European Epilepsy Day 2012 takes place on February 13th. Brainwave – The Irish Epilepsy Association is focusing on the issue of epilepsy stigma and is organising a public awareness campaign called “Shatter the Stigma of Epilepsy”.

The campaign includes an online survey aimed at assessing the level of epilepsy stigma that exists among people with the condition today. The anonymous survey, consisting of 7 questions began on January 20th and was conducted via SurveyMonkey.

Respondents were sourced via Brainwave’s membership, subscribers to our e-newsletter and through social media sites. The results below are up to and including Friday 10th February 2012.

The total number of respondents was 464.

**Question 1: Do you generally feel comfortable telling your friends and family members that you have epilepsy?**

462 people answered this question. 327 (71%) replied that they were comfortable telling friends and family, while 29% stated that they weren’t.
**Question 2: Do you generally feel comfortable answering questions and concerns about your epilepsy from friends and family?**

459 people answered this question. 368 people (80%) said that they were comfortable answering questions from friends and family, while 91 people (20%) said they were not.
Question 3: Do you think that friends’ and family members’ attitude towards you changed after you told them that you have epilepsy?

462 people answered this question. A total of 223 (48%) said that they felt friends/family members attitudes had changed after they revealed their epilepsy, while 239 (52%) thought that their attitudes had not changed.

Amongst the sub group of those who felt comfortable telling friends and family about their epilepsy (Question 1), 42% felt that their attitudes had changed following disclosure. However, amongst those who did not feel comfortable disclosing epilepsy, 63% felt that their friends or family’s attitude changed.
Question 4: If you are or have been in employment, do you generally feel comfortable telling your employer and work colleagues that you have epilepsy?

458 people answered this question. 161 people (35%) were not in employment. 131 people (29%) said that they feel comfortable telling their employer and colleagues about their epilepsy. 166 people (36%) said that they do not generally feel comfortable doing so. Of those who are / have been in employment, 44% were comfortable disclosing their epilepsy, while 56% were not.

Question 5: Have you found that your employers'/ work colleagues attitude towards you changed after you told them that you have epilepsy?

452 people answered this question. 162 people (36%) were not in employment. 146 people (32%) said that they felt their employers or colleagues attitude changed following their disclosure of epilepsy. 144 people (32%) said that they did not think this was the case. Of those who are / have been in employment, 50% felt their employers or colleagues attitude changed following their disclosure of epilepsy, while 50% felt it had not.

Amongst the sub group of those who felt comfortable telling their employer or colleagues about their epilepsy (Question 4), 28% felt that their employers/ colleagues attitudes had changed following disclosure. However, amongst those who did not feel comfortable disclosing epilepsy, 67% felt that their employers or colleagues attitude changed.
Question 6: In your own personal experience, have you ever experienced stigma as a result of having epilepsy?

458 people answered this question. 237 (52%) said that they have experienced stigma as a result of having epilepsy while 221 (48%) stated that they have not.

Amongst the sub group of those who felt comfortable telling friends and family about their epilepsy (Question 1), 47% said that they had experienced stigma. However, amongst those who did not feel comfortable disclosing epilepsy, 62% said that they had experienced stigma.
**Question 7: Do you take offence when you are referred to as “an epileptic”?**

457 people answered this question. 219 people (48%) said that they found being referred to as “an epileptic” offensive while 238 (52%) said that they did not find the term offensive.

Amongst the sub group of those who felt comfortable telling friends and family about their epilepsy (Question 1), 41% said that they found the term offensive. However, amongst those who did not feel comfortable disclosing epilepsy, 64% said they found the word offensive.

Amongst the sub group of those who said that they have experienced stigma as a result of having epilepsy (Question 6), 53% said that they found the term offensive. However, amongst those who did not experience stigma, 42% said that they found the term offensive.

Amongst the sub group of those who said that they found the term offensive, 57% said that they have experienced epilepsy stigma. However, amongst those who do not find the term offensive, only 47% have experienced epilepsy stigma.
Summary

The survey shows that epilepsy stigma is a very real issue for many people with epilepsy today, with over half of all respondents reporting that they have experienced it. While people are more comfortable being open about epilepsy amongst friends and family, they are less so inclined when dealing with their employer or work colleagues.

- 29% or almost 1 in 3 people with epilepsy do not feel comfortable telling their friends and family about their condition.
- 20% or 1 in 5 people with epilepsy are not comfortable answering questions from friends and family about their epilepsy.
- 48% or almost half of respondents felt that friends or family attitudes towards them changed after they revealed their epilepsy.
- 56% of people with epilepsy who are in employment are not comfortable telling their employer or colleagues that they have epilepsy.
- Half of all people with epilepsy responding who are in employment said that their employer or colleagues attitudes towards them changed after they were aware of their epilepsy.
- 52% of people responding have experienced stigma as a result of their epilepsy.
- 48% found the use of the label “an epileptic” to be offensive. Of these 57% have experienced stigma as a result of epilepsy.

Quotes from respondents

- "I have found that there is an initial stigma attached to you when let them know but I always encourage them to ask any questions they may have and the stigma quickly disappears once they are more informed."
- "We need to wipe out the Stigma NOW for the future generations to understand it is just like any other condition. You learn to adapt, gain knowledge and encourage"
- "I've have epilepsy since i was 11 yrs old. I'm now 70 and feel society in general hasn't changed. People dont understand...my family understand - they have grown up with my epilepsy"
- "I suppose the term epileptic is usually the main issue I find difficult. People always have a need to label others but I find this label discriminatory"
- "With regards to how I feel about my 12yr old son - I have to do the explaining to his friends mothers about his condition. I have found that play dates, birthday parties and generally him going to his friends houses are difficult"
- "European Epilepsy Day is a great initiative. Let's hope it helps educate people further and remove some of the needless stigma."
- "I don't have any problem telling people about my condition, but, often find people don't know how they should react - almost embarrassed when I discuss it. This is particularly
apparent socially when you explain why you’re not drinking alcohol - people don’t know how to react."

• "I think the stigma is still very much there & in my own experience it’s because people don’t understand what’s happening & some are even scared. Knowledge is key! "

• "I am embarrassed telling acquaintances but not good friends/ family. After a seizure at my kids school I feel other parents think of me differently. I am embarrassed by term "an epileptic". I find it easier to say I suffer from seizures"

• "Stigma still exists towards people with epilepsy. When I mentioned it to friends over the years, some became very distant towards me. People do not want to know about it."

• "I would like to be confident enough to tell people casually about my condition in the same way as people with other conditions. However, I find when I do that people distance themselves and I don’t feel comfortable explaining why I feel they are treating me differently because I have opened up. Consequently I tell as few people as possible."

• "I told somebody once that I had epilepsy and there reply was "you don't look like you have". Sums up people's attitude really!!! Also I wouldn't volunteer the information that i had epilepsy unless it came up in conversation."

• "It is my personal opinion that once you tell people that you have epilepsy their attitude towards you changes. They think that you are now physically ill and unable to carry out the tasks of a 'normal person'!"

• "I have found that I have kept my condition a secret in work because of how I have heard my colleagues discuss people who have epilepsy. When I did eventually have a seizure, I lost my job. Similarly I am afraid to tell parents of my kids friends in case it stops them from letting their children come and play."

• “When I was in Secondary school, one person thought he was going to catch epilepsy from me like the flu!! It should be made well are the you can't catch it from people”

• “I have been told I am drunk when I stagger after trying to stand up from having a seizure. I have been called a nut case. People just do not understand.

• “I don't mind being called "an epileptic" but I would prefer not to have a label”

• “Generally most people have a positive attitude with the occassional acception. After all epilepsy is another disability & life goes on. However people can often become over concerned because of their lack of knowledge.”

• “I just feel that in Ireland people are oblivious to what epilepsy is, I know some people who think that it is caused by blinking lights, I for one wish that more people can understand it, it's a medical condition not a mental health issue.”
• “I don't believe attitudes will ever change”

• “I was diagnosed when 8 and am now 34. I find friends/ family fantastic and treat it as a 'characteristic' of me but have never made me feel anything but normal. Saying that, a primary school nun told people to keep away from people with epilepsy as they were 'possessed by the devil'.”

• I did not tell my employer that I have epilepsy but I had seizures at work. There was a worldwide redundancy program in my previous work and I have the feeling I was one of the first to be made redundant because of my condition”

• I have had some negative reaction from friends and workmates but on the whole it has been positive because I never hide my epilepsy and I'm not in any way ashamed of my condition

• “I have no problem talking to people, friends, and family member about my epilepsy but I do feel their attitudes change, they get nervous of what might happen when around me.”

• While people may attach a stigma to epilepsy, it has no nasty side to it - for them it is purely fear of the unknown. They are not sure how to cope with the information.