

ADVOCATING IN A PANDEMIC WORLD: BACK TO BASICS

13 October HAAB Webinar: Discussion Report

The Hemophilia Advocacy Advisors Board (HAAB) held a dedicated webinar to reflect on how the hemophilia advocacy community can advocate in a pandemic world, and the fundamental advocacy skills and tools that we need to use when doing so.

In addition to the informative presentations from Brian O'Mahony (European Haemophilia Consortium MASAG & Irish Haemophilia Society), Amanda Bok (European Haemophilia Consortium CEO) and Declan Noone (European Haemophilia Consortium President), an open discussion took place to identify how equipped the hemophilia community is to advocate in a pandemic world and what areas we should focus on moving forward.

Below is a summary of the key points discussed and presented (in addition to the slides).

The impact of the pandemic on our advocacy work

Inequalities have been exposed

- Pandemic is exposing existing inequalities in healthcare, e.g. system flaws and under-served populations. Health systems are being forced to address and fix issues.
- Developing markets expected to be hit the hardest by the global economic recession.

Threats to standard of care and emerging therapies

- We should start having conversations with key decision-makers about telemedicine's impact on patient care:
 - Family members are unable to attend telemedicine appointments and ask questions.
 - Patients less likely to think of questions before a virtual meeting.
- Psychosocial support is under threat in EU.

Redeployment of healthcare staff

- Nurses can be pulled from specialty areas and redeployed to general areas due to the state of emergency.

New opportunities

- Chance to rebalance healthcare efficiency, champion patients' added value and define shared vision of future with key decision-makers.
- Home deliveries for patients may improve care.
- New grants may be offered.

Advocacy tools and skills in a virtual world

Creating connections virtually

- Creating and keeping connections is vital to making our work successful.
- How you present yourselves virtually is important, particularly with people you don't know: people judge you even more quickly with less information in a virtual setting.
- The environment people work in affects their ability to engage. Clarify decisions made in virtual meetings so that everyone is on the same page at the end of the call.

Problem-solving

- In a virtual setting, you have limited time to make sure your point is heard. Avoid being conversational and get straight to the ask.
- Doctors need partners for solutions for their working environment – they are the closest allies we have in healthcare centers. We can build community with these people.
- Making decisions in collaboration with key decision-makers provides the opportunity for patient interests to be put at the center of the solutions provided.
- Provide media with sharp, clear arguments that can be contextualized.

Using interactivity to boost engagement

- Some people need to interact directly with ideas to engage in conversations. Try to use the right tool for the person you are interacting with, as well as using right tool for right purpose.
- The more we use digital platforms that engage people, the more we create emotional connections that will help them support us.
- NHF chapters meet regularly with state legislators to get feedback on what types of interactions with advocates they find successful – creates connections with key decision-makers and strengthens relationships moving forward.

Social/digital communications

- Digital tools change our relationship with key stakeholders. Before, we were fighting to get into space where very limited stakeholders were – in a digital world, things are public, so our footprint stays for longer.
- Technology gives us ability to gather intelligence on key stakeholders in different ways. We can map digital footprint and opinion of decision makers, tune into the channels they use, find out what matters to them and present it that way.

Using data to support our advocacy work

Why we need robust data

- Helps protect existing standards of care by demonstrating their value.
- Need to collect data from people with bleeding disorders and their families to ensure we have the right data to show how new treatment or care methods impact them.
- Protects counter arguments by registry data.
- Can lead to decision being avoided altogether.

Risks of poor data

- Poor data = not analyzed, insufficient detail.
- Likely to be countered by registry data.

How to collect robust data

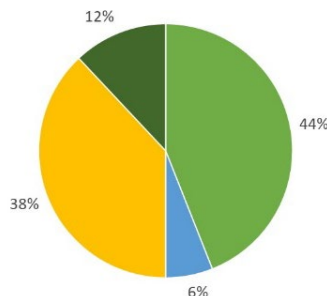
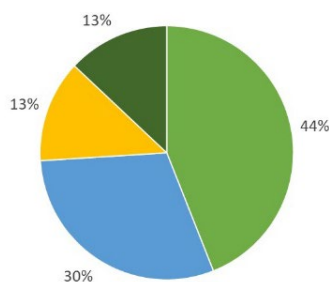
- Consider what data will be supported by other sources of information.
- How do I think about data collection in a way that doesn't stop me doing something else?
- Provide strong local data. Use international, interconnected data (e.g. PROBE, national surveys) data if you do not have data from your country.
- Analyze data regularly.
- Use WFH guidelines to advance national treatment guidelines.
- Use international data, e.g. PROBE, to block counter arguments from registries.
- Ensure how we collect data remains agile, building on top of existing data collected by community.
- Create strategic data collection that has direction and can be used for more than one reason.

Data poll

- Below are results from a data poll conducted during the webinar:

What will be the biggest challenge faced in 2021?

In 2024, what will then be the biggest challenge?



- Getting access to new treatments
- Maintaining growth in current level of access to treatment
- Maintaining Hemophilia Treatment Centres
- Maintaining/growing the community within the NMO

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