

WGPPM Summit Attendee Pre – Survey Results



NATIONAL
BLEEDING DISORDERS
FOUNDATION
Formerly NHF

75
YEARS OF SERVICE
1948 · 2023



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



NATIONAL
BLEEDING DISORDERS
FOUNDATION
Formerly NHF

OUR MISSION

The National Bleeding Disorders Foundation (NBDF) is dedicated to finding cures for inheritable blood and bleeding disorders and to addressing and preventing the complications of these disorders through research, education, and advocacy, enabling people and families to thrive.

NUESTRA MISIÓN

La Fundación Nacional de Trastornos de la Sangre (NBDF, por sus siglas en Ingles) trabaja para encontrar la cura de los trastornos de la sangre y hemorrágicos hereditarios, así como para tratar y prevenir las complicaciones de estos trastornos a través de la investigación, educación y apoyo, permitiendo que las personas y las familias prosperen.



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NBDF STRATEGIC IMPERATIVES 2022

ACCESS

Advocate for equitable access to safe and effective care and treatment for all

CHAPTERS

Build a strong and diverse national network of aligned stakeholders through collaboration and partnership

INNOVATION

Implement and support a national collaborative research blueprint that is grounded in community input and amplifies a diverse patient voice

ORGANIZATION

Cement NBDF as the premier patient-centric organization supporting the inheritable blood disorders community, advancing health equity, diversity, and inclusion

SUSTAINABILITY

Diversify and increase funding and partnerships to ensure sustainability and growth

VISION

Prioritize and advance the 2030 Blue Sky Vision



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**MENTAL
HEALTH**



**FUTURE
THERAPIES**



**DIGITAL
HEALTH**

MISSION

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**RARE
BLOOD
DISORDERS**



**VON
WILLEBRAND
DISEASE**



**ULTRA RARE
BLOOD
DISORDERS**



Methods

- A confidential electronic survey was sent to all participants prior to the summit
- Questions aligned with participants' role
 - Lived Experience Expert (LEE)
 - Health care provider
 - Partner organization member
 - NBDF staff
 - Pharmaceutical company partners
- Open comments were thematically analyzed
- Qualitative analysis was performed to calculate frequencies and filter out the most common answers provided

1. Pathway to diagnosis
2. Access to appropriate treatment at the HTC's
3. Lack of education, especially of health care providers

What do you perceive to be the 3 most pressing issues/challenges currently facing WGPPM with bleeding disorders today?

- Development of guidelines for care of WGPPM
- Increased access to HTC's
- Education of health care providers and the general public on issues pertaining to WGPPM

What change do you believe would make the greatest positive impact for WGPPM?

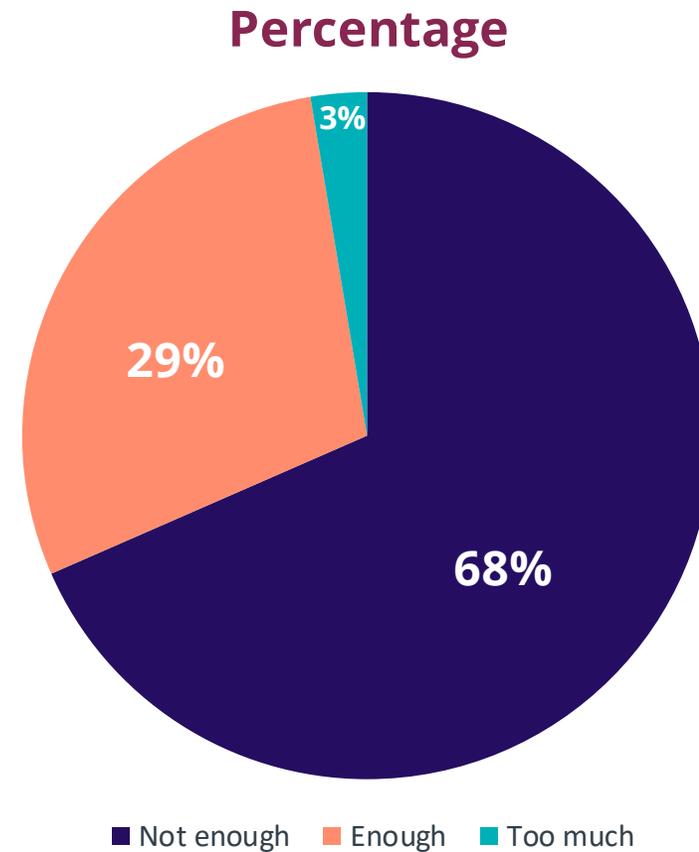
- Specific goals and actionable items/next steps
- Increased collaboration between the different organizations
- Increased understanding and awareness of issues pertaining to WGPPM by all stakeholders

How will you know if this Summit has been a success from your perspective?

Approximately what percentage of your total time and resources are focused on issues facing WGPPM?

42.43% of total time

Do you believe this is:



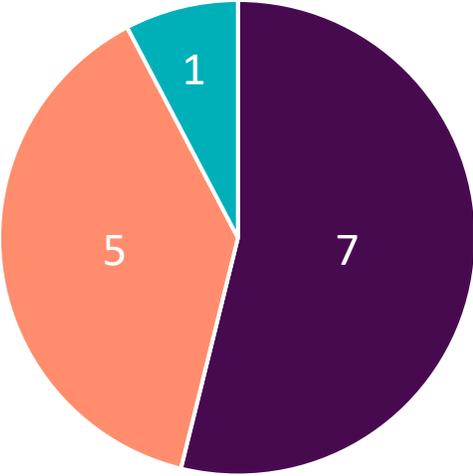
What type of work pertaining to WGPPM are you or your organization involved in?

Consumer Education



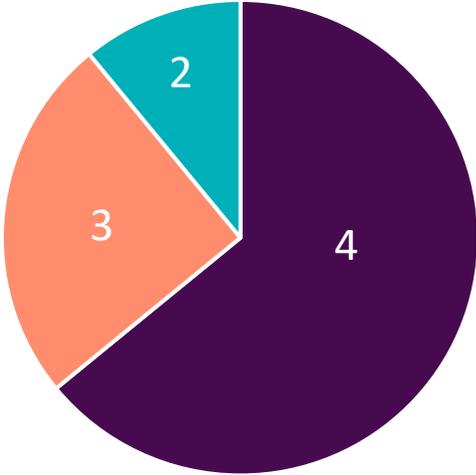
- HCPs
- Organizations
- Sponsors

HCP Education



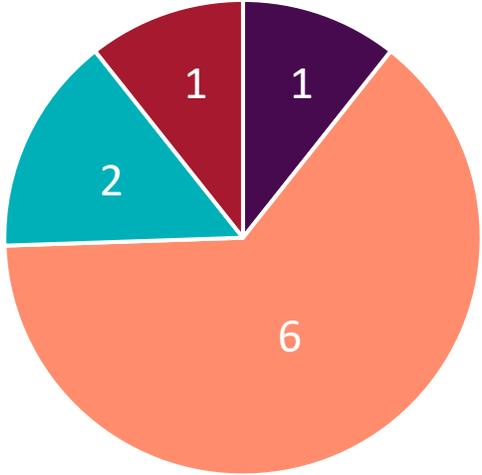
- HCP
- Organizations
- Sponsors

Research



- HCPs
- Organizations
- Sponsors

Advocacy



- HCPs
- Organizations
- Sponsors
- Policy

- Collaboration on:
 - **Organizational initiatives**
 - **Resource distribution**
 - **Research**
- Funding

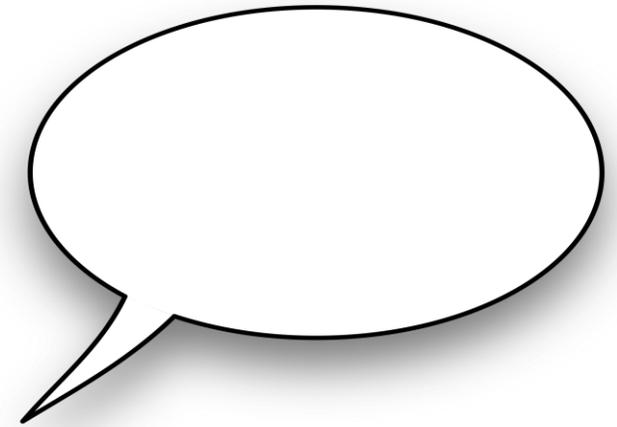
What kind of support/ collaboration would you/ your organization find most useful in helping you to achieve your goals in supporting WGPPM?



We asked the following questions to our Lived Experience Experts:

What is the 1 thing you would like to tell doctors and other health care providers out there about how to better help WGPPM?

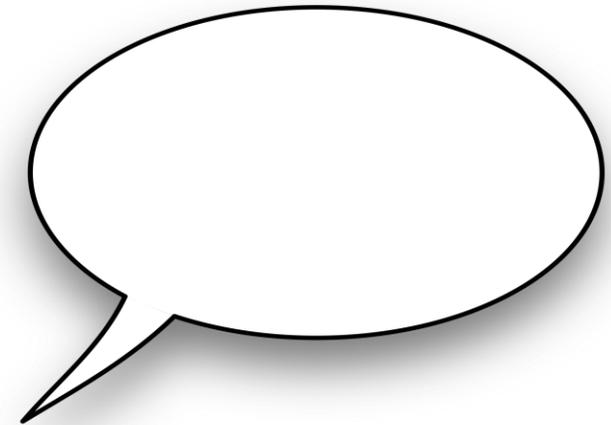
Listen and believe your patient.



“Women need to be believed when they say they are having a bleed despite what our levels say. We are trusted with our sons' bodies but not our own.”

What is the 1 thing you would like to tell local and national organizations serving the bleeding disorders community about how to better help WGPPM?

Continue to raise awareness and advocate for the needs of all WGPPM

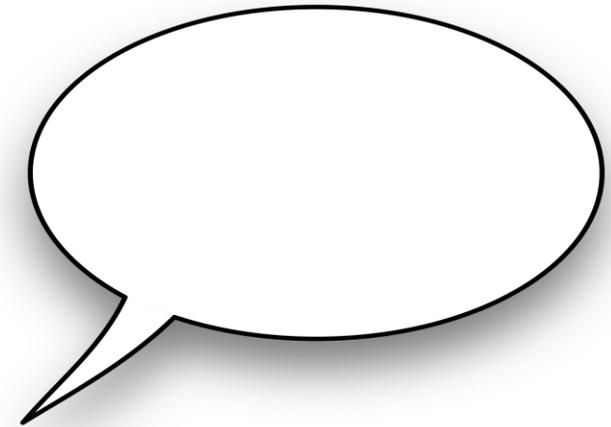


“Please work on awareness of signs and symptoms/ abnormal bleeding in your outreach, with the goal of reaching those inside and OUTSIDE of the BD community.”

What is the 1 thing you would like to tell government agencies and elected officials serving the bleeding disorders community about how to better help WGPPM?

Access to appropriate and necessary healthcare

- Insurance coverage
- Contraception
- Period products
- Abortion if needed



“I think WGPPM is a major issue around the country that has not been recognized to its full capacity, and it would be in their favor to make sure that it access to healthcare becomes a priority in their political agenda.”

What is the 1 thing you would like to tell insurance companies and payers serving the bleeding disorders community about how to better help WGPPM?

Enhance coverage and ease the burden of the process.

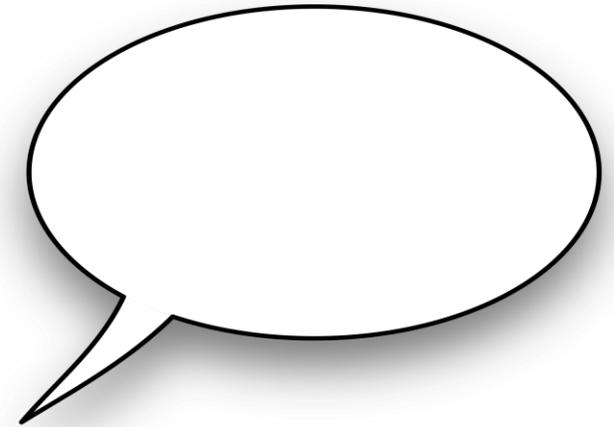
- Copays
- Prior authorization
- Access to approved medication



“The doctor should be able to write the care plan and you should not make them jump through hoops for the patient's care.”

What is the 1 thing you would like to tell pharmaceutical companies serving the bleeding disorders community about how to better help WGPPM?

Include more WGPPM in clinical trials

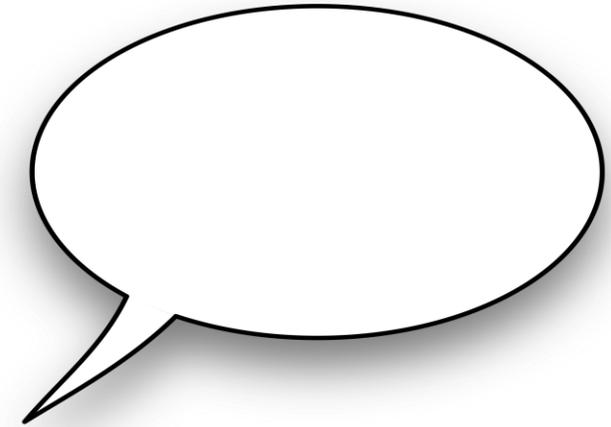


“Make sure you have WGPPM in your trials and do your best to recruit transgender and non-binary people as well. Medications react to different hormone profiles in different ways, so even if it may seem unrelated, do your best to include a diverse sample anyway.”

What is the 1 thing you would like to tell other WGPPM in the community?

Advocate for the care you need.

Find support in your community.



“We are all in this together, and we will work as a team to better our community and make sure that every individual with a bleeding disorder gets the help they need.”

“You're not alone.”

Q/A

Lena Volland, Director of Education
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