

Centers for Disease Control and Prevention

Adolescents with Epilepsy Campaign

**Exploratory Discussion Group Findings
Topline Report
(DRAFT)**

**Prospect Associates
May 1999**

Introduction

On behalf of the Centers for Disease Control and Prevention (CDC), Prospect Associates conducted five telephone discussion groups with adolescents who have been diagnosed with epilepsy. The purpose of the groups was to explore issues concerning disclosure of information about epilepsy with others, social interaction, and stigmatization. In addition, information was sought about the kinds of materials and channels the adolescents would find useful for themselves and others. Groups were conducted February 23-25, April 28, and May 6, 1999.

The Epilepsy Foundation (EF) provided Prospect with contacts for recruiting participants throughout the country. For the groups held in February, EF mailed a letter describing the purpose of the discussion groups along with a bounceback card, which were developed by Prospect, to parents of adolescents with epilepsy using an organizational mailing list. The names and contact information for all parents and adolescents were kept confidential and were only provided to Prospect if parents consented by returning the card indicating that they would submit to the screening process. Parents that returned the cards were then contacted and screened by Prospect staff. Screening criteria were developed by Prospect with guidance from CDC, EF, and other experts who work with adolescents with epilepsy. Participants recruited:

- Were between the ages of 15 and 19.
- Had epilepsy.
- Had experienced a seizure within the past 6 months.
- Had not missed school more than 3 days in a month.
- Were controlling their epilepsy with at least one, but not more than two, medications.
- Spent at least half their school day in regular classes (as opposed to special education).
- Came from households with a variety of income levels.

Two groups were conducted with girls and one group was conducted with boys who met these criteria.

Two additional groups were recruited using other methods. EF relied on several of their contacts to provide names of potential discussion group participants. In addition, the EF Houston Affiliate provided the names of adolescents that attended their summer camp, "Camp Kaleidoscope." To increase participation, these potential participants were contacted and screened using criteria that increased the number of school days missed in a month from three to six. This criteria was chosen to be expanded because it was felt that it was the least likely to alter the dynamics of the groups or dramatically affect the methodology. These recruitment methods resulted in one group of boys and one group of girls.

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

Disclosure of Epilepsy to Other People

- Most participants said they have told other people, usually close friends or teachers, about having epilepsy or seizures. Although some say this is no big deal or a relief. Others have experienced an awkwardness in the relationship after sharing the information.
- Some feel telling others is not necessary, saying their seizures cannot be detected by others or **“I don’t tell a lot of people because I don’t feel it is any of their business ...”**
- One reason cited for telling others is for a sense of safety. Participants want friends and teachers to know what to do and how to help them if they have a seizure.
- Many participants tell their friends and teachers so that they will not be shocked, scared, or worried when they see a seizure occur.
- Several participants used disclosure to determine who their real friends were. **“... if I tell them, and let them know and everything, that will be one way for me to find out whether or not they’re gonna’ be my true friends.”**
- In a few cases, participants’ noted that their parents told school counselors, teachers, and others about having epilepsy. Several participants felt relieved or comfortable that their teachers knew about their epilepsy and the possible side effects from their medication. A few of the females noted that at first they were angry that their parents told their teachers because so many people already knew or they felt it was a family issue; however, they had come to understand why their parents did so.
- One participant said her principal told her not to tell her teachers and classmates about having epilepsy. However, she chose to tell her classmates anyway because she wanted to be accepted for who she was.

Reactions of Others

- Some participants said they were not treated differently by their peers after telling them about having epilepsy or seizures, while others said their peers were scared or shied away initially after seeing a seizure. There were a few that indicated they continued to be treated differently and lost friends as a result of them being afraid of seizures and not knowing what to do. One example of a participant’s experience is as follows: **“There was a time when I used to be really cautious of who I told I had seizures because I didn’t know how they would react. And there was a time... I got to know this girl and we became best friends. And I can hide my seizures so that nobody knows and**

they are over in like fifteen seconds so it is no big deal. And I have known her for like three months and I finally I decided to tell her. And just like that she ... and I haven't spoken to [her] since. Just because I have seizures and it scared her."

Social Interaction

- Some participants indicated that they can do many of the everyday things most teenagers do, but must be careful not to do too much. For example, **"like playing basketball or football or anything, then that wasn't okay because sometimes it would make [me] feel dizzy because of my medication. But if it was something less strenuous like jogging or walking or something, then that would be okay."** Another said, **"I swim ... I just have this thing where I just try to pile [on] as much as possible. And I usually go to bed like one or two in the morning. I have to make sure that I just watch myself."**
- Participants said they socialized with their friends and went to parties or dances just like other kids their age. Some said they went on dates.
- When going out with friends or to a party, some participants made sure someone knows their parents' phone number in case of emergency. In many cases, they left the number(s) where they would be with their parents.
- A few of the participants indicated that because of their medication they could not drink [alcohol] at parties. In these situations they sometimes explained about having epilepsy and seizures if someone asked them why they were not drinking so that they were not thought of as a **"weirdo."** It was possible that the desire to fit in led some participants to share information about having epilepsy. They may have felt that having a good excuse (i.e., epilepsy) was preferable or more acceptable than just choosing not to drink. For example, **"...drinking's a big thing in high school and when you're going into college, and so often, you know, it comes up and I say, oh, I can't drink. And they say, why not? So then I just flat out explain to them, well, I have a seizure disorder and because of it, with the pills I take, I can't drink."**¹
- Some participants who participated in sports had experienced discrimination because of having epilepsy and as a result seemed hesitant to share information with their coaches. Some actually had either been cut from the team or put on the bench, even if they were better players than others. One participant said she had not told her dance teacher about having epilepsy for fear the teacher would not allow her to perform.

¹ It is interesting to note that in a discussion with an EF counselor immediately following the formal discussion group, one participant asked about marijuana. He was aware that his condition and medication ruled out drinking alcohol, and may have been looking for other ways to take part in the "teenage experience."

- Most of the females who date said they told their dates about having epilepsy and those who were not yet dating said they would tell. Several participants said they would not tell a date right away because it might scare him/her off. They said they would wait until the relationship had advanced a little before telling them, but that they do need to know eventually.
- In general, most participants said it was not difficult to tell their dates that they have epilepsy and that it is important to be honest. For example, **“...with the girlfriend thing, you have to be like totally honest, so if there’s anything that they don’t know that they might need to know whenever they’re with you, if you just came up with one [seizure], they might not understand and...you have to be honest with them at what it is – you can’t just hide it from them.”**

Driving

- Most of the participants did not drive because they were not old enough, their seizures were not under control for the required amount of time, or their parents or doctors did not want them to.
- Those participants that were old enough to drive but could not were unhappy about always having to ask friends for rides. Even though several participants said their friends did not mind driving, they sometimes felt guilty and frustrated, like they were **“taking advantage”** of their friends.
- A few indicated their social life, especially dating had been impacted by being unable to drive, saying for example, **“I will say one thing. It is hard to date when you can’t drive.”** Another agreed, saying, **“How can you go on a date? It is kinda’ embarrassing especially when your parents are driving you.”**
- When discussing driving, some participants brought up the length of seizure-free time required before being able to drive. Some participants were confused or misinformed about driving requirements in their state.

Employment

- A few participants had jobs, and some had experienced discrimination when applying for jobs. One female said, **“I put in my [sic] two applications – one saying I had epilepsy and one saying I’m not [sic]. And, you know, same qualifications and they would like turn me down because I had epilepsy. I had like four or five companies do that to me.”**

- Employment rights came up as a topic when discussing jobs and whether or not participants were being hired if they disclosed on their application that they had epilepsy. Some seemed not to be aware of their rights and were informed, during the group, by other participants, who said for example, **“You know that’s against the law, right? ...it’s against the law. They can’t do that.”**

Effect of Epilepsy Medication

- Many of the participants said their medication made them sleepy and forgetful, particularly when the dosage or type of medication was being adjusted. Some mentioned that they had a hard time staying awake to complete homework or difficulty taking tests because they forget what they studied due to fatigue and loss of **“short-term memory.”** For some, this affected their grades. They said for example, **“...it would keep the left side of my brain almost sedated. It would keep it almost like dead. I’d be totally drugged in the morning. I couldn’t do my algebra. I remember for the first like ... nine weeks of Algebra I had a C average, which wasn’t like me because I usually make A’s in math things”** and **“...it has kind of effected my grades too. And so like my transcript for my junior year does not look good. The medicine that I was on made me like not be able to concentrate as much. I was always like not really sure. I couldn’t remember things a lot. So it was kind of hard for me.”**
- These side effects were not viewed negatively by all participants. One female said, **“I used to be able to stay up much later studying, and now I just find that I have to go to sleep which could be for the better since I have to pace myself a little differently and organize myself differently.”**
- While some participants said they felt more independent or more empowered by taking on the responsibility for remembering to take their medication and caring for themselves, several mentioned feeling more dependent because they must take medication to control their seizures. In a few cases, parents checked up on participants to make sure they were taking their medication which also seemed contribute to feelings of dependence. One participant said she understood that her parents were checking up on her for her own good because sometimes she does forget to take her medication.
- Participants usually took their medication twice a day, once in the morning and once in the evening, so they said they were not usually observed by others. If someone did see them taking their medication, they explained that they were taking the medication for their epilepsy and then they were left alone. They seemed comfortable taking medication in front of others, but would rather not have to.

Self-esteem and Perception

- While for the most part participants felt like they were similar to their peers, there were some issues that made them feel different such as driving and drinking alcohol. **“I feel the same about most of the other things and everything ‘cause most of the other things I’m doing I’m normal. I feel different on the driving issue because of the fact that I’m not allowed to drive. I’m not able to because of my seizures.”**
- As for positive things resulting from epilepsy, some appeared to feel empowered by learning skills for dealing with people, becoming closer with parents, and developing new interests such as drawing. A few indicated they have been praying and **“feel closer to the Lord.”**
- Some said they started out feeling sorry for themselves when they were diagnosed with epilepsy. Then they realized that there were worse things that could happen, which put things in perspective for them. One participant said, **“You get feeling pretty sorry for yourself like I can’t drive, I can’t drink, you know, that type of thing. But I remember when I was in there for my MRI, I saw some girl with cancer just coming out on a stretcher and I’m thinking this is nothing compared to what I could have.”**
- Several males discussed being depressed as a result of having been treated differently by others because they have epilepsy. They said they go off on their own rather than talk to others to **“get things off my mind.”** Other participants indicated that sometimes their feelings were hurt by people calling them names or making fun of them, by, for example pretending to have a seizure.

Types of Information and Messages for Teens with Epilepsy

- Several participants said they would like information suggesting approaches for telling other people about epilepsy.
- Some suggested that hearing about other people’s experiences and advice would be useful when someone was first diagnosed. This could be useful in helping people who were newly diagnosed explain what epilepsy is to others and how others could help them if they experience a seizure.
- Other messages suggested for people who are newly diagnosed included: using parents and friends as a support system; taking it one day at a time; maintaining self-esteem, and finding out about support groups.

- Participants suggested that information describing a seizure, discussing what goes on during a seizure, outlining the causes for seizures, and defining the different types of seizures would be useful. They said being able to see what seizures looked like would be helpful. The participants themselves said they did not know what a seizure looked like because they usually have no memory of having a seizure. One said, for example, **“... you really don’t know what’s happening ... someone’s taken scissors and cutting [sic] out a piece of your life and you have no idea where that went. It’s just strange – a big void.”**
- Participants also discussed wanting to know more about their rights, driving regulations, employment, and sports. It seemed that they lacked information regarding discrimination and what they can do about it.
- Information about medications and cures for simple seizures, side effects of medications, and new medications being studied and researched were also noted as an area of interest.

Types of Information and Messages for Other People

- Several participants suggested information correcting misconceptions about epilepsy. For example, several participants said, **“people thought that it [epilepsy] would be contagious, and ...there’s no way to catch it.”** A few also noted that others need to know that they should not shove items in a person’s mouth when they are having a seizure. Participants would also like others to know not to be scared of people with epilepsy and that **“epilepsy isn’t a person, it’s what a person has. It is not gonna’ change the whole person [or] how they act towards you. It is just something that they had that they can take control of ...”** They seemed to want people to know that epilepsy did not define them as a person, but that they just happened to have a condition called epilepsy.
- A few males noted that it was important for others to know that they could hurt a person’s feelings by making fun of them because they have seizures or epilepsy.
- Participants said they would like other people to know about the different types of seizures, different symptoms, and causes of epilepsy and seizures.
- Participants also said they would like other people to know what to do if they saw someone having a seizure such as who to call and how to react so that they do not panic.

Formats and Resources for Information about Epilepsy

- Several participants said that a Website or chat room with links to other sites and with stories or experiences of teenagers who have epilepsy would be useful. A few participants indicated they had seen a Website before, possibly the EF Website. One participant noted another site, the Harvard Epilepsy Chat Room (possibly called Harvard Neurology Chat Room).
- Email, clubs, and pen pals were also suggested as ways of sharing information about epilepsy. One person also suggested that doctors could pair people newly diagnosed with epilepsy with someone previously diagnosed as a form of support.
- Support groups and camps such as “**Camp Kaleidoscope**” were mentioned by a few.
- Other suggestions included programs or seminars and videos of people who have epilepsy who have succeeded and “**made something of themselves.**”
- Participants also suggested that information be provided in books (textbooks and library books) and made available at school.
- Others said information should be included articles in magazines that teenagers read, such as *Seventeen*, and a few suggested pamphlets in a doctor’s office, such as a neurologist.
- A few participants said that some kind of awareness week might be a good way of communicating about epilepsy, and that awareness could be raised via television or radio shows. A few mentioned seeing portrayals of seizures or epilepsy in the popular media, and said that some were inaccurate. They would like to see storylines on epilepsy and more positive images about the condition.

Implications and Recommendations

The discussion groups were what appeared to be a welcome opportunity for participants to interact with one another and they provided much insight into the lives and feelings of our audience. While participants strive to “be just like other teens” and are frequently successful in doing so, they are sometimes thwarted in their attempts by factors such as misinformation (e.g., beliefs that epilepsy is contagious), discrimination (e.g., in employment and sports), and circumstances (e.g., having a seizure in class, not being able to drive). A number of issues seemed particularly important to the participants and have led us to the recommendations provided below. Among these are the desires to:

- Interact with and learn from other adolescents with epilepsy.
- Have information available at school and in group settings.
- Dispel misperceptions, yet not be solely responsible for educating others about epilepsy, its causes, seizure first aid, etc.
- Understand one’s rights related to driving, employment, and sports participation.

To help address some of these needs, we recommend the development of an organization kit for dissemination to groups that work with adolescents with epilepsy, adolescents in general, school populations, parents, and others. In addition to the specific recommendations provided below, we suggest that the components of this kit incorporate opportunities to promote EF and other organization products and services for adolescents (e.g., existing opportunities to meet/talk with other adolescents with epilepsy such as EF’s teen chat room and summer camps, information on seizure safety and first aid, employment rights). Furthermore, care should be taken in the development of new products to ensure that they are complementary to and not duplicative of existing products and services.

1. Participants expressed interest in interacting with other adolescents with epilepsy and learning how they deal with social, academic, and employment concerns. In addition to recommending interactive types of products (e.g., chat rooms), participants offered one another advice and strategies during the groups. A number of participants expressed their appreciation for being included in the discussion groups when follow up telephone calls were placed by Prospect and one group ended with participants exchanging telephone numbers so that they could correspond in the future.

- To provide teens with continued opportunities to learn from others and participate in interactive discussions, we recommend the development of a **documentary-style video** featuring adolescents with epilepsy discussing issues of concern such as dating/socializing, driving, employment rights/experiences, playing sports, etc. The needs and concerns of our target audience would drive the video. The direction would include certain topics and questions, but the participants would not be scripted. Rather, they would respond in their

own words and discuss issues of importance to them and that they want to share with others.

- To support group discussion, the video could be provided to organizations with an accompanying **facilitator's guide**. The video and moderator's guide should be designed for use in various types of groups, e.g., adolescents with epilepsy, adolescents with and without epilepsy, parents, etc.
2. Many participants also alluded to their frustration at misinformation/misperceptions that exist about epilepsy (e.g., that it is contagious) and concern that others do not know how to react when someone has a seizure.
 - To assist adolescents with epilepsy in dispelling myths and misperceptions and communicating about proper seizure first aid, we recommend the development of a wallet-sized **tip card** to reinforce some of the main points made in the video and provide information that can be shared with others. The card will help teens discuss epilepsy by providing them with a reminder of discussion points that others have used successfully. The card could be made available to organizations in camera-ready form for duplication and dissemination.
 3. The important role of parents was also discussed. While parents have their own perspective on their teens with epilepsy, the discussion groups made it clear that parents could benefit from an awareness of issues that their kids may or may not share with them directly, in other words, from their kids' perspective.
 - With this in mind, we recommend the development of a **parent brochure** (to be made available to organizations in camera-ready form) to inform parents about the issues on the minds of their adolescents with epilepsy and provide tips on addressing these issues in ways that will resonate with their kids.