumor types were represented in the survey.

Survey #1 – Headline Findings



- During the early days of the pandemic, brain tumour patients and caregivers experienced **increased stress** and **treatment delays**.
- The most common and **biggest fear** for patients was a **delay** in their brain tumour-related appointments or treatment.
- Patient/caregiver priorities: there is a need for **enhanced support and up-to-date, reliable, accessible information** on how COVID would affect their treatment and prognosis.
- Patients and caregivers ranked **physicians, brain tumour charities/not-for-profits as the most trusted sources** of information.
- A significant increase in the **caregiving burden** was reported by **43% of caregivers**.

Neuro-Oncology Advances

2(1), 1–16, 2020 | doi:10.1093/oaajnl/vdaa104 | Advance Access date 23 August 2020

Brain tumors and COVID-19: the patient and caregiver experience*

Mathew R. Voisin[®], Kathy Oliver, Stuart Farrimond, Tess Chee, Jean Arzbaecher, Carol Kruchko, Mary Ellen Maher, Chris Tse, Rosemary Cashman, Maureen Daniels, Christine Mungoshi, Sharon Lamb, Anita Granero, Mary Lovely, Jenifer Baker, Sally Payne, and Gelareh Zadeh

Division of Neurosurgery, Department of Surgery, University of Toronto, Toronto, Ontario, Canada (M.R.V., G.Z.); International Brain Tumour Alliance (IBTA), Tadworth, UK (K.O., S.F.; J.A., C.K., M.E.M., C.T., R.C., M.D., C.M., S.L., A.G., M.L., J.B., S.P.); McMaster University, Hamilton, Ontario, Canada (T.C.)

Corresponding Authors: Kathy Oliver, BA, International Brain Tumour Alliance (IBTA), PO Box 244, Tadworth, Surrey KT20 5WQ, UK (kathy@theibta.org); Mathew R. Voisin, MD, Division of Neurosurgery, Department of Surgery, University of Toronto, Toronto, ON, Canada (mathew.voisin@mail.utoronto.ca).

*This manuscript was edited by Dr. Priscilla Brastianos and it was evaluated in an external, blinded peer-review process.

Survey #2: Brain Tumour Not-for-Profits & Charities



- Brain tumour not-for-profits and charities around the world have stepped in to provide **crucial, amplified support** to patients and caregivers.
- These organisations are also facing their own **existential challenges**.
- The **IBTA's second survey** – “The Brain Tumour Not-for-Profit and Charity Experience of COVID-19” was published December 2020 highlighting these important issues.

Neuro-Oncology Advances

3(1), 1–11, 2021 | doi:10.1093/noajnl/vdaa166 | Advance Access date 7 December 2020

The brain tumor not-for-profit and charity experience of COVID-19: reacting and adjusting to an unprecedented global pandemic in the 21st century

Christina Amidei, Jean Arzbaecher, Mary Ellen Maher, Christine Mungoshi, Rosemary Cashman, Stuart Farrimond, Carol Kruchko, Chris Tse, Maureen Daniels, Sharon Lamb, Anita Granero, Mary Lovely, Jenifer Baker, Sally Payne, and Kathy Oliver

IBTA Survey Timeline



March 11, 2020

WHO declared
COVID-19 a
pandemic

May-June 2020

IBTA Survey #2:
Not-for-Profit &
Charity Survey

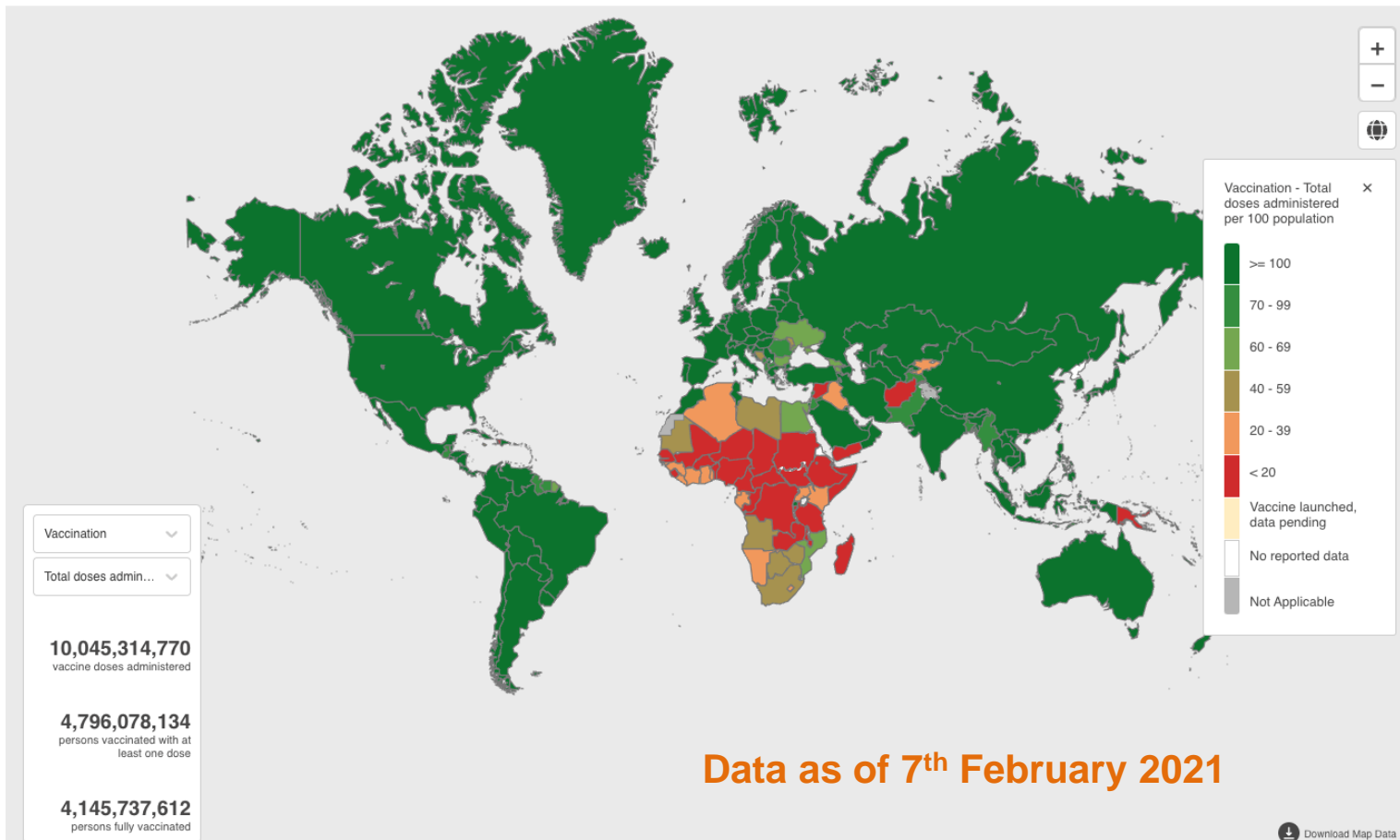
June - August 2021

IBTA Survey #3:
**COVID Vaccines and Brain
Tumour Patients Survey**

April-May 2020

IBTA Survey #1:
Patients and
Caregivers Survey

WHO Coronavirus (COVID-19) Dashboard

[Overview](#)[Measures](#)[Data Table](#)[Explore](#)

Survey #3: COVID Vaccines and Brain Tumour Patients



- We used a **similar development and format** as the first two IBTA surveys.
- We sent out an online **31-question survey, in eight languages**; the survey was conducted from **June 30th to Aug 31st 2021**.
- We received **965** unique surveys from **43** countries.

Survey #3 – Headline Findings



- At the time of this survey (summer 2021) **69%** of brain tumour patients have been tested for COVID-19.
- Of those who have been tested, only **6%** have tested positive.
- At the time of the survey, **85%** of brain tumour patients had received one or both doses of a COVID vaccine. Boosters were not yet given at this point.
- **64%** of patients who received the vaccine were **prioritized in their countries**, with the most common reason being that they have a brain tumour (31%).
- In summer 2021, the most common vaccine received by adult brain tumour patients was the **Pfizer/BioNTech** jab.

Survey #3 – Headline Findings



- **90%** of brain tumour patients' **caregivers** received one/both doses of a COVID-19 vaccine.
- **No major vaccine side effects** were reported by any respondent. Good news!
- At the time of the survey, **7.5% of brain tumour patients decided not to get the vaccine**. The largest concerns were: safety of the vaccines and whether the vaccines were effective. Another reason for vaccine hesitancy was lack of trust and worry about the effects of a vaccine on brain tumour diagnosis and/or treatment.
- In the survey, patients indicated that they want **specific information** on how the vaccines might directly **impact their brain tumour and their treatment**.

Limitations to our surveys: for example, the first and third IBTA surveys consisted of self-selected volunteers and there may be response bias in that the survey results may not be fully representative of the entire brain tumour patient and caregiver population such as those from ethnic minorities and low-income households.

A final word about next steps

- We need to take a careful look at our healthcare systems and ensure that **continuity and quality of care for rare cancer patients** is protected.
- We need to use **evolving data** to determine which patients may be at greater risk from the impact of COVID-19.
- We need to build appropriate **risk stratification** into treatment pathways.

**Cancer doesn't stop because of a pandemic.
We mustn't let brain tumours and other rare cancers
become the forgotten "C" in the fight against COVID-19.**

Acknowledgements and thanks

- IBTA Senior Advisors and SNO COVID-19 Task Force for developing the survey questions
- Survey Review Group for final edits and review of the survey
- Brain tumour not-for-profits, charities and clinicians for disseminating the survey
- Translation support



www.theibta.org



@theibta



The International Brain Tumour Alliance