

Centers for Disease Control and Prevention

Teen Epilepsy Campaign

**One-on-one Interviews
Topline Report**

**Prospect Associates
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Introduction

On behalf of the Centers for Disease Control and Prevention (CDC), Prospect Associates conducted eight one-on-one interviews with teens that have been diagnosed with epilepsy. The purpose of the interviews was to get reactions to a video trailer produced to provide ideas about the content of a planned documentary-style video, obtain teens' insights into appropriate venues for showing and promoting the video, and assess additional types of information that would be beneficial to the audience. Interviews were conducted August 13-14 in Seattle, Washington, during the Epilepsy Foundation Annual Meeting.

The Epilepsy Foundation (EF) recruited teens to participate in the interviews. All participants had epilepsy and were between the ages of 14 and 18. Four interviews were conducted with girls and four interviews were conducted with boys.

The ideas presented in this report are based on the opinions of at least one and generally several participants in the discussion groups. Care is taken in presenting the results to give an accurate depiction of the degree to which opinions were shared both within and across the groups. However, the findings are not quantitative in nature, and a word of caution regarding interpretation is in order. The findings are based on a relatively small sample of participants and thus do not provide a statistically representative picture of the audiences examined. Therefore, while the findings presented in this report accurately reflect the opinions expressed in the groups, they should be interpreted as suggestive and directional rather than definitive.

Key Findings

Reactions to Video Trailer

- Most of the teens responded positively when asked how they felt after seeing the video. Participants said:
 - “I’ve had all the same thoughts.”
 - “Pretty good...kids spoke their mind.”
 - “A little bit enlightened, a little bit happy...[there are] other people out there.”
 - “It’s neat to watch other people with epilepsy and how they deal with it.”
 - “No different.”
- Many of the teens interviewed felt that some or most of the issues discussed in the trailer were relevant to them personally. One participant, who had hosted a youth group, mentioned that they “talked about these issues every time.” In particular, participants noted that the issues of talking to friends/telling other people about epilepsy and dealing with misperceptions were relevant and important.
- Most participants thought a video like this would be helpful to teens newly diagnosed with epilepsy, while some thought they might be more interested in the physical/medical aspects of epilepsy.

- Some teens thought the video would be useful for those with whom they came into contact who did not understand what it is like to have epilepsy, but a few thought that to work for this audience the video would have to include more factual/medical information.
- Additionally, participants recommended using a different type of music (more up-tempo).

Other Topics of Interest for the Video

- In terms of other types of information they would like to see covered in a video, participants mentioned:
 - How teens featured in the video got epilepsy and what type they have.
 - How epilepsy affects each person featured in the video.
 - The impact of epilepsy on getting a job after college.
 - Issues at school (school work, teachers, other kids).
 - Focus on activities they can do.
 - What to do if someone has a seizure.
 - Myths and facts.
 - How people without epilepsy think about it (suggested showing them in the video).
 - How friends deal with it
 - How the adults in one’s life deal with it
 - Sports.
 - Driving.
 - What happens in the brain during a seizure?
 - Famous people with epilepsy.

Please note that the final two suggestions, what happens in the brain and famous people with epilepsy, are probably best addressed in collateral materials as opposed to in the video itself.

One participant felt that the video should include some people with less controlled epilepsy to avoid sending a message that “all epileptics are totally normal.”

Audience and Placement

- When asked who should watch a video like this one, the most frequent response was people (teens) that were newly diagnosed with epilepsy. Other responses included “somebody in denial of it (epilepsy) and their parents,” friends/peers of people with epilepsy, and other kids/not just kids with epilepsy.
- Teens felt appropriate places to show the video were in schools, at conferences, and in doctor’s offices (particularly neurologists). One participant recommended making the video available over the Internet.

Length

- Participants had varying ideas about the appropriate length for the video, ranging from 10-12 minutes to 30-45 minutes. The most frequent response was ½ hour.

Additional Information Interests

- Regarding other types of information they would like to have about epilepsy in general, participants mentioned:
 - Causes.
 - Treatment/control (medications, vagus nerve stimulators).
 - What to do if someone has a seizure.
 - Types of epilepsy/seizures.
 - Medical terminology.
 - Statistics (how many people have epilepsy; does race/gender affect risk).

Interest in Journal/Diary

- Most participants said they would be interested in a journal or diary that they could write in. One male participant added that this would probably go over better with females.
- Of those who said they would use this product, most said that incorporating quotes from either the teens in the video or famous people would enhance it.
- Those who said they did not like the idea either felt that they themselves would not use it or that something more interactive, such as an e-mail list or buddy list (instant messaging) would be more useful.

Interest in Fact Sheets

- Almost all of the participants agreed that fact sheets would be helpful. Those who did not felt that they had most of the information they needed. Topics considered to be of interest included:
 - How to explain epilepsy to other kids.
 - Medical/technical information including
 - Definition
 - Causes
 - Upcoming technology (e.g., treatment, new medications)
 - What to do if someone is having a seizure.
 - Misperceptions.
 - Statistics (e.g., how many people have epilepsy, famous people who have the condition).
- Additional suggestions included an on-line Q&A.

Implications and Recommendations

The video trailer provoked mostly positive reactions from teens with epilepsy, indicating that the planned documentary style video will be a useful vehicle for communicating about experiences and generating discussion. The issues discussed by the teens in the video, particularly talking to friends/telling other people about epilepsy and dealing with misperceptions, were also top of mind for most of those interviewed.

It is important that the video documentary and accompanying materials address the broad concerns of teens with epilepsy. Our recommendations for doing so follow.

1. Produce the video from the teens' perspective and tell a range of stories.

- The teens were quite interested in the details and impact of epilepsy among those featured in the video trailer, therefore, as planned, the video should be developed from the teens' perspective with a focus on the real and personal impact of the condition. We recommend involving teens in the actual production, such as filming and interviewing their peers.
- To show a complete picture of what it is like to live with epilepsy, we will look to incorporate the perspectives of teens and/or family members who do not have epilepsy in addition to showing a number of teens with epilepsy who have had different experiences, have different coping mechanisms and support systems, etc. We will also endeavor to have the teens discuss as many issues of interest as possible.

2. Address additional information needs through fact sheets.

- Teens expressed a great interest in factual and medical information, including causes, what happens in the brain during a seizure, treatments, statistics, what to do if someone has a seizure, and famous people with epilepsy. These types of interests are best addressed in the collateral materials to be developed. We recommend investigating existing sources of information and including or repackaging them for teen use.
- Teens also were interested in a fact sheet on how to explain epilepsy to others. This fact sheet could be developed with teens featured in the video, to get their suggestions in their own words.

3. Develop a journal for use by teens with epilepsy.

- This idea appealed to most of the teens interviewed, and provides an opportunity to inspire and to reiterate some of the video's main points. Using direct quotes from teens featured in the video was an appealing idea as well.