

Hemophilia B Consumer Advisory Boards

For over a decade, successful meetings generating impactful patient education programs for rare disease



Overview

When a Fortune 500 pharmaceutical company needed to understand the challenges being faced by a well-established community of patients, they tasked ENA to devise a plan to listen, learn, and execute an on-going program within the patient community.

In a patient population of 1500 suffering from a chronic bleeding disorder, it takes more than a flashy advertising campaign to make a difference. By identifying and recruiting influencers, social media opinion leaders, and community volunteers and advocates, ENA formed a board of educated consumers to provide guidance and insight into the ever-changing hemophilia community.

Ten years and 20 advisory board meetings later, we have built a lasting, dynamic, and hugely successful case for the importance of listening to patients' voices.

Goal

To engage the hemophilia B community, define unmet gaps in patient education, and provide a forum to give patients a voice within the community.



Brand Challenges

- To find the right mix of community members with complimentary perspectives
- Ensure equal representation from a variety of stakeholders when defining the most important issues
- Instill brand loyalty with a multitude of new competitors launching in the marketplace



Strategic Imperatives

- Uncover and promote unique patient perspectives
- Define and satisfy unmet needs within the hemophilia B community
- Provide a forum for to give patients a voice
- Establish a group of advisors that would be committed and connected to the board
- Ensure brand loyalty by providing educational tools to the patient community



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ENA Solutions

- Recruit 25 patients, caregivers, and influencers within the hemophilia B community
- Maintain on-going relationships with the advisory board members on an on-going basis
- Strategize and develop engaging workshop content promoting participation and feedback for bi-annual meetings
- Plan, execute, and facilitate two 2-day off-site meetings annually (20 advisory boards to date)
- Design and develop full, integrated patient education programs consisting of live, print, and web components:

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| - Content marketing program | - Patient and Caregiver stories: online and video |
| - Print and e-book series (9) | - Podcast series |
| - Dedicated website with on-going content generation | - Newsletters |

- Gain brand ambassadors who are motivated to educate and share
- Establish a board name, logo, and mission statement to provide the means to help ambassadors promote educational and supportive materials and collateral
- Establish and maintain relationships with patient support organizations



Results

Through exploratory discussion and activities designed to create open and honest communication, these meetings facilitate a full understanding of the therapeutic area, the challenges within the community, and the valuable insights from the patient perspective. The advisory board is a brand that is recognized within the entire hemophilia community and the model has been proven and repeated by other therapeutic categories with ENA's help.



More Than a Meeting

Ideas and programs formulated by consumers create inherent buy-in from target populations. And board members build relationships with each other and the company, creating a unique identity that exists solely for the benefit of the brand.

ENA Marketing Communications Offers Extensive Experience in Advisory Board Planning, Execution, Facilitation, Content Creation, and Cultivating On-going Relationships

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| <ul style="list-style-type: none"> • Vast experience in executing advisory boards for both Fortune 500 and Fortune 50 pharmaceutical companies for over 20 years • Deep knowledge of recruitment tactics • Expertise in all facets of implementation and execution of meetings and advisory boards | <ul style="list-style-type: none"> • Comprehensive creation of meeting content and activities designed to promote communication and insights • Experience with both professional and patient audiences • Knowledge of compliance regulations and guidelines |
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