



Joining forces for action

RCE-ESMO-ESO Training Course for  
Rare Cancer Patient Advocates

**Patient café:**

**COVID-19 and rare cancers; lessons learned  
and pathways to the future**

- **Welcome to this session – Kathy Oliver, IBTA**

TOPIC 1 – 16:40 to 17:10

- **The rare cancer patient perspective – Kathy Oliver**
- **Discussion – All participants**
- **Conclusion – Kathy Oliver**

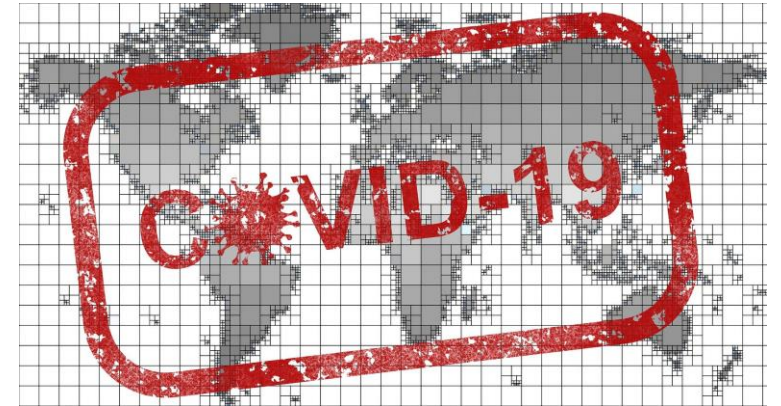
TOPIC 2 – 17:10 to 17:40

- **The rare cancer patient organisation perspective – Markus Wartenburg, SPAEN**
- **Discussion – All participants**
- **Conclusion – Markus Wartenburg**

TOPIC 3 – 17:40 to 18:10

- **The physician perspective – Fedro Peccatori, ESO**
- **Discussion – All participants**
- **Conclusion – Fedro Peccatori**

**SUMMARY - 18:10 to 18:15 - Kathy Oliver**



# LOGISTICS FOR THIS SESSION

- All questions should be addressed via the Q&A box only. We may also take questions and comments from the floor during the discussion time. Please use the "raised hand system" in Zoom.
- Kindly note that the questions in the chat box will not be considered.
- For any technical issues, please send us an email at: [rarecancerseurope@esmo.org](mailto:rarecancerseurope@esmo.org) and we will get back to you
- The above information will also be posted in the chat box, so everyone is aware.

**I have no real or perceived conflicts of interest regarding this presentation but for the sake of transparency, provide this Disclosure of Interests**

## **Disclosure of Interests (2005 to date)**

### **International Brain Tumour Alliance (IBTA)**

The IBTA has, since its establishment in 2005, received funding support from AbbVie, Accuray, Antisense Pharma, Apogenix, Archimedes, Ark Therapeutics, Astra Zeneca, Bayer, Boehringer Ingelheim, Brain Tumor Network (USA), Brain Tumor Resource and Information Network (USA), Bristol-Myers Squibb (BMS) Celldex Therapeutics, Crusade, Dijon Designs (UK), Elekta, Eli Lilly, Gerry & Nancy Pencer Brain Trust (Canada), Gosling Foundation (UK), GlaxoSmithKline (GSK), Ivy Foundation (USA), Lilly, Link Pharmaceuticals, MagForce, Medac, Merck Serono, Merck, MGI Pharma, MSD Oncology, NeoPharm, Neuroendoscopy (Australia), Northwest Biotherapeutics, Novartis, Novocure, Pediatric Brain Tumor Foundation (USA), Pfizer, Photonamic, Roche, Schering-Plough (Global), Sontag Foundation (USA), Spink (UK), to-BBB, Vane Percy (UK), VBL Therapeutics and the Wallerstein Foundation (USA).

Patient Advisory Boards: Novartis, Bristol-Myers Squibb, AbbVie, GSK, Lilly, Novocure

Committees/Projects: EURACAN, All.Can, ECCO Patient Advisory Committee, Rare Cancers Europe, GLIOTRAIN, EORTC SISAQOL project, SNO Guidelines Committee, WECAN, INSERT, NCRI Brain Tumour Subgroup on Palliative and Supportive Care, EANO Palliative and Supportive Care Task Force, NCI-CONNECT

**For full details of the IBTA's sponsorship policy, and comprehensive details of our funding organisations, please see our website at [www.theibta.org](http://www.theibta.org)**

# COVID - 19: general introductory comments

**Although the impact of COVID-19 has been very much the same around the world, there are in-country factors that have reflected different approaches to dealing with the pandemic.**

## General considerations

- What is an individual country's exposure to and burden from the pandemic?
- How does a particular country's government manage COVID-19?
- How robust is a country's healthcare system (how many intensive care unit (ICU) beds, how many healthcare workers, situation with the procurement of PPE, etc)?
- How have a country's social and every-day survival systems worked (are key workers like teachers in place, are social services still able to function, are food deliveries able to be made, can people still pursue activities which are good for their health and mental well-being, etc)?

## Rare cancer specific considerations

- What is the level of health information policy and dissemination of information directed at the rare cancer community?
- How is a country dealing with rare cancer diagnoses?
- Do the type of rare cancer and the standard therapies in place influence diagnosis and access to care during a pandemic?
- What is the level of rare cancer research in a country?
- What is progress with a COVID-19 vaccination programme?
- Rare cancer patients want to have information on how COVID-19 might specifically affect them in terms of medical care and treatment. Is this yet available?

Patient café: Covid -19 and rare cancers

# The rare cancer patient perspective

Kathy Oliver, International Brain Tumour Alliance (IBTA)

# COVID-19: the rare cancer patient perspective

11<sup>th</sup> March 2020

“Thick darkness has gathered over our squares, our streets and our cities. It has taken over our lives, filling everything with a deafening silence and a distressing void... we feel it in the air ... We find ourselves afraid and lost.”

(Pope Francis, 27<sup>th</sup> March 2020)

## IBTA Surveys

(1)

Brain tumours and COVID-19: the patient and caregiver experience

(2)

The Brain Tumour Not-for-Profit and Charity Experience of COVID-19: Reacting and Adjusting to an Unprecedented Global Pandemic in the 21<sup>st</sup> Century



## Neuro-Oncology Advances

XX(XX), 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<sup>o</sup>, 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

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

# COVID-19 related challenges for rare cancer patients...



## Negative factors

- Fear, stress, uncertainty, affect on mental and physical wellbeing
- Treatment delays, adjustments, substitutions, cancellations
- Financial worries - potential job loss, payment delays
- Additional burden on caregivers – can't rely on other family members to help, fear of catching COVID and not being able to look after loved ones
- Homeschooling challenges
- Having to set up offices at home and get up to speed with technology
- Telemedicine – reduction of in-person contact with healthcare professionals
- Travel curtailed/not allowed – treatment abroad stopped or delayed
- No in-person patient events/conferences/meetings
- Where to go for trusted information?
- Others?



## Positive factors

- Telemedicine – saves time, expense, inconvenience of travel (but should it be the normal procedure post-COVID?)
- Events (patient conferences, meetings, information) now all online so much more easily accessible to a wider audience anywhere in the world
- More precious time with immediate family as everyone is home
- If COVID-19 vaccines can be developed in record time, maybe there is hope that rare cancer research will eventually be able to speed up too?
- Patients benefitting from new collaborations and new, streamlined regulatory processes developed in response to COVID-19
- Others?



# Solutions? Comments?

Please post your thoughts in the Q&A. We may also take questions and comments from the floor during the discussion time.



Patient café: Covid-19 and  
rare cancers

# The rare cancer patient organisation perspective

Markus Wartenburg  
Sarcoma Patients EuroNet (SPAEN)

2019 - 2021:

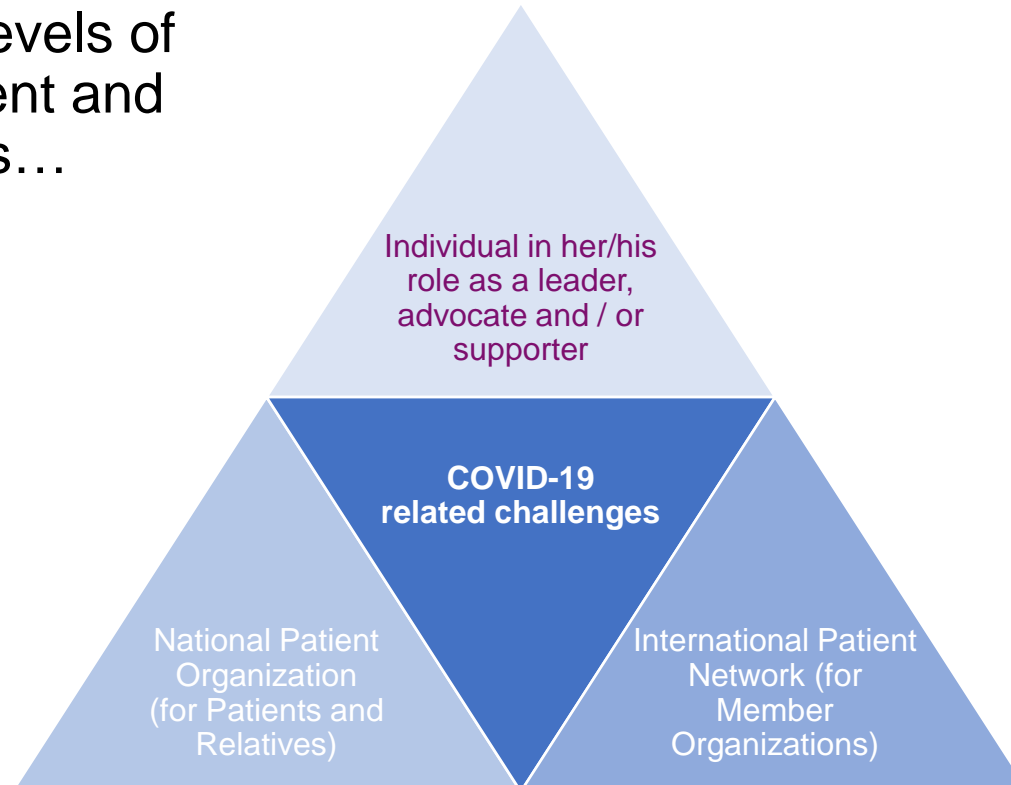
- No direct or personal payments from researching industry
- No consultancy or financial research relationships

Sustaining Partnerships, grants, project-sponsorships or honoraria only directly to the organisations:

- SPAEN Sarcoma Patients EuroNet e.V. (since 2009)
- German Sarcoma Foundation (since Jan. 1st, 2020)

# COVID-19 related challenges...

Different levels of engagement and challenges...



## For the individual...

- Many advocates are cancer patients/relatives themselves... (indiv. challenges, uncertainty, fear...)
- Personal (additional) burden: home-office, home-schooling, child care, financial problems, social contact, concerns for loved ones, family members/friends lost by corona – psychological pressure...  
**Who takes care of those who take care of others?**
- Additional time efforts, dealing with the patient's situation, less personal exchange with colleagues and stakeholders...
- Limited digital infrastructure, skills:  
**If you want to participate, you have to be digitally connected!**

*(Now that many stakeholders have discovered the “virtual world” we are increasingly “showered” with meetings / invitations!)*

Individual in her/his role as a leader, advocate and / or supporter



Sometimes a feeling that you are working in a call center ...

## For the National Patient Organisation...

- **A surge in demand for informing patients in a quickly evolving environment (...often answers are not available or reliable...)  
Lack of clarity from experts, healthcare-sys., authorities**
- **Sometimes patients expect us to manage their individual problems with clinics / centers / experts...**
- **Resources shift to COVID support / home working – stops/reduces capacity for other planned projects/activities**
- **Cancelling face to face activities with other good virtual alternatives leaving patients behind in need**
- **Pat. Orgs. need to be digitally developed**
  - \* to support their patients –
  - \* but also to ensure close collaboration (intern./extern.)
- **Fundraising massively impacted >>> creating financial crisis for some patient orgs.**
- **Many important stakeholders give too little attention because of Corona (advocacy, funding, collaboration...etc.)**

National Patient  
Organization  
(for Patients and  
Relatives)



## For the International Patient Network...

- **Difficult for an intl. Network, as the Covid situation is different nationally**  
**Only general support, exchange or listing of national support**
- **Difficult: keeping in touch with national organizations**  
**There you have your own problems / challenges**  
**Currently: Little attention / resources for intl. cooperation**
- **Difficult: keeping in touch with all relevant stakeholders.**  
**In the past, people often met at conferences and exchanged also informally.**
- **In 2020 it is very difficult to plan sensibly in advance for 2021**
- **Maybe possible: Financial pressure due to a lack of funding...**
- **BREXIT may create additional challenges for future cooperation between the UK and EU**
- **IMPORTANT to have umbrella organisations such as WeCan across cancer diseases for collaboration, exchange, advocacy, training etc.**



# COVID-19 related opportunities...

## Example: Patient Online-Tools



### Online-Seminars (since middle of May):

- 26 webinars with leading Sarcoma./GIST-Experts
- Each session 60 – 75 min.
- Nearly 1.500 participants live
- Access to our YouTubeChannel: 7.500
- Dramatic increase in traffic to our website [www.sarkome.de](http://www.sarkome.de)



### Just launched (middle of November)

- For direct exchange



# Solutions? Comments?

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comments from the floor during the  
discussion time.



Patient café: Covid-19 and rare cancers

# The physician perspective

Fedro Peccatori, European School of Oncology (ESO)

## Declaration of interests

- ✓ **Personal financial interests:** I received honoraria in the last 5 years on occasional basis from Roche, Astra Zeneca, Takeda, Roche Diagnostics, Ipsen
- ✓ **Non-financial interests:** I am member of ASCO, ESMO, AIOM and ESGO
- ✓ **Other:** I act as Scientific Director of the European School of Oncology

**NO CONFLICTS OF INTERESTS FOR THIS PRESENTATION**

## Negative factors

- ✓ **Unpreparedness:** The pandemic changed the health care system in just a few weeks. COVID patients overwhelmed hospital capacities, beds and ventilators were lacking. Many patients died at home without diagnosis. Effective treatment was not available and loneliness and isolation were common. Doctors were re-located, individual protection devices were not available. Uncertainties and fear were the most common feeling.
- ✓ **Communication failure:** Patients with (rare) cancers wanted more info about the risks of treatment during infection, but no data were at hand. Information to citizens was contradictory and inconclusive. Patients and doctors felt “they were left alone to fight an invisible enemy”.

## Negative factors

- ✓ **Psychological crisis and lockdown:** Fragile individuals paid the highest toll of economical crisis and isolation. Doctors' burnout was poorly addressed and it was quite fast the transition from heroes to culprits.
- ✓ **Diagnosis and treatment delay:** “Sorry, your CT scan/visit/treatment has been cancelled and it is not safe to come to the hospital anyway”. Oncological diagnoses were postponed, follow-up visits completely stopped. (Rare) cancer patients had to adapt to a new normal with treatments done in loneliness and with objective difficulties in reaching the cancer centre. Doctors had to adapt.

## Positive factors

- ✓ **Adaptiveness:** COVID-free hospitals and catch-up strategies. Regular Sars-CoV-2 testing and individual protection devices for all health care providers. COVID-adapted protocols and easier access to oral drugs for patients. Telemedicine as a means of better (?) doctor patient communication. Permanent re-organization of healthcare.
- ✓ **Vaccination strategy:** The light at the end of the tunnel. Living a normal life with the virus. Going back to teaching, meeting people and exchanging experiences with all your five senses. A de-Zooming perspective.

# Solutions? Comments?

Please post your thoughts in the Q&A. We may also take questions and comments from the floor during the discussion time.

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Thank you!