

PI 31

Parents Empowering Parents (PEP) Community Survey: How does the community want to stay engaged, communicate, and receive information?

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Submission Group

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Abstract

Introduction: Parents Empowering Parents (PEP) is a program designed for parents of children with a bleeding disorder (BD). With multi-dimensional content and exercises, PEP provides educational material and tools to strengthen parenting skills focusing on children to becoming independent, capable adults. PEP reduces isolation and feelings of hopelessness and helplessness. While most parents seek books or talk with friends for parenting advice, PEP offers a support network for parents who not only have difficulty trouble shooting parenting skills, but also has a child with a bleeding disorder. The PEP program, administered by Energizing and Empowering Minds (EEMinds), have been launched in over 13 different countries since 1996. To ensure that PEP remains relevant and meaningful, EEMinds launched a survey to capture data about how the PEP Community wants to stay engaged, communicate, and their technology preferences.

Method: The PEP Community Survey is a 24-question survey of quantitative or qualitative questions. Data was captured electronically via Survey Monkey using multiple choice, Likert scales, and comment functionality. The request to complete the survey was sent out to community members via email on May 2, 2018. The survey included questions regarding community member's demographics, number of PEPs participated in, and technology and communication preferences.

Results: Forty-one (N=41) community members responded to the survey request. Most of the respondents were either parents of children with BDs or professionals that work at the Hemophilia Treatment Center (HTC). Sixty-seven (67%) percent of the respondents use Facebook daily. Over 87% of respondents would like to receive PEP information via email and over 73% would like to be more involved with PEP. The key PEP program aspects that were most recognized by respondents is 1. having a safe place to share personal stories, 2. connecting/bonding with other parents, and 3. learning new and effective parenting skills. One-hundred percent of respondents have recommended PEP to other parents.

Conclusion: The Community has spoken. EEMinds is not only listening, it is taking action. PEP helps parents of children with BDs to develop skills that directly influence their ability to parent. The survey results show that the PEP program is valued by the community. The results also provide specific guidance and direction on how EEMinds needs to invest its resources in relevant and meaningful ways. There are several workstreams that have been triggered based on the survey, which is to be more active emailing newsletters, posting on our Facebook page, and connecting families.