

**Epilepsy Progress Report Meeting
August 21, 1998**

CDC and Prospect Associates staff met with Epilepsy Foundation (EF) representatives to report progress on development of a communications plan to help teens with epilepsy make informed decisions about what details of their epilepsy to share and with whom (revised from original focus on increasing teens' willingness to share details of their condition).

Attendees:

NCCDPHP/CDC: Lynda Anderson
Mike Greenwell
Kathy Harben
Pete Hunt
Patricia Price
Suzanne Smith

EF: Sandra Parks-Trusz
Patty Shafer
Donna Stahlhut

Prospect: Leslie Brenowitz
Debbie Lurie

Summary of Events/Progress since January 1998 meeting:

Suzanne Smith summarized events and progress in the three areas of epilepsy emphasis since the group met early in 1998.

Communications: Patricia Price was hired to serve as epilepsy coordinator, and work is progressing to develop a communications plan for a campaign targeted at teens with epilepsy to increase their self-efficacy and ability to make decisions about sharing their condition with others. Teens with epilepsy were targeted as a result of discussion at the January meeting.

AH CPR: Plans are being made for development of an evidence report to determine if there are credible criteria for deciding on effective care for persons with epilepsy. These criteria may be used in the future as a framework for organizing the clinical processes necessary to provide optimal care for people with epilepsy.

Surveillance: This component, which primarily tracks seizures after traumatic brain injury, is being coordinated with the National Center for Injury Prevention and Control.

Communications Plan Timeline:

Debbie Lurie and Leslie Brenowitz presented the communications plan timeline, incorporating details about communication objectives and segmentation strategies. Brief outline of timeline:

Target Audience Development	9/98-12/98
Communication Planning	11/98-1/99
Message Development	1/99-3/99
Prototype Materials Development	4/99-6/99
Pretesting	Summer 1999?
Launch/Dissemination	Late Summer 1999?
Evaluation	Spring 2000?

During discussion of the timeline, issues related to audience/influencers, desired outcomes, message development, dissemination of messages, and pilot testing were raised.

Audience Issues

Age range: The age range of the teens we target for the communications campaign needs to be explored. Epilepsy in children tends to peak before teen years and then remit; focus should be on children who continue to have seizures into teen years and teens who begin experiencing epilepsy in their teens. Epilepsy camps in Houston are divided into pre-teens and young teens (8-14) and older teens (15-19).

Segmentation: Some options for segmenting teens

- developmental level
- interest in assistance
- middle school/high school (age)
- seizure control or severity of condition

Employment: At the '98 camps, an employment counselor was available but not often consulted; Donna surmised that either teens had little interest in employment while in the camp setting or that they may already foresee employment problems and aren't ready to address them. Patty indicated that data will be available in Winter '99 from the cost of epilepsy study on employment concerns of people with epilepsy.

Fear factor: A real issue for teens is fear of dying as a result of their seizures; many teens fear the reactions of influencers who do not know about their epilepsy and also have concerns about their safety.

Diversity: When defining the final audience for the communication campaign, diversity is a factor from a couple of perspectives: cultural diversity and the spectrum of types of epilepsy in teens. When the Department of Health and Human Services reviews the communications campaign concept for clearance, it will look closely at the diversity of the audience, particularly whether it includes black or Hispanic populations. Patty commented that EF to date has not reached minorities well at the national level, although some local affiliates have as a result of their surrounding population.

Influencers: It was suggested that principals of schools (who set tone in schools) be added to the list of identified influencers: peers, parents, teachers, employers.

Environment

EF representatives cautioned that we not put the entire burden on teens to share their condition with others. Encouraging teens to share without doing some work to heighten awareness of the influencers in their environments would be cruel. Sandra suggested that all of us review a videotape of a seizure so that we know what happens during one. (Note: HealthStyles 98 data, which included our questions on perceptions about epilepsy, should provide some clues about the current environment.)

Desired action of target audience

For teens with epilepsy, being “cool” and fitting in may compete with acknowledging their condition. Some teens with epilepsy are very open and others don’t talk about it at all. When seizures are controlled by medication, the audience may perceive there is no need to talk about it. Therefore, the potential for having a seizure may be the deciding factor in a teen’s decision to share his/her condition with others. To whom to disclose details is another key issue; disclosing active seizures to a physician can affect ability to drive, etc.

Pete commented that in keeping with our overall goal of improving self-efficacy in people with epilepsy, we could focus on increasing the ability of teens to determine what’s important to share with people in their lives. This approach would lend itself to a multi-year campaign with specific objectives for each stage. An important step is to define “controlled” and “having a seizure.”

Lynda echoed agreement that we should stay away from a model that's too prescriptive; rather, we should help teens decide what different details need to be shared with different people for a variety of reasons.

Another factor to consider, according to Sandra, is that different teens have different pre-seizure experiences and they may need help describing to someone else the details of what happens when they have a seizure (for purposes of making colleagues, peer, others aware of the possibility of a seizure). Many times, people with epilepsy don't know what happens during the seizure; they may be able to describe what they felt like before or after.

Message Development

Based on formative research and results of focus groups, multiple creative concepts will be developed; only 3-4 will be tested among the target audience. Patty cautioned that a common problem within the epilepsy community is striking a balance between minimizing the condition (epilepsy can be controlled; you can live with it without problems) and resorting to scare tactics to get people to pay attention to it. In reality, it's a spectrum of conditions. Different messages prompt different emotions. Depending upon how well controlled a person's epilepsy is, they may be offended by the scare tactic approach or feel worse than they need to about the condition.

Information Needs/Tasks:

NCCDPHP/Prospect staff asked EF representatives for nominations for the epilepsy advisory group NCCDPHP wants to form. The core group would include Sandra, Donna, Patty. Other possible members of core group: Joan Austin, Indiana University, Colleen Dilorio, Emory University, Nancy Santelli, marketing/pharmaceutical rep. Rotating members, who would serve for a time and then be replaced by others with different expertise might include an EF teen group leader, a counselor from a teen camp, staff member from Division of Adolescent and School Health, representative from National Association of Epilepsy Centers. Other possible consultants: Pat Dean, Florida (Hispanic issues); Patricia Crumrine, Pittsburgh; Marcia Collins, Cleveland. **(Note: Comments are solicited on the structure of the workgroup: how will we use the rotating members framework?)**

Other ways to gather information about services provided to teens by EF affiliates:

NCCDPHP staff hand out a simple questionnaire at Affiliates dinner on Sept. 16; send same survey out through EF monthly mailouts from national headquarters; follow up with telephone interviews.

NCCDPHP staff survey state health departments to find out how many have epilepsy services (also inquire about whom EF affiliates could contact for liaison).

Next Steps

Kathy will summarize meeting and send minutes to attendees for review, comment

Kathy will ask group to indicate convenient days/times for monthly conference calls

Mike will provide Kathy with generic stigma articles for distribution

NCCDPHP/Prospect will prepare survey tool for querying affiliates at San Antonio meeting

Suzanne, Patricia, Kathy will meet with Cindy Brownstein, Anne Scherer (EF director and communications director) at San Antonio meeting.

Prospect will start identifying segmentation strategy

EF will provide information they have about teens with epilepsy as well as examples of newsletters produced by teens at local affiliates