

**Take Charge of the Facts:
Changing Teen Perception Related to Chronic Conditions –
The Impact of School Based Curricula**

Epilepsy affects an estimated 50 million people worldwide and is the most common serious neurological condition in every country (WHO, 2009). In the US, epilepsy affects approximately 3 million Americans, and results in an estimated annual cost of \$15.5 billion in medical expenses and lost or reduced earnings and production (CDC, 2008). However, only in the last 15 years has the Centers for Disease Control and Prevention (CDC) recognized epilepsy as a public health issue and worked with nonprofit organizations to raise awareness of the disorder (CDC, 2003).

Currently, few adults or teens recognize or understand epilepsy. Even though epilepsy is much more common than HIV/AIDS or Parkinson's disease -- and more likely to affect an adolescent population -- research shows that youth are much less familiar with epilepsy than either AIDS or Parkinson's disease (Austin, Shafer, & Deering, 2002). This lack of familiarity leads to misconceptions regarding individuals with epilepsy and appropriate seizure first aid, and even the belief that epilepsy can be contagious – views that often lead to stigma. Goffman (1963) was the first to propose that individuals are stigmatized for possessing an attribute that is "undesirably different." These attributes include race and religion, individual character blemishes, and "abominations of the body," such as epilepsy and other chronic conditions. Goffman argued that stigmatized individuals are classified as "not quite human" and are considered to be targets for social exclusion.

Research conducted by Westbrook et al. (1992) noted that although the majority of youth surveyed (60%) never thought about whether having epilepsy affected if people wanted to be their friends, approximately a third of participants reported experiencing stigma. In addition, 53% of the sample admitted to keeping their epilepsy a secret from others at least some of the time and almost three-quarters (70%) rarely or never talked to others about their epilepsy. Research comparing adolescents with epilepsy to those with other with chronic illnesses show that the individuals with epilepsy are significantly more likely to avoid discussing their disorder with peers. Although 59% of adolescents with other chronic illnesses report that all of their friends know about their illness, only 15% of adolescents with epilepsy report the same (Westbrook, Silver, Coupey, & Shinnar, 1991). It appears that youth with epilepsy may be even more hesitant than adults to share information about the disorder due to the stigma associated with the condition.

Unfortunately, these adolescents may be right to be concerned about the stigma. Previous research conducted by the Epilepsy Foundation found that adolescents in the general population were unfamiliar with epilepsy, had little accurate knowledge regarding epilepsy or seizures and often held views that reflected stigma (Austin, Shafer, & Deering, 2002). Of the 19,000

American teenagers surveyed, more than half had never heard of epilepsy, 46% were not sure if it was contagious, and 40% were not sure if people with epilepsy were dangerous. Slightly less than a third reported that they would consider dating someone with epilepsy. A full three-quarters of survey participants suggested that teenagers with epilepsy were more likely to be bullied or picked on than their healthy peers.

Public education is the key to ending the stigma associated with epilepsy. Studies show that although stigma and discrimination are related to a lack of knowledge and negative attitudes, increasing individual knowledge about the condition leads to more positive attitudes towards people with epilepsy (Birbeck, 2006). The goals and responsibilities of the educational system coupled with various theories of education and child development suggest that school children are an ideal audience for education about epilepsy (Martiniuk, Speechley, Secco, & Campbell, 2007). School-based educational programs have been correlated with a significant increase in epilepsy knowledge and positive attitudes (Martiniuk, Speechley, Secco, Campbell, & Donner, 2007); an increase in healthy behaviors related to cancer prevention (Peterson, Goodwin, & Ellenberg, 2004) and an increase in the ability to identify the signs of depression and appropriate actions to help peers at risk of suicide (Tacker & Dobie, 2008). School-based programs have also been shown to improve knowledge of asthma (Shaw, Marshak, Dyjack, & Neish, 2005); and reduce health-risk behavior (Collins et al., 2002). Research conducted with adolescents and young adults with diabetes demonstrates that even an hour of instruction – approximately the length of a class session -- can have an impact up to a year later in terms of participant's self-awareness (Hernandez & Williamson, 2004).

Adolescents with epilepsy are at risk for being stigmatized because of their diagnosis but through education, both stigma and stigmatizing behavior can be reduced. For this reason, the Epilepsy Foundation developed the educational program, *Seizures and You: Take Charge of the Facts*. The Epilepsy Foundation believes that the school-based *Take Charge* program can increase awareness of epilepsy, provide youth with the skills necessary to respond to seizures appropriately, and reduce the stigma often associated with the disorder. The purpose of this article is to present the results of our evaluation of this program. Specifically we asked two questions: (1) Does participation in the *Seizures and You* program improve students' knowledge of epilepsy, and (2) Does participation in the *Seizures and You* program change adolescents' attitudes toward people with epilepsy?

Methodology

Program Description

The *Take Charge* program was developed as a training module on basic seizure recognition and first aid. The program targeted high school and middle school students, ages 11 to 18 and was designed to be completed in one 40- to 45-minute class.

During the 2006 to 2007 school year, Epilepsy Foundation affiliates distributed the *Take Charge* training materials to science and health teachers at local middle and high schools nationwide. Both teachers and schools were chosen by local affiliates based on previously established community partnerships. Teachers were given a comprehensive facilitator's guide and presentation notes, a DVD on epilepsy, overhead slides, a PowerPoint presentation, worksheets and copies of the survey tool.

The *Take Charge* program was designed to help students (1) achieve a basic understanding of epilepsy as a medical condition; (2) identify and learn about different types of seizures; and (3) learn what to do -- and what not to do -- when someone is having a seizure. During the project implementation, teachers showed a PowerPoint slide of famous historical figures (e.g., Socrates, Julius Caesar, Vincent Van Gogh, Harriet Tubman and Agatha Christie) and asked students to suggest what these individuals had in common. After revealing that many historians believe each of these figures had epilepsy, the teacher then transitioned to the focus of the lesson by asking for a show of hands of students who had some familiarity with epilepsy. The instructor then reviewed the learning objectives and asked for students' "first thoughts" and questions regarding epilepsy. These comments were listed on a board or flip chart for later comparison.

The teacher then presented the PowerPoint slides with information on key facts, statistics, and myths about seizures and epilepsy. Afterwards, students were given a matching terms worksheet and shown a DVD that discussed the different seizure types. Students were directed to complete the worksheet by matching the seizure types with the appropriate description. The teacher then provided the correct answers for the worksheet, discussed the appropriate first aid for each seizure type and explained when a seizure might be an emergency. If there was sufficient class time, students were engaged in a demonstration of the different seizure types.

At the end of the training, the teachers reviewed the questions from the "first thoughts" exercise and students completed the post-learning survey. To reinforce learning, students were given a take home epilepsy fact sheet in addition to informational materials, such as bookmarks with seizure first aid information.

Design

Assessment of program outcomes consisted of a pre- and post-test to determine the change in student knowledge and attitudes. Although the pre- and post-tests were anonymous and not graded by the teachers, students were asked to list their school name, birth month and initials on both survey tools. This information was then used to compare pre- and post-test results in the students who took both tests.

Instruments

The evaluation instrument used for the pre-test and post-test survey was developed by the Epilepsy Foundation. Questions were further revised by the research firm, Matthew Greenwald and Associates, after conducting validation tests with teens. The majority of questions focused on attitudes and knowledge about epilepsy; however, several questions focused on demographic data such as race, gender, age and geographic region.

Data Analysis

Data was collected and analyzed in SPSS. Matthew Greenwald and Associates was responsible for data entry and coding of the one open-ended question (e.g., “What fact about epilepsy did you find most interesting?”) Improvements were identified by comparing post-test answers to pre-test answers and analyzed by demographic characteristics. Changes between evaluation periods were tested for significance using t-tests. The overall margin of error for the study (at the 95% confidence level) is a plus or minus of approximately 1.5%. Subgroup responses have a larger margin of error, depending on the size of the group.

Sample Demographics

The *Take Charge* program was implemented in 156 schools (middle and high school-level) in 26 states during the 2006-2007 school year. The Foundation collected pre-test forms from a total of 4,705 respondents and post-test forms from 4,915 students. A total of 2,934 teens and preteens completed both a pre-test and post-test. Sample demographics for participants at the post-test are presented in Table 1.

Table 1: **Demographic Characteristics of Students (Post-Test)**

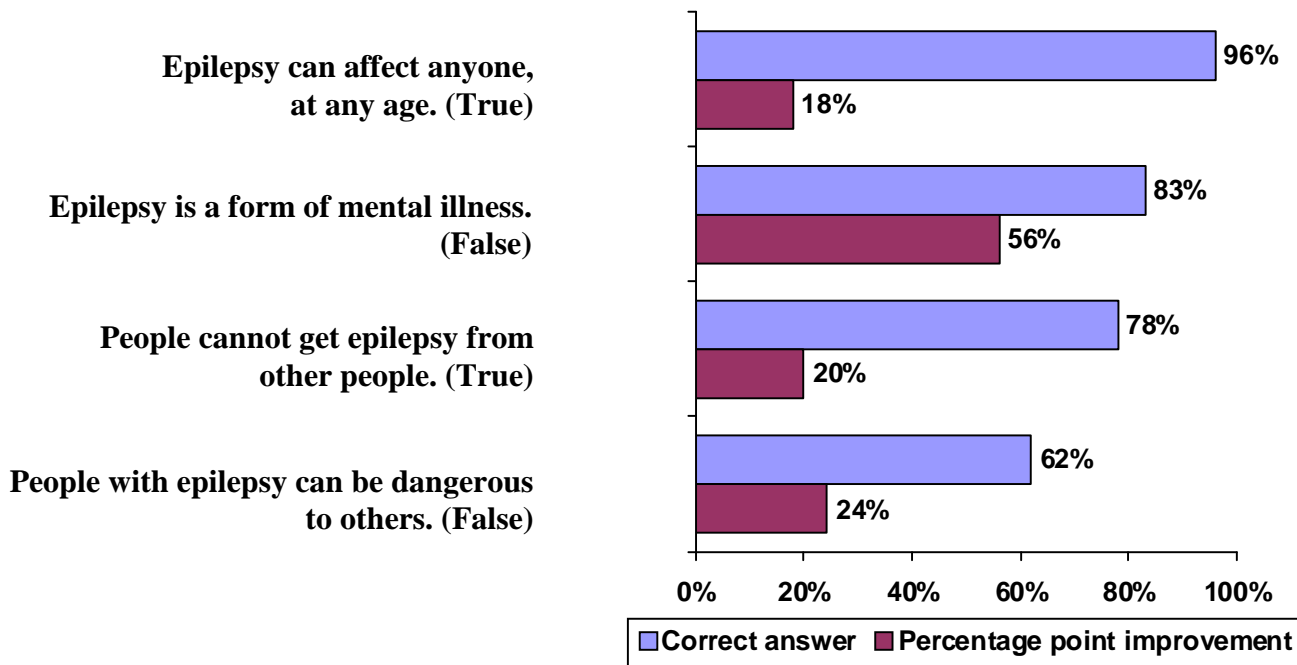
Gender (n=4,393)	
Male	46%
Female	54%
Age (n=4,712)	
10 to 12 years of age	15%
13 to 14 years of age	38%
15 to 16 years of age	39%
17 to 19 years of age	8%
Race (n=4,699) (multiple responses allowed)	
White/Caucasian	74%
Black/African-American	14%
Latino/Hispanic	9%
Native American	4%
Asian	3%
Other	4%
Region (n=4,832)	
South	40%
Midwest	36%
East, Mid-Atlantic	20%

Results

In terms of knowing someone who had epilepsy, only 44% of the participants said they had known an individual with epilepsy. However, the program appears to have clarified the definition of epilepsy for participants: in the post-test, 50% of students said they have known someone who had epilepsy.

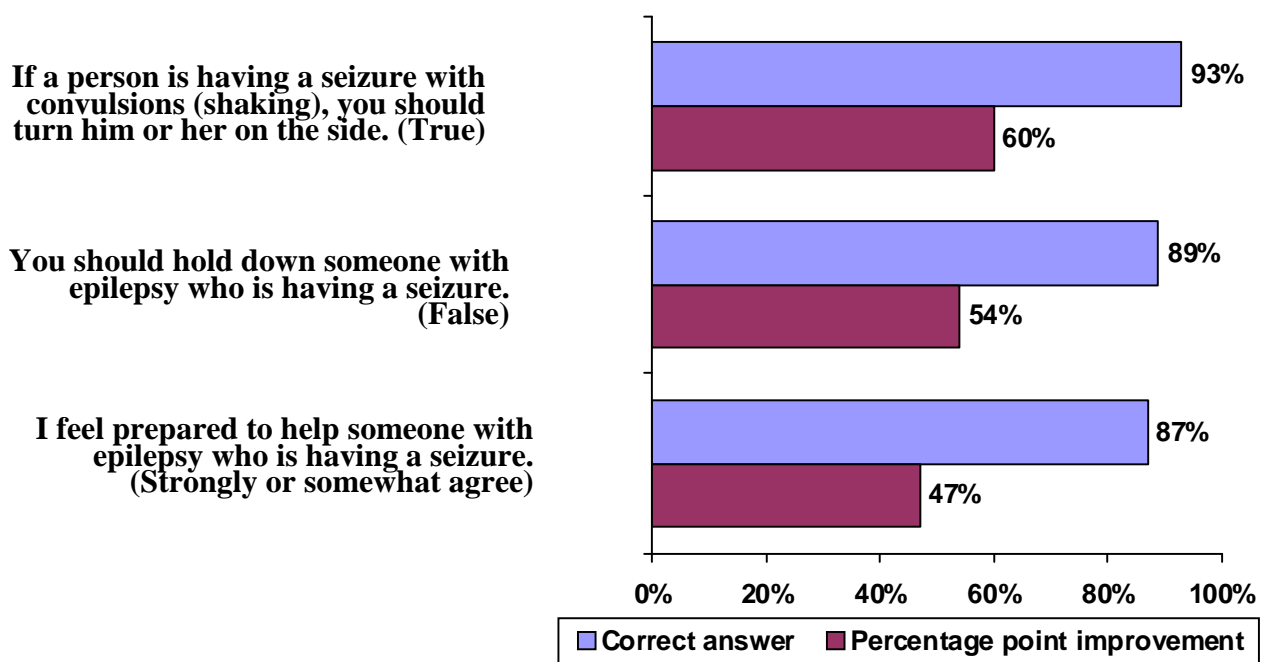
The Epilepsy Foundation's *Seizures and You: Take Charge of the Facts* program is highly successful in teaching students that epilepsy can affect anyone at any age (96% of students understand this at the post-test) and in helping students to understand that epilepsy is not contagious (78%). The program is especially effective in teaching youth that epilepsy is not a form of mental illness (83% understand at the post-test, an increase of 56 percentage points) and that people with epilepsy are not dangerous to others (62%, a 24 percentage point increase.) These results remain fairly constant by gender, age, race and region, although the post-test indicates that black and Latino/Hispanic students are somewhat less likely to say that people cannot get epilepsy from others (68% and 64% respectively.)

Figure 2: **Thoughts and Ideas about Epilepsy (Post-Test)**



The program is also effective in educating students about seizures and the appropriate first aid response. After the class, the vast majority of teens responded correctly that when a person with epilepsy experiences a seizure, it is usually not life-threatening (83%). This is a 58 percentage point increase between the pre-and post test results, making it one of the questions with the most considerable improvement. An even larger increase between the pre-test and post-test occurs in the question about whether or not to turn someone having convulsions on his or her side (60 percentage point increase).

Figure 3: **What to Do Regarding Seizures (Post-Test)**



Students also recognize that having a seizure does not necessarily mean having convulsions (52 percentage point increase) and nearly 9 in 10 teens knew that when someone with epilepsy was experiencing a seizure, they should not be held down (89%, experiencing a 54 percentage point increase from the pre-test). After attending the class, nearly 9 in 10 students (87%) feel prepared to help someone who is having a seizure.

Although *Take Charge* is highly effective in educating youth about epilepsy, attitudes are much more difficult to change. After participating in the class, most students become comfortable with the idea of dating a person with epilepsy (66%, with a 21 percentage point increase from the pre-test to post-test). However, it should be noted that there are some gender and racial differences on this question: females are more comfortable dating someone with epilepsy (73% compared to 60% for males), as are whites (70%) compared to Latinos/Hispanics (59%) or blacks or Asians (both 57%). This question also experienced an age difference: whereas 70% of 17 to 19-year-olds would be comfortable dating a person with epilepsy, only 62% of 10 to 12-year-olds would be equally comfortable. It is likely that this openness to dating a person with epilepsy, which increases with age, (65% of 13 to 14-year-olds, 69% of 15 to 16 year olds), is due to the fact that fewer 10 to 12-year-olds are actively dating.

In addition, participants show an increased awareness of the stigma that is often attached to individuals with epilepsy. In the post-test, a larger percentage of students -- four in 10 (a 20 percentage point increase) -- believe that students with epilepsy would be more likely to be teased or bullied than youth with other health conditions. However, even after taking the class,

slightly fewer than half of the students feel that epilepsy would not affect their popularity (46% disagree that epilepsy would make them less popular).

Although most students believe that epilepsy does not change a person's capabilities, they made an exception when it comes to driving a vehicle. Nearly all of the students who completed the post-test believe that people with epilepsy can do anything that anyone else can do (94%). Even before taking the class, however, many students already knew this (78%). Interestingly, this positive attitude does not hold for driving: only one in five students would *not* be concerned if they were riding in a vehicle driven by a person with epilepsy (18% strongly or somewhat disagree with the statement).

Further evidence of the success of the program can be seen by comparing the completed pre-test and post-test results of the 2,934 students who took both tests. Significance testing performed using paired variable T-tests demonstrates that these students show a considerable improvement (significant at the .000 level) for all questions (see Appendix II for detailed information on the improvements from the pre-test to the post-test.) The largest improvement is seen in the two questions referring to the fact that epilepsy can affect anyone at any age and that a person who is having a seizure with convulsions should be turned on his or her side (for each, 92% of those answering incorrectly on the pre-test responded accurately on the post-test). In addition, the following concepts were answered correctly on the post-test by 80% or more of the students who replied incorrectly on the pre-test: you should hold down someone with epilepsy who was having a seizure (80%); people with epilepsy can do anything I can do (85%); I feel prepared to help someone with epilepsy who is having a seizure (84%); epilepsy is not a form of mental illness (83%); and when a person with epilepsy is having a seizure it is usually not life-threatening (83%).

Discussion

The data suggests that the *Take Charge* program is an engaging educational intervention that has had a positive impact on student knowledge and attitudes. In all but two questions (whether students knew someone with epilepsy or would be comfortable riding in a vehicle driven by someone with epilepsy), the improvement from the pre-test to the post-test is 25 percentage points or more. The most dramatic change is in one of the most important areas: the four questions regarding appropriate first aid for someone with a seizure. For these questions, the percentage of questions answered correctly on the post-test increased by 78 percentage points or more.

In addition, the program appears to be successful in reducing some of the misconceptions associated with epilepsy. The four questions dealing with thoughts and attitudes about epilepsy -- including questions on whether epilepsy is contagious, a form of mental illness, or if people with epilepsy can be dangerous -- experienced at least a 20 percentage point improvement in the post-

test. The change is especially striking on the true/false question dealing with whether epilepsy is a form of mental illness: the post-test showed a 56 percentage point increase in students who recognized that epilepsy is not a form of mental illness. These improvements in knowledge are a good start, but also point to the need for additional education: after the program, almost 4 in 10 youth are uncertain if people with epilepsy are dangerous to others and slightly more than 20% still don't realize that epilepsy is not contagious.

When participants were asked if they would want their friends to tell them if they had epilepsy, the great majority of respondents indicated that they would want to know. It may be that the program raises awareness of epilepsy -- and the appropriate first aid procedures -- so that students would want to know about a friend's epilepsy in order to be better prepared.

However, as noted before, the positive attitudes toward people with epilepsy do not hold for driving, and the question about riding in a vehicle driven by a person with epilepsy continues to be problematic. Given that the respondents are part of the age group targeted by driver's education classes, there is a distinct possibility that this view is impacted by an awareness of the driving restrictions placed on individuals who are still experiencing seizures -- especially since the class did little to change this view (only a six percentage point increase from the pre-test to the post-test). Future programs should increase their focus on reducing this stigma, especially since driving is considered so crucial for youth independence. It may be advisable to launch a secondary program focused on youth driver's education classes or to provide supplementary materials that could be shared with driving instructors.

While this program was designed to increase adolescents' knowledge of epilepsy and was informed by research suggesting that education helps to reduce stigma (Birbeck, 2006; Martiniuk, Speechley, Secco, Campbell, & Donner, 2007), it may be helpful to have future program iterations focused on behavior change and informed by public health or educational theory. For example, the Behavioral Ecology Model, which integrates public health and behavioral science theories of change by focusing on five levels of influence (intrapersonal factors, interpersonal processes and primary groups, institutional factors, community factors and public policy), would allow for increased attention to creating a supportive environment and influencing multiple levels simultaneously. Under this ecological model, future program efforts could include implementing a school-wide Epilepsy Awareness Week in conjunction with the scheduling of the *Take Charge* curriculum or making program modifications that would allow *Take Charge* to be implemented at the community level.

Additional research is needed to determine the long-term impact of this program on reducing the stigma associated with epilepsy. Because the post-test was completed immediately after the conclusion of the program, it may be that the program's positive effects are short-term and do not lead to longer term attitude change. In addition, it is impossible to determine if an increase in

positive attitudes – and decrease in stigma – leads to a decrease in discriminatory behavior. We do not know if the program reduces the incidence of bullying experienced by youth with epilepsy although participants believe that youth with epilepsy would be bullied or teased more than students with other health conditions. Follow-up studies with students are recommended to ascertain if they have retained the information on appropriate first aid measures.

It may also be advisable to study the effect that additional resources have on the *Take Charge* program. For instance, the Epilepsy Foundation recently launched the website TakeChargeTeens.org, which focuses on teaching teens how to respond to a seizure. Future research should explore the role that this website plays in further cementing the learning that occurs from the *Take Charge* classroom program, how the website may contribute to teaching youth about epilepsy and driving or bullying, and how the website can be used to reach a larger percentage of the youth population.

Conclusions

Even with these limitations, this research demonstrates that the *Seizures and You: Take Charge of the Facts* program is effective in educating youth about epilepsy, including the different types of seizures and appropriate first aid, and is useful tool for reducing the stigma experienced by people with epilepsy.

In addition, this evaluation demonstrates that the *Take Charge* program contributes to the CDC's Healthy People 2010 goals as outlined by the Living with Epilepsy Task Force. The *Take Charge* program contributes to the goal to remove all barriers to education, community, and workplace opportunities for children and youth with epilepsy by reducing the stigma associated with the disorder and it contributes to the goal of increasing access to care by ensuring that youth within a community know how to effectively and safely respond to a seizure.

Appendix I: Survey Instrument

Student Survey on Epilepsy¹

Please provide the following information and answer the questions below to help us see how well this program works. Keep in mind that you are not graded on your responses.

Today's date: _____

1. Your initials _____ 2. Your school name _____

3. Your birth month _____ 4. Your age _____ 5. Your gender: M F
(Circle one)

6. Your race/ethnicity: ¹ Asian ⁴ Native American
(Check all that apply) OPTIONAL ² Black/ African American ⁵ White/ Caucasian
³ Latino/ Hispanic ⁶ Other _____

7. Have you ever known anyone who had epilepsy (seizures)? ¹ Yes ² No

8. Have you ever been taught what to do if someone has a seizure? ¹ Yes ² No

9. Please mark below whether you think each statement is true or false.

	True	False	Don't know
A Epilepsy can affect anyone, at any age	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
B People cannot get epilepsy from other people	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
C People with epilepsy can be dangerous to others	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
D Epilepsy is a form of mental illness	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
E When a person with epilepsy has a seizure, it is usually a life-threatening event	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
F Every time a person with epilepsy has a seizure, he or she has convulsions (shaking)	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
G You should hold down someone with epilepsy who is having a seizure	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
H If a person is having a seizure with convulsions (shaking), you should turn him or her on the side	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
I Students would pick on kids with epilepsy more than they would pick on kids with other health conditions	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³

10. Please mark below how strongly you agree or disagree with the following statements.

¹ The pre- and post-survey tools were identical except for the addition of questions 11 and 12 in the post-survey.

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
A I believe people with epilepsy can do anything I can do	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
B I would be concerned if I was riding in a car or bus driven by a person with epilepsy	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
C I feel prepared to help someone with epilepsy who is having a seizure	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
D If a friend had epilepsy, I would want him or her to tell me	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
E I would be comfortable dating a person with epilepsy	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
F Having epilepsy would make me less popular with people my age	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵

11. Please rate the video that was shown in this program.

Excellent	Very good	Just ok	Poor
<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴

12. What fact about epilepsy did you find most interesting?

Appendix II: Improvements from the Pre-test to the Post-test

	% of those Scoring Incorrectly on Pre and Correctly on Post	n
<u>Thoughts & Ideas About Epilepsy</u>		
Epilepsy can affect anyone, at any age.	92	2,912
Epilepsy is a form of mental illness.	83	2,881
People cannot get epilepsy from other people.	71	2,894
People with epilepsy can be dangerous to others.	55	2,872
<u>Facts About Seizures</u>		
When a person with epilepsy has a seizure, it is usually a life-threatening event.	83	2,875
Every time a person with epilepsy has a seizure, he or she has convulsions (shaking).	75	2,889
<u>What to Do Regarding Seizures</u>		
If a person is having a seizure with convulsions (shaking), you should turn him or her on the side.	92	2,867
You should hold down someone with epilepsy who is having a seizure.	88	2,887
I feel prepared to help someone with epilepsy who is having a seizure.	84	2,821
Have you ever been taught what to do if someone has a seizure?	78	2,648
<u>Social Implications for a Teenager with Epilepsy</u>		
If a friend had epilepsy, I would want him or her to tell me.	62	2,818
I would be comfortable dating a person with epilepsy.	46	2,825
Students would pick on kids with epilepsy more than they would pick on kids with other health conditions.	35	2,666
Having epilepsy would make me less popular with people my age.	30	2,844
Have you ever known anyone who had epilepsy (seizures)?	16	2,871
<u>Impact of Epilepsy on Daily Life</u>		
I believe people with epilepsy can do anything I can do.	85	2,877
I would be concerned if I was riding in a car or bus driven by a person with epilepsy.	15	2,847

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