

COMMUNITY-BASED RESEARCH NETWORK (CBRN) MEMBER DESCRIPTION

Hemophilia Federation of America is seeking community leaders to form a research network focused on the engagement of women in research.

This network is forming as part of a project called the Females in Research Sharing and Translation (FIRST) project. The vision for this network is to assemble a group of stakeholders and female patients in the bleeding disorders community to commence discussions, become further educated, and begin outlining a research agenda in an effort to increase female influence and engagement in research development, implementation, and the dissemination of results; with the objective of ultimately affecting clinical care for females with bleeding disorders, and potentially other rare disease states.

The overall goals of the CBRN are to:

- ✓ Have a group of active participants
- ✓ Bridge the gap in communication between stakeholders and women in the bleeding disorders (BD) community
- ✓ Apply knowledge gained through focus group discussions into action to reduce barriers to integration of females in patient centered outcomes research
- ✓ Educate the CBRN members about research and participation
- ✓ Identify and prioritize health issues and research topics in the BD community
- ✓ Work in partnership to develop a research agenda
- ✓ Work to engage the larger community of women in research in the BD community

What CBRN members may gain:



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What CBRN members will do:

- ✓ Attend the training & monthly meetings (date and time TBD per the group)
- ✓ Communicate outside of meetings through HFA's engagement platform
- ✓ Share knowledge and experiences
- ✓ Establish group goals and objectives for the CBRN
- ✓ Establish a research agenda
- ✓ Participate in the planning for the sustainability and growth of the CBRN
- ✓ Share about the work of the CBRN

Successful members will be able to:

- ✓ Willingness to engage in meaningful conversations about women's health and research with various stakeholders, including active listening and constructive feedback
- ✓ Respect differing opinions
- ✓ Look for opportunities to partner with other stakeholders
- ✓ Collaborate as a partner on the team
- ✓ Engage with the group on a regular basis within the designated platform
- ✓ Evaluate the process of the network
- ✓ Share their perspective about their experience as a part of the network

For more information please contact:

The HFA Research team at research@hemophiliafed.org
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