

## PSO 87

### A look from within: a needs assessment of educational support for the Rare Bleeding Disorders Community

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#### Submission Group

Peer Support/Outreach/Integration Models

#### Abstract

**Objective:** The National Hemophilia Foundation Education team partnered with an evaluator to conduct a needs assessment of the rare bleeding disorder (RBD) community to help inform the development of programming tailored to the community's unique experiences and needs. **Methods:** A guided discussion with the attendees of a Bleeding Disorder Conference (BDC) session titled, "The Lonely Island: Dealing with Being Rare" in 2018 as well as brief surveys at the end of the session were compiled as part of the needs assessment. Additionally, 12 one on one interviews of those part of the RBD community (either affected themselves or a close relative to someone that is affected) were conducted. **Summary:** Various challenges for this population were identified, including: connecting with others who have the same RBD; healthcare providers' lack of knowledge/understanding of specific RBDs; accessing knowledgeable hematologists and RBD experts; accessing the latest science specific to their RBD; scarcity of treatment resources; difficulty getting diagnosed. Other secondary challenges were also expressed. While challenges were identified, those that participated in the needs assessment also highlighted the ways in which they see the RBD community can best be served. Common suggestions included: the addition of RBD-specific programming at NHF's Bleeding Disorder Conference (BDC); continuing to make NHF and Chapters inclusive; creating more opportunities for the RBD community to connect with others with the same RBD (at NHF's BDC and other events); creating targeted educational materials and opportunities for the RBD community; creating opportunities for members of the RBD community to identify and engage with the medical community. **Conclusions:** By conducting this needs assessment, NHF took an important step in asking the RBD community directly how they can best be supported given their unique experiences and needs. While challenges for the RBD community were identified, several opportunities to support the RBD community were also identified.