

ENTITLED TO RESPECT

Highlights from a national survey

Teens living with epilepsy don't get respect from their peers/Social stigma associated with teens who have epilepsy

- Nearly four in ten teens (36%) think kids with epilepsy are likely to get picked on or bullied more than other kids; only one in four (25%) think this is unlikely to happen.
- Nearly one-third (31%) of teens are not sure whether they would tell their friends if they had epilepsy.
- While many (46%) of the respondents would tell friends if they had epilepsy, nearly one-third (31%) are not sure if they would and 10% say they would not tell their friends.
- Although three in ten (31%) teens say they would date a person with epilepsy, many teens (44%) are not sure if they would date someone with epilepsy and 11% say they would not date someone with epilepsy.
- Many of the teen respondents (43%) are unsure whether people with epilepsy should not have children. Half of respondents (50%) correctly disagree (27% disagree and 23% strongly disagree).

Teens don't know about or understand epilepsy

- Nearly half of America's teens (49%) have not even heard or read about epilepsy (only 20% know someone who has epilepsy).
- Nearly half of America's teens (49%) think epilepsy may be contagious or don't have enough knowledge to know that it isn't a communicable disease.
- Familiarity with epilepsy among teens is lower than familiarity with all six other diseases tested. More than two-thirds (68%) are either "not too familiar" or "not at all familiar" with epilepsy. Fewer than one in ten (8%) of teens surveyed are very familiar with epilepsy.
- Only a bare majority (52%) says they have ever heard of or read about epilepsy.
- Awareness and understanding of epilepsy tends to be higher among girls, older students, and whites.
- Teens are often unable to answer questions about the nature of epilepsy, such as whether it is contagious, if it is a mental illness, whether doctors know its cause, or if people die from seizures. More than half (52%) say people die from seizures and nearly one in five (19%) say epilepsy is a mental illness.
- Survey responses can be usefully combined into two indices: one related to attitudes and the other relating to awareness. According to these indices, only 34% are informed about epilepsy (based on their attitudes) and only 16% have high epilepsy awareness scores. Nearly two-thirds (62%) have low awareness scores.

Teens don't know how to help when a seizure happens

- Over two-thirds of teens (68%) would not know what to do if someone had a seizure.

Editor's Note: The survey results are based on a two-page survey collected from 19,441 teens in select schools nationally by 20 affiliates of the Epilepsy Foundation from March 2001 through July 2001. The margin of error for this study (at the 95% confidence level) is plus or minus approximately 1%. The survey was funded by the Centers for Disease Control and Prevention.

Entitled to Respect

**A national survey of teens' attitudes and behaviors about
epilepsy and acceptance**

Executive Summary



Epilepsy Foundation

November 2001

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Introduction

Research Method and Objectives

This report presents the results of a study conducted by the Epilepsy Foundation to evaluate teen awareness about epilepsy, and to gain a better understanding of their knowledge, attitudes, and perceptions about epilepsy and people with epilepsy.

The questionnaire for the study was designed by the Epilepsy Foundation in consultation with Social Research Corporation of Philadelphia, PA. Respondents were asked about their awareness of epilepsy, their knowledge about the health condition, stigma associated with epilepsy, and their awareness of several health conditions. A series of questions was also asked to gather demographic characteristics.

The two-page survey was distributed to teens nationally by 20 affiliates of the Epilepsy Foundation from March 2001 through July 2001 in schools selected by the affiliate. A total of 19,441 valid surveys were collected. Mathew Greenwald & Associates, Inc. edited the surveys and performed the data entry. Greenwald & Associates was also responsible for the tabulation, analysis, and reporting of the data. The data were weighted by age and region to reflect national percentages.

The margin of error for this study (at the 95% confidence level) is plus or minus approximately 1%. Subgroup responses will have larger margins of error, depending on the size of the group.

Overview

A growing number of teens are dealing with chronic health conditions. These conditions affect teens' self esteem, leaving them feeling stigmatized, isolated, and discriminated against. Sometimes these teens are even teased and bullied. Of chronic health conditions, including epilepsy, asthma, and diabetes, epilepsy is the least understood among teens (36% not familiar), and likely the most stigmatizing.

This new survey data on teens' attitudes and behaviors about epilepsy shows that the stigma are caused by a huge lack of basic knowledge about the disorder. Looking at the dynamics of a teen's everyday life, this added dimension can cause a teen with epilepsy to suffer unnecessarily when it comes to such basic things as making friends and interacting with others.

Profile of Survey Respondents

Over half (53%) of the respondents to the Teen Survey are females and 47% are males.

Twenty-five percent (25%) are in grades 6 through 8 and 40% are in 9th through 10th grades. One-third (33%) of the respondents are in grades 11th through 12th while 1% are in college.

Sixty-three percent (63%) of the respondents are white, while 14% are black and 12% are Latino. Additionally, 5% of the respondents are Asian and 1% are Native American. Six percent (6%) reported being some other ethnicity or chose more than one race.

Table 1
Demographic Characteristics of Survey Respondents

Age *		
13-14 years of age		35%
15-16 years of age		33
17-18 years of age		32
Gender		
Male		47%
Female		53
Grade in School		
Sixth - Eighth		25%
Ninth - Tenth		40
Eleventh - Twelfth		33
College		1
Race		
White/Caucasian		63%
Black/African-American		14
Asian		5
Latino		12
Native American		1
Other/Chose more than one race		6

* Results were weighted to national census data on age.

Detailed Findings

Teens Living with Epilepsy Don't Get Respect from their Peers

Social Stigma Associated with Epilepsy

Many teens feel that there are indeed social stigma associated with this health condition. While many (46%) of the respondents would tell friends if they had epilepsy, nearly one-third (31%) are not sure if they would and 10% say they would not tell their friends.

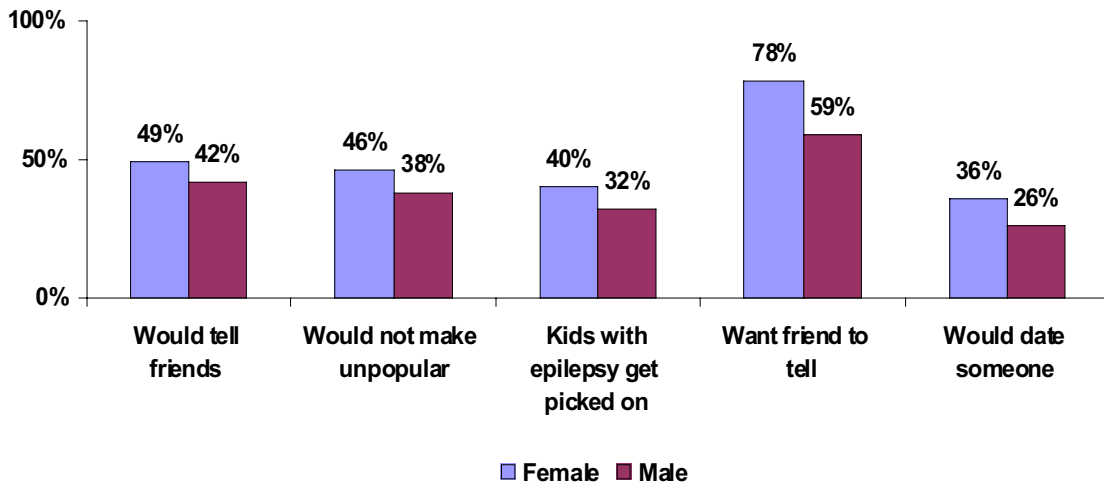
Similarly, many (42%) respondents say having epilepsy would not make them unpopular. However, nearly one-third (31%) say they are not sure if it would make them unpopular and another 13% say it would make them unpopular. Thirty-seven percent (37%) of respondents say kids with epilepsy are likely to get picked on more than other kids. More than one-quarter (26%) are not sure if this is so, and 24% say kids with epilepsy do not get picked on any more than other kids.

Although three in ten (31%) teens say they would date a person with epilepsy, many teens (44%) are not sure if they would date someone with epilepsy and 11% say they would not date someone with epilepsy.

Despite the social stigma teens feel are associated with epilepsy, they would still want a friend to tell them if they had the condition (69%). Only 5% say they do not want a friend with epilepsy to tell them.

Female teens appear to be less affected by the possible social stigma associated with epilepsy. Nearly half (49%) of females surveyed say if they had epilepsy they would tell their friends. In comparison, 42% of males surveyed report the same. Forty-six percent (46%) of female respondents compared to 38% of male respondents say having epilepsy would not make them unpopular. Female respondents are also more likely than males to say they think kids with epilepsy get picked on or bullied more than other kids (40% vs. 32%). Additionally, female respondents are more likely than males to say they would want a friend to tell them if they had epilepsy (78% vs. 59%) and they are more likely to say they would date a person with epilepsy (36% vs. 26%) (See Figure F).

Figure F
Social Concerns by Gender



Teens Unsure about Impact on Lifestyle

Many teens are unsure if having epilepsy has a great impact on one's lifestyle. While nearly half (47%) of those surveyed are aware that people with epilepsy usually attend regular schools, a notable share are uninformed. Three in ten (31%) are not sure whether people with epilepsy attend regular schools and 14% say they do not know about epilepsy. Fewer than one in ten (9%) say persons with epilepsy do not usually attend regular schools.

Regarding the ability of someone with epilepsy to work, many respondents are unsure whether or not the condition would limit them. Thirty-five percent (35%) of respondents are unsure if people with epilepsy can work, 15% say they do not know about the condition, and 8% believe they would be unable to work. Forty-two percent (42%), however, correctly state that people with epilepsy are usually able to work.

Nearly half of respondents surveyed (48%) do not know if most persons with epilepsy can drive cars. Just over three in ten either agree (26%) or strongly agree (6%) that most people with epilepsy are able to drive, while one in five disagree with this statement (14% disagree and 5% strongly disagree).

Similarly, a plurality of the teen respondents (43%) are unsure whether people with epilepsy should not have children. Half of respondents (50%) correctly disagree (27% disagree and 23% strongly disagree). Fewer than one in ten agree that people with epilepsy should not have children (5% agree and 3% strongly agree).

Teens Don't Know about or Understand Epilepsy

General Knowledge about Epilepsy among Teens

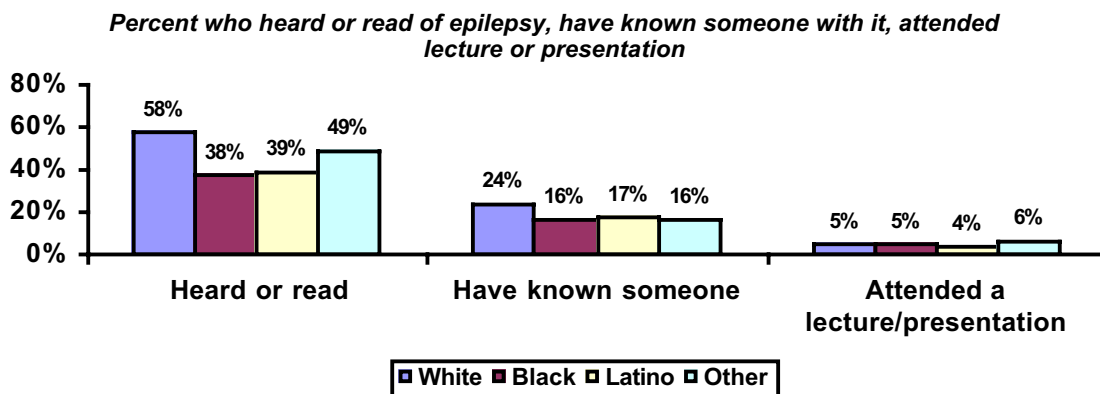
Just over half (52%) of all teen respondents have heard of or read about epilepsy, while a lesser 21% have known someone who had epilepsy and fewer still (5%) have attended a presentation or lecture on the topic. There are significant differences by gender, race, and age regarding general knowledge about epilepsy.

Female teens are significantly more likely than male teens to have heard or read about epilepsy or to have known someone with the condition. Fifty-five percent (55%) of females versus 48% of males report hearing of or reading about epilepsy. Additionally, 24% of females compared to 18% of males say they have known someone with epilepsy. There are no significant differences in presentation or lecture attendance by gender.

White respondents are more likely to know someone who has had epilepsy than their non-white counterparts. Nearly one in four (24%) white respondents have known someone with epilepsy compared to 17% of Latino respondents, 16% each of black teens and those who classify themselves as “other” ethnically.

As expected, younger respondents are less likely to have heard of or read about epilepsy and are less likely to have known someone with epilepsy.

Figure A
Knowledge about Epilepsy



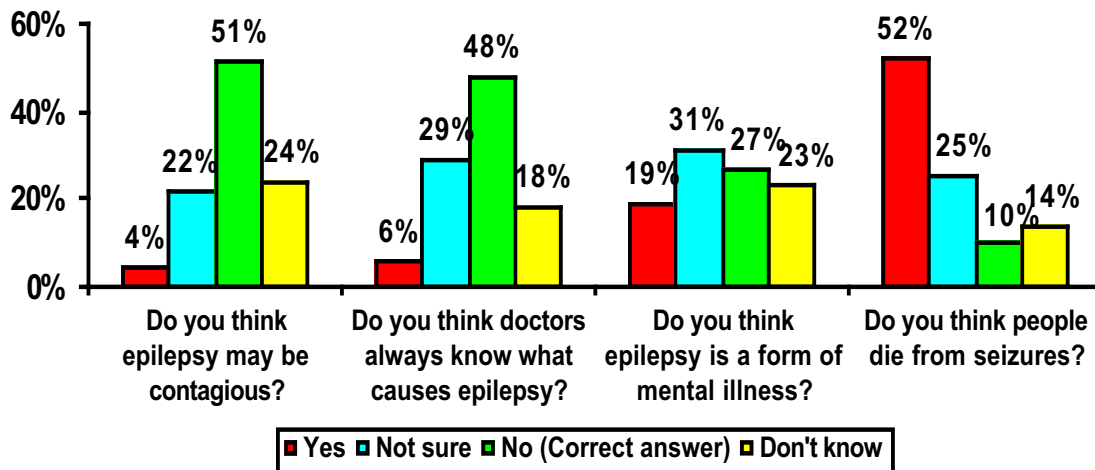
Misconceptions about Epilepsy

Many teens are unclear about various aspects of epilepsy and hold misconceptions about the condition and persons with the condition. Half (51%) know that epilepsy is not contagious. However, 45% report that they are either not sure if it is contagious (22%) or don't know about epilepsy (23%), and 4% believe that epilepsy is contagious.

Twenty-eight percent (28%) of respondents know that epilepsy is not a form of mental illness. On the other hand, nearly one-third (31%) are not sure if it is or not, nearly one-quarter (23%) say they don't know about epilepsy, and 19% report that they think epilepsy is a form of mental illness.

There are also misconceptions among teens about the likelihood of dying from seizures and the causes of epilepsy. Thirty-nine percent (39%) either are not sure (25%) whether people die from seizures or don't know about epilepsy (14%). The majority (52%) think people do die from seizures. Forty-six percent (46%) say they are either not sure (29%) if doctors always know what causes epilepsy or don't know about epilepsy (17%).

Figure B
Misconceptions about Epilepsy



Females and whites are the sub-groups that have more general knowledge about epilepsy and they also tend to answer some general questions about epilepsy correctly. Fifty-six percent (56%) of females know that epilepsy is not contagious compared to 46% of males. Three in ten (31%) females know epilepsy is not a form of mental illness compared to one-quarter (25%) of males.

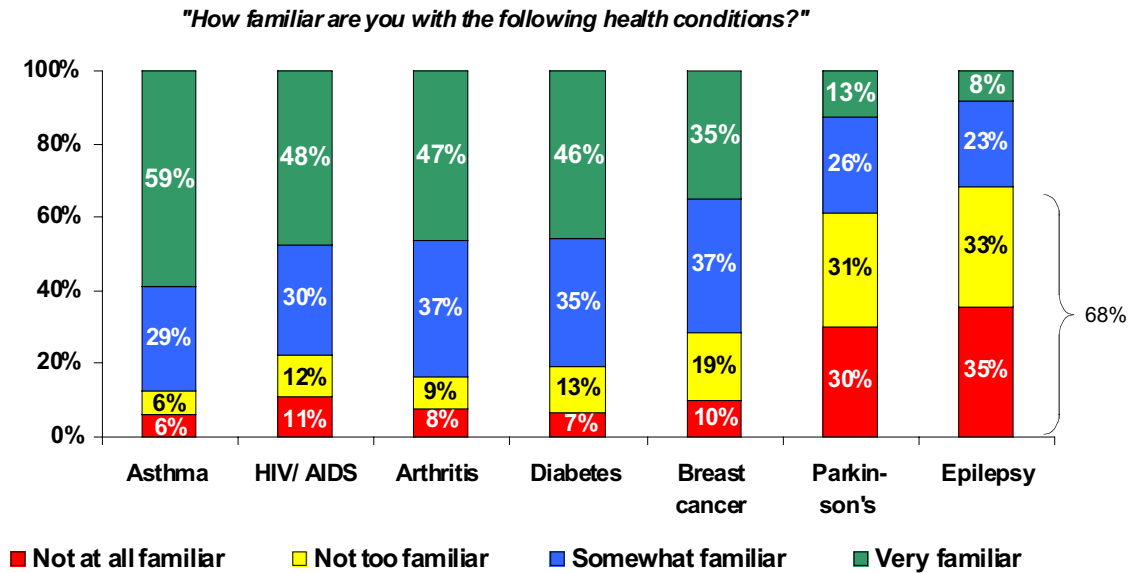
Similarly, whites are more likely to know that epilepsy is not contagious, that it is not a form of mental illness and that doctors do not always know the causes of it. Fifty-seven percent (57%) of white teens surveyed know that epilepsy is not contagious. This compares to 45% of teens who ethnically classify themselves as “other,” 40% of Latinos, and 39% of blacks. Three in ten (31%) white respondents know that epilepsy is not a form of mental illness compared to 27% of the “other” segment, 23% of Latinos, and 21% of blacks. Over half (52%) of white respondents, compared to “other” respondents (42%), blacks (39%), and Latinos (37%) also are aware that doctors do not always know what causes epilepsy.

Younger respondents tend to have more misconceptions about epilepsy. They have a lower tendency of saying that epilepsy is not contagious and a higher tendency of saying that it is a form of mental illness. They are also more likely to report that they do not know about epilepsy. Forty-two percent (42%) of 13 and 14 year olds say epilepsy is not contagious. In comparison, more than half (55%) of 15 and 16 year olds and 58% of 17 and 18 year olds know that the health condition epilepsy is not contagious. One in five (20%) 13 and 14 year olds say epilepsy is a mental illness compared to 18% each of 15 and 16 year olds and 17 and 18 years olds.

Familiarity with Health Conditions

Greater awareness of epilepsy is key to improved understanding of the condition. Of the seven health conditions that teens were asked about in the survey, teens are least familiar with epilepsy. Less than one in ten (8%) teens surveyed are very familiar with epilepsy. In comparison, teens are more likely to be very familiar with each of the other conditions asked about – asthma (59%), HIV/AIDS (48%), arthritis (47%), diabetes (46%), breast cancer (35%), and Parkinson’s Disease (13%). More than two-thirds (68%) are either “not too familiar” or “not at all familiar” with epilepsy.

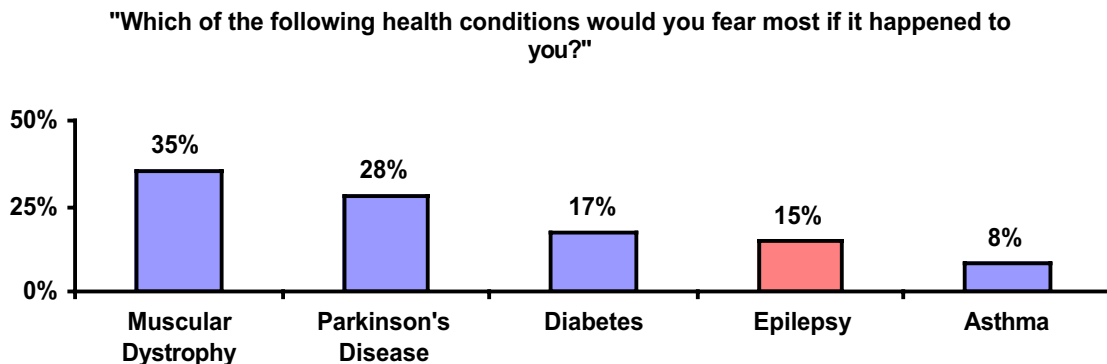
Figure C
Knowledge about Epilepsy



Health Conditions Feared Most by Teens

Among the health conditions asked about in the survey, epilepsy is one of least feared by teens. Teens are most concerned about the likelihood of having Muscular Dystrophy (35%) and Parkinson’s Disease (28%). Of lesser concern to teens are diabetes (17%), epilepsy (15%), and asthma (8%).

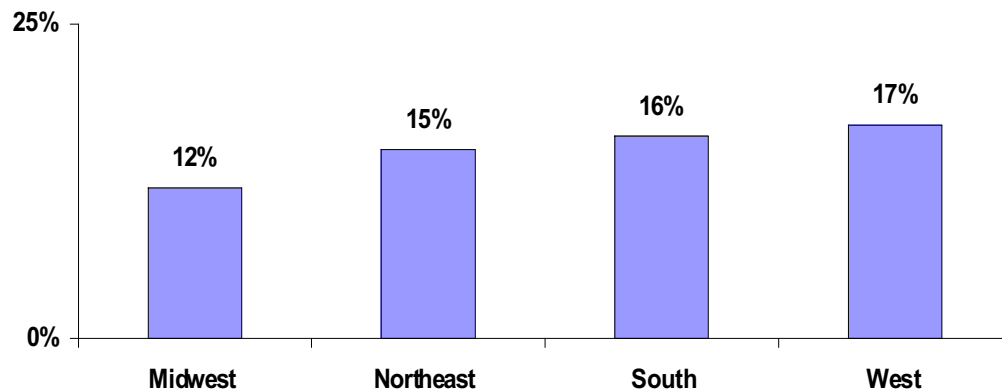
Figure D
Health Conditions Teens Fear Most



Some sub-groups express greater fear of having epilepsy than others. Females are more likely to fear epilepsy. Seventeen percent (17%) of female respondents in comparison to 12% of males would fear epilepsy most if they had it. Latino teens also show greater fear of epilepsy than their counterparts of other ethnicities. Eighteen percent (18%) of Latino teens fear epilepsy while a lesser 15% of black teens and 14% of white teens fear it.

Teen residents of the Midwest region are significantly less likely than those from other regions to fear epilepsy. Twelve percent (12%) of teens in the Midwest fear epilepsy, lower than their counterparts in the Northeast (15%), the South (16%), and the West (17%).

Figure E
Fear of Epilepsy by Region



The low level of fear that teenagers feel towards epilepsy is related to their low awareness of and knowledge about the disease. Respondents who are less familiar with epilepsy are not as likely to fear it, while those who know of someone with the condition are more fearful. Eleven percent (11%) of respondents who report being “not at all familiar” with epilepsy fear the condition. In comparison, a significantly higher 23% of teens who say they are “very familiar,” 19% who say they are “somewhat familiar,” and 16% who are “not too familiar” with epilepsy fear it.

Among those who know someone with epilepsy, 19% would fear having it themselves, compared to 14% who are not sure they know someone with it and the 13% of respondents who do not know anyone with it.

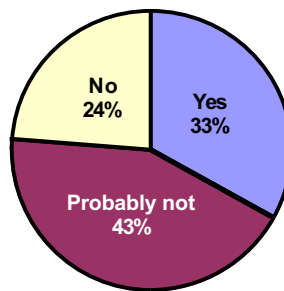
Teens Don't Know How to Help When a Seizure Happens

Responding to a Seizure

Two-thirds of respondents say they would not (24%) or probably would not (43%) know what to do if someone had a seizure. One-third (33%) believe that they would know what to do when someone had an epileptic seizure. While female respondents have more knowledge about epilepsy, fewer females (32%) than males (35%) say they would know what to do if someone had a seizure.

Figure G
What to Do Regarding Seizures

"Would you know what to do if someone had a seizure?"



Meanwhile, black teens tend to be less aware of epilepsy, yet a notable 39% say they would know what to do if someone had a seizure. In comparison, 34% of white teens, 30% of those who are of some other ethnicity say they would know what to do, and 25% of Latino teens say they would know.

More believably, respondents who have known of someone with epilepsy are more likely to say they would know how to deal with an epileptic seizure (48%) compared to those who did not know someone (33%) or those who were unsure if they knew someone (25%).

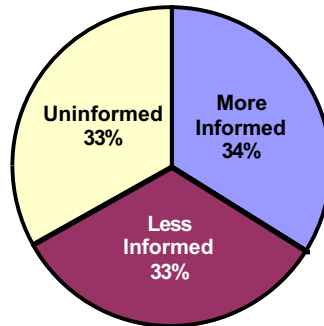
Attitude and Awareness Results

Survey responses can be usefully combined into two categories: one related to teen attitudes about epilepsy and people with the condition, and the other relating to awareness or self-declared knowledge about epilepsy. According to these, only 34% are informed about epilepsy (based on their attitudes) and only 16% have high epilepsy awareness scores. Nearly two-thirds (62%) have low awareness scores.

Attitudes or Opinions about Epilepsy

As shown in Figure H, 34% of respondents share high scores (+6 to +10) and are referred to as the “more informed” group, 33% have scores in the medium range (+1 to +5) and are called the “less informed” and 33% have low scores (-10 to zero) and are called the “uninformed” group.

Figure H
Attitudes



Awareness or Knowledge about Epilepsy

As shown in Figure I, 3% of respondents have high scores (+16 to +20) and are referred to as the “very aware” group, 13% have scores in the second highest range (+12 to +15) and are called “aware”, and individuals in the middle range (+8 to +11) account for 22% of respondents and are known as the “somewhat aware” group. Those with the second lowest scores (+4 to +7) comprise 27% of the total and are labeled the “not very aware” segment, while those with the lowest scores (zero to +3) are called the “not at all aware” group and comprise 34% of respondents.

Figure I
Awareness

