

**Communication Plan
Centers for Disease Control and Prevention
Adolescents with Epilepsy Project**

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I. Situation Analysis

Epilepsy is a chronic neurological condition that affects approximately 2.5 million people in the United States. The condition is defined as the occurrence of more than one seizure on more than one occasion and is characterized by abnormal electrical activity in the brain. Each year 50 per 100,000 individuals (125,000) will be diagnosed with epilepsy, and of those, 30% will be under age 18 at time of diagnosis.

As noted in the document “Living Well with Epilepsy: The Roles of Health Communication,” many voluntary health organizations in the epilepsy community strive to increase awareness about the condition and improve the quality of life for persons with epilepsy and their families. These efforts have been successful in raising general awareness of the condition. In fact, a 1987 Gallup survey found a 92% level of awareness of the condition among Americans. However, of those who responded positively, 49% were unable to identify a cause and only 19% identified epilepsy as being caused by brain disease or a brain disorder. Furthermore, there exists widespread confusion regarding the causes, appropriate first aid for, and impact of epilepsy/seizures, which may adversely affect the quality of life for people with epilepsy. For example, lack of understanding contributes to discrimination (e.g., “people with epilepsy should not have children”), stigmatization (e.g., “epilepsy is a form of mental illness”), and safety concerns (e.g., you should put something in the mouth of a person experiencing a seizure to prevent them from “choking on their tongue”).

The impact of the condition on specific populations including youth and women may be even greater, and fewer programs have attempted to address their specific issues. Among adolescents, for example, studies have shown that those with fairly well-controlled seizures are less likely to discuss their condition than peers with other chronic illnesses and may be subject to greater stigmatization than those with other chronic medical conditions. In one study, adolescents with epilepsy who felt stigmatized by their condition were more likely to report low-self esteem than were adolescents who did not feel stigmatized. Another found that adolescents with epilepsy who were doing the best neurologically (i.e., fewer seizures) had the poorest communication, self image, and future expectations, which is consistent with studies of stigma and the price paid for “passing” or “covering defects.” Several studies have found that the better seizures are controlled the less likely the adolescent is to have discussed the condition. These types of findings led CDC and its partner, the Epilepsy Foundation (EF), to focus on adolescents with fairly well controlled seizures as the initial audience for its communication program.

Interestingly, telephone discussion groups conducted by Prospect Associates on behalf of CDC and EF found that many in the target audience do share information about having epilepsy with friends, teachers, employers, and others, while others hesitate to do so for fear of ridicule, embarrassment, or discrimination. Some participants shared concerns that athletic coaches or dance instructors would not allow them to play or perform if it was known that they have epilepsy, and others cited examples of not being hired for jobs when they disclosed that they had epilepsy during the application process. Thus while the discussion group findings did not wholly support what had been seen in the literature, they did reinforce the perceived costs of disclosure and desire of the participants to learn positive coping skills.

Challenges and Opportunities

The following assessment of challenges and opportunities in the immediate future will help to establish the best positioning for the CDC/EF program and its message, and will provide a guide to issues that need to be addressed in campaign development.

Challenges

- Some of the developmental processes of adolescence may create issues for adolescents with epilepsy. At this stage of life, self image is formed by:
 - Comparing oneself with peers. This may lead some adolescents with epilepsy to hide the fact that they have the condition, as the perceived price of disclosure (e.g., potential embarrassment, appearing different from peers) is high.
 - Exercising autonomy and separating from parents. The reliance on, for example, medications to control seizures or friends and parents for rides challenges this new-found sense of autonomy and may lead to resentment.
- As mentioned above, misunderstanding and inaccurate information about epilepsy abound.
 - This has the effect of creating an environment in which it is perceived as more difficult and less acceptable to share information about one's condition, perhaps even more so by adolescents who, developmentally, yearn to be just like their peers. The burden of informing others not only about their own condition but also about epilepsy in general is a heavy one to place on anyone, let alone an adolescent.
 - Lack of understanding may also lead to discrimination (e.g., in employment).
- While general awareness of the condition is high, epilepsy is not prominent on the radar screen of the news and entertainment media. As a result, there is little coverage of the issue, and some recent portrayals in the entertainment media have been incorrect or disrespectful.
- Community groups and voluntary organizations are pressed for time and resources. It will be a challenge to engage those that do not deal with epilepsy directly.

- The complexity of the condition and the diversity of messages being communicated by various voluntary and government organizations probably contribute to public confusion and misunderstanding of the issue.

Opportunities

- The telephone discussion groups demonstrated that teens with epilepsy appreciate the opportunity to talk with others who have had similar experiences. This presents a unique opportunity to present information from a teen perspective, and to promote the availability of interactive activities such as chat rooms and camps.
- EF's network of state affiliates and parents provides a rich system for gathering information, reaching teens and the general public, and promoting the availability of products and services.
- CDC's Division of Adolescent and School Health (DASH) has connections in schools nationwide and provides a strong link to administrators and school personnel.
- Epilepsy can be linked to issues that are top of mind for teens and the media, such as diversity, accepting differences, and stereotypes.

Competition

The competition for the attention of teens and the general public, as well as for time in the school setting, present challenges.

- Teenagers are the darlings of marketers, being courted as customers for everything from soda and fast food to jeans and athletic shoes to credit cards. The quantity of advertising seen by the average teen is mind-boggling and creates an environment of almost unlimited choice and opportunity. The challenge is to have messages about epilepsy break through this mass of information.
- In terms of social issues, the competition includes things like school violence, AIDS, and the environment. Epilepsy is not on the radar screen of most people who do not deal with the condition directly.
- The competition for classroom time is also fierce, with so many subject areas required (and tested) that educators perceive little freedom in lesson planning and topic selection.

An overarching strategy for this campaign will be the promotion of existing EF materials and services related to adolescents with epilepsy.

II. Program Objectives

- Increase the comfort level of adolescents with epilepsy who choose to talk with others about epilepsy and seizures.

- Enhance parent’s understanding of the personal issues facing their adolescent children with epilepsy.
- Educate and inform communities about epilepsy and the experience of teens with the condition.

III. Target Audiences

- Adolescents with epilepsy, including the newly diagnosed.
- Parents of adolescents with epilepsy and others who come into daily contact with teens with epilepsy.
- Community groups (e.g., religious organizations, sports clubs, schools, youth service organizations, physicians, PTAs, community-based organizations, EF affiliates, etc.)

IV. Strategies

- A. Provide skills to adolescents with epilepsy who choose to talk about their condition by modeling effective communication.
- B. Enhance parents’ understanding of challenges faced by teens with epilepsy by developing materials that identify and discuss these personal issues from a teen perspective.
- C. Enhance the local environment by creating awareness in the community about teens and epilepsy through facilitating group discussion.
- D. Work with the media and entertainment industry to integrate accurate information about adolescents with epilepsy into stories and programming.

V. Tactics

Strategy A: Provide adolescents with epilepsy with skills to talk about their condition by modeling effective communication behaviors.

Strategy B: Enhance parents’ understanding of challenges faced by teens with epilepsy by developing materials that identify and discuss these personal issues from a teen perspective.

1. Materials Development

Develop tools that models successful communication about epilepsy, encourage discussion about teens with epilepsy, and provide important epilepsy information to target audiences.

- **Documentary-Style Video and Facilitator’s Guide.** Produce a video featuring teens with epilepsy discussing, in their own words, issues of concern such as dating/socializing, driving, employment rights/experiences, playing sports, etc.

The direction of the video will include agreed-upon topics, however, participants will not be scripted; the needs and concerns of adolescents with epilepsy will drive the filming of the video and the production of the accompanying facilitator's guide. The video will give teens an opportunity to learn successful communication and coping skills, and feel a part of larger group that has epilepsy. The video will also help group and community leaders facilitate an open dialogue about epilepsy. The facilitator's guide will reinforce the successful communication methods used in the video. Both tools will be developed to facilitate discussion among a variety of individuals (e.g., adolescents with and without epilepsy, parents, teachers, youth organizations, etc.).

- **Tip Card/Notepad/Journal.** Develop a tip card for adolescents with epilepsy to provide them with points other teens have used successfully when talking about their condition. The card could serve as the basis for discussion about epilepsy and seizures, and assist adolescents with epilepsy in dispelling myths and misperceptions about their condition. The card could also be expanded into a notepad or journal with space for teens to write down their thoughts and record their experiences.
- **Parent Brochure.** Create a brochure that informs parents about the pertinent issues on the minds of their adolescent children with epilepsy that may or may not be shared with the family. The brochure will provide tips on addressing these issues in ways that resonate with kids. Existing EF materials targeted to parents with teens with epilepsy will be listed in the brochure as additional resource information.
- **Resource Guide.** Develop a guide that includes information about existing EF materials, pertinent Websites and chat rooms (including EF resources), listserves, and telephone numbers.

2. Dissemination

Distribute above mentioned tools to adolescents, parents, and community groups via the following:

- **Video and Facilitator's Guide Marketing Brochure.** A marketing brochure, highlighting the benefits of the video for teens and others, would be developed and mailed directly to a targeted list of key audiences (e.g., parents; teachers; school psychologists, counselors, administrators and librarians; coaches, etc.) to facilitate interest in obtaining the video and guide.
- **CDC's Division of Adolescent and School Health (DASH).** Utilize DASH's established connections with schools, principals, and administrators to disseminate materials and build support for the campaign. Post/advertise campaign materials on DASH's website.

- **Interactive Teen Chat Rooms.** Research chat rooms that are popular with teens with and without epilepsy and determine the feasibility of establishing a special room where teens could “chat” with adolescents from the video (information from the video and tip card for adolescents could also be posted in the room). Structure the room in such a way that teens with and without epilepsy are motivated to visit; this could be done via a “Did You Know?” format where the focus would be on overcoming odds to live with epilepsy. In addition, other “challenging situations” could be discussed as a way to helping other teens relate to the condition. Advertise campaign products and existing EF materials on teens with epilepsy in this room. Utilize existing EF’s chat room to disseminate information, advertise campaign products and “chat” with teens from video as well.
- **EF Summer Camps.** These camps serve as an ideal environment to utilize the video as a discussion tool for group discussion and to provide the tip card to teens with epilepsy.
- **Websites and Listserves.** Post/advertise campaign materials on websites and listserves that explore issues regarding teens and epilepsy, such as the EF website and Harvard Neurology website/chat room.
- **Banner Ads.** Work with on-line search companies (e.g., AOL, Yahoo, etc.) to advertise the availability of campaign products and existing EF materials via banner ads. These ads would appear when the search term “epilepsy” or related issues are typed in.

Strategy C: Enhance the local environment by creating awareness in the community about teens and epilepsy through facilitating group discussion.

1. Materials Development

Develop materials targeted to community organizations that facilitate discussion about teens with epilepsy and increase awareness about the condition.

- **Organization Kit/Video.** Develop and package an organization kit featuring the video and facilitator’s guide to increase awareness about teens with epilepsy and encourage open discussion about the condition (video can be used in conjunction with the organization kit or by itself depending on audience). Disseminate to organizations that work with adolescents with epilepsy, adolescents in general, school populations, etc. Such groups might include PTAs; child neurology associations; school nurses and psychologists organizations; boys and girls clubs; hockey, soccer, baseball and football leagues; service organizations; community volunteer associations; companies with a high percentage of teen employees (e.g., McDonalds, 7-Eleven, etc.); religious organizations; teen advocacy groups; etc. EF affiliates could also incorporate kit contents into their local materials and help distribute the kit to their local contacts, if desired.

The kit could include the following collateral materials:

- Background information on epilepsy as it relates to teens (e.g. definition, types, symptoms, etc.).
- Fact sheets on seizure safety, first aid, employment rights, etc.
- Master copy of parent brochure and adolescent and parent tip card (for duplication).
- Ideas to encourage open dialogue about epilepsy within community.
- Sample media materials and tips on how to work with the media.
- Case studies from adolescent youth advocates (e.g., their experiences and “lessons learned”).
- Resource guide.
- Form to order available CDC and EF products related to teens.

2. Dissemination

Distribute above-mentioned materials via the following:

- **Organization Kit Marketing Brochure.** Develop a brochure highlighting benefits of organization kit for community groups that would be mailed to a targeted list of community-based organizations (list will be developed using information from EF affiliates and established community contacts).
- **National Meetings of Organizations with Local Affiliates or Chapters.** Advertise organization kit and showcase video at national meetings of adolescent, parent, physician, neurologist, pharmacist, teacher, and administrator organizations (among others) with local affiliates or chapters. Distribute organizational kit and video at meetings and encourage groups to disseminate materials to their members, patients, and customers.

Strategy D: Work with the media and entertainment industry to integrate information about adolescents with epilepsy into stories and programming.

1. Media Relations

Create a media relations program that includes the development of media tools for national and local use, training of EF affiliates to work with the media, and national and local media efforts. National and regional media efforts (listed below) would focus on linking the topic of teens with epilepsy to issues that are top of mind for the media (e.g., diversity, accepting differences, stereotypes, overcoming challenges, etc.) in order to generate stories that appeal to a broader audience.

- **Media Tools.** Develop tools for national and local media efforts that educate the media about teens with epilepsy.
 - **Media Kit.** Develop a media kit that can be sent to the to 20 national print media with health, youth or parenting sections, and major magazines targeting teens, parenting, health, etc.

- The kit could also be distributed to EF affiliates who could tailor contents (e.g., include community information and activities) for their local efforts. Kit might include:
 - Press release on program.
 - Background information on epilepsy as it relates to teens (e.g. definition, types, symptoms, etc.).
 - Top issues faced by teens with epilepsy (e.g., employment, driving, seizure safety, etc.).
 - Fact sheet dispelling the myths and misperceptions about epilepsy.
 - Tips on how to work with national and local media (this would be inserted in the media kits that are provided to EF affiliates only to help them with local efforts).
 - Possible story angles about epilepsy.
 - Print and radio PSAs.

- ***Print and Radio Public Service Announcements (PSAs).*** Convene a daylong workshop where adolescents with epilepsy could interact with each other; learn how they deal with social, academic and employment concerns; dispel epilepsy myths and misperceptions; and, ultimately, work with creative staff to use this knowledge to develop print and radio public service announcements for national and local media activities. PSAs would describe the experiences of teens with epilepsy (e.g., a “Did You Know That....?” or “Overcoming the Barriers” format) and be used to sensitize the public to the realities of teens living with epilepsy. Print PSAs would be distributed to major youth, parenting, school and health magazines. Both radio and print PSAs could be distributed to local media as part of community media efforts.

- **EF Affiliate Training.** Enhance EF affiliates’ advocacy and media relations skills to generate stories and increase awareness about teens with epilepsy.
 - ***“Train the Trainers” Program – Youth Advocacy and Media.*** Provide an in-depth youth advocacy and media training session for EF affiliates at regularly scheduled meetings to teach them youth advocacy and media skills. The video and guide, adolescent tip card and tips for working with the media would be provided at the training. EF affiliates could work with teen advocates in their chapter to promote epilepsy awareness in the local media.

 - ***Youth Speakers’ Bureau.*** Work with EF affiliates to develop a youth speaker’s bureau comprised of adolescents with epilepsy recruited from affiliate chapters and/or the community. EF affiliates could host a meeting to train teens in their chapter to serve as campaign spokespeople on the bureau. These youth spokespeople would be encouraged to help create awareness of issues facing teens with epilepsy by telling their stories when and wherever possible. The speakers’ bureau could be promoted via media relations efforts (local and national) and at community outreach activities. The bureau could

give interviews with the media and make presentations at national or community events.

- **National Media Activities.** Develop a national media campaign targeted to select newspapers and parenting, teen, and health, etc. magazines.
 - ***Pitching Stories.*** Disseminate media kits and print public service announcements to targeted national print outlets (major publications) with *health or features* reporters (e.g., USA Today, Los Angeles Times, Washington Post, etc.). Media would be referred to the youth speakers' bureau for interviews with local teens with epilepsy (having youth share their stories is essential to getting articles written about teens with epilepsy).
 - ***Syndicated Columnists.*** Send a letter along with the media kit to syndicated columnists (e.g., those that write about teens, family issues and health) encouraging them to write about teens with epilepsy and the barriers they overcome each day.
 - ***Deskside Briefings.*** Hold deskside media briefings with popular national youth, parenting, school, and health magazines (e.g., Parenting, Glamour, Jane, Jump, Fitness, etc.) to encourage them to run stories about teens with epilepsy. Interviews would be conducted with CDC, EF and youth and affiliate spokespeople (with an emphasis on the youth spokespeople telling their stories and the challenges they face).
 - ***Long-Lead Publications.*** For those magazines that do not participate in the deskside briefings, a letter will be sent along with the media kit, encouraging such publications to write articles on the lives of teens with epilepsy. The publications will also be sent a list of youth spokespeople for possible interviews.
 - ***Matte Releases.*** Develop a matte release centered on teens living with epilepsy and the issues they face. Work with North American Precis Syndicate to distribute release to targeted smaller, weekly print publications (who are more likely to run an ready-made story than national outlets) and encourage them to run the release.
 - ***Satellite Media Tours.*** Conduct satellite media tours in three markets across the nation to raise awareness about epilepsy and encourage discussion about teens with the condition. Work with EF to research market demographics (e.g., number of adolescents with and without epilepsy in market) and receptivity to issue (e.g., Have community organizations done activities around epilepsy? Has the media written stories on the issue? Is there a media spokesperson that is involved in the issue and would be willing to feature teens with epilepsy in their outlet?). Choose markets for tours based on this research. Local celebrities with epilepsy would be featured as well as youth spokespeople. Select media in these markets would be saturated with

materials about the campaign and interviews would be secured with celebrities, CDC, EF, youth and affiliate spokespeople.

- **Regional Media Activities.** Coordinate local media efforts with EF affiliates serving as local program spokespeople.
 - **Youth Forum.** Host a youth forum where adolescents in the community discuss their experiences with epilepsy. Feature a panel of organizations that deal with teens with epilepsy (e.g., EF affiliate spokespeople, neurologists, youth athletic clubs, service organizations, etc.). Send a letter to media inviting them to attend the forum, hear the personal stories and see how communities are helping adolescents live with their condition.
 - **Pitching to Local Media.** Work closely with EF affiliates to distribute media kits, and print and radio public service announcements to targeted print and radio outlets in affiliate cities (we will look for outlets that are targeted to teens, have run epilepsy stories or have worked with EF affiliates to ensure a better response of covering the condition). Affiliates would encourage outlets to generate stories on the personal life experiences of community teens living with epilepsy.

2. Entertainment Education Program

Develop an entertainment education program aimed at correcting the myths and misperceptions about epilepsy and accurately portraying the lives of teens with the condition, using the following tenets. As with media, the topic of teens with epilepsy will be linked to such issues as diversity, accepting differences, etc. to generate greater interest among a broader audience.

- **Assessment of Previous Coverage.** Conduct an assessment and report on the entertainment industry's prior coverage of epilepsy, researching how epilepsy and teens with epilepsy have been depicted, the industry's attitudes towards the epilepsy and the receptivity of "teens with epilepsy" as a basis for future storylines.
- **Entertainment Kit.** Develop a kit designed for the entertainment industry that includes information on teens and epilepsy. Kit would be distributed to entertainment contacts in advance of one-on-one meetings and at entertainment conferences sponsored by CDC or EF. Kit contents might include:
 - Background information on teens with epilepsy.
 - "Dispelling the myths and misperceptions" question and answer sheet.
 - "Why the entertainment industry needs to get involved" sheet (e.g., how the industry can change the social environment for teens with epilepsy).
 - Copy of parents' brochure and adolescent and parent tip card.
 - Youth speaker's bureau information.

- Adolescent youth advocates' stories (e.g., their experiences and "lessons learned").
 - Possible show, film, music story ideas.
 - Resource guide.
 - Video.
 - Print and radio PSAs.
- **Interpersonal Relationship Building.** Build on existing industry contacts and seek to establish new ones that will accurately depict teens living with epilepsy, and dispel myths and misperceptions about the condition.
 - *Established Contacts.* Provide campaign materials and existing EF tools related to teens with epilepsy to established contacts and work to integrate the condition into the entertainment industry. Seek to provide an accurate portrayal via music, film and television of teens living with epilepsy.
 - *Desired Contacts.* Develop a list of desired contacts. Pursue education opportunities with these contacts.
 - **Scriptwriters Conference.** Host a one-day conference (through EF and/or CDC sponsorship) in Los Angeles to target writers of television programs popular with teen audiences to raise awareness about epilepsy and how the condition is depicted on television. Work with the major networks to build support for the program and encourage their scriptwriters to attend the conference. Feature a panel of campaign spokespeople - EF and affiliates, CDC, youth advocates and celebrities with the condition to provide insight and answer questions, and disseminate the entertainment kit at the conference. Writers will be invited via a letter from CDC, EF and major television studios that support the program.
 - **Entertainment Awards.** Bestow annual awards to plays, series, episodes and documentaries that best portray life with epilepsy. Both CDC and EF would sponsor these awards and work to ensure that they do not duplicate EF newsmaker awards.