Public Education & Awareness Campaigns on Epilepsy

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Identifying the Goals

- Education on Epilepsy
- Changing Attitudes & Removing Stigma
- Promoting Inclusion/Eliminating Barriers
- Proper First Aid & Seizure Recognition
- Promote Need for Funding (Services, Research)
- Promote Need for Research
- Educate Public About Treatment Changes
Epilepsy Foundation Public Education & Awareness Campaigns

• Since 1970s, conducted public awareness campaigns focused on improved recognition & awareness, eliminating stigma and overcoming barriers

• Annual Public Service Announcements, using TV spots, complementary radio spots, print messages, letters, editorials, posters, billboards. Distributed through affiliates, national and local markets
History of Epilepsy Campaigns

• 1970’s – Celebrities Bring Epilepsy Into the Public Eye - Jack Lemmon, Henry Winkler, Marty Allen public service activities, TV shows

• Concurrent Changes in Laws & Medical Treatment

• Consolidation of Epilepsy Advocacy Groups & Campaigns

• Establishment of federally funded comprehensive epilepsy centers
History of Epilepsy Campaigns

• 1980s to early 1990s - Annual Campaigns
  Focus on Awareness & Recognition of Epilepsy, Inclusion, Eliminating Stigma
  – Presidential Proclamations Recognize November Epilepsy Awareness Month & Message
  – Get the Facts theme
  – Epilepsy. It’s Not What You Think. Get the Facts
  – Count Me In and Walls campaigns
  – The Hidden Signs – Daydreaming, spacing out – could it be epilepsy? Get the Facts
History of Epilepsy Campaigns

- 1990s – see changing messages, use of different vehicles to reach public
- It’s An Emergency (ambulance) – need for support
- We Are Women - multi-faceted multi-year campaign to change behavior and treatment
- Is It Old Age or Epilepsy? – recognition of expanding numbers
- 2000s – targeting teens, minorities, selected audiences who interact with people with epilepsy
Campaigns Appear Effective in Changing Attitudes

- Gallup polls show steady improvement in attitudes in US towards people with epilepsy
- More people know what epilepsy is, do not think it is contagious, would allow their children to play with children with epilepsy, and think people should be employed.
- Contrast with attitudes in other countries which lag considerably behind
Improved Public Awareness Doesn’t Always Mean Improved Understanding

• 1987 Gallup survey shows despite better awareness of epilepsy, not necessarily greater inclusion, or understanding of proper first aid
• One in three still think less of someone with epilepsy and their families
• Almost half say put an object in a person’s mouth or hold them down
• One in six think you can tell who has epilepsy by looking at them
Improved Public Awareness Doesn’t Mean Changed Behavior, Nor Is Message Heard by All Audiences

Targeted campaigns develop– specific issues, multiple mechanisms used to reach audience, change behavior

Pre and post campaign testing and evaluation is needed
Campaigns of the 21st Century Are Targeted, Use New Tools

- CDC No Limits (teens)
- Entitled to Respect – 2002 (teens)
- Take Charge of the Facts – 2005 (teens)
- Get the Word Out – 2004 (African Americans)
- Know the Difference – 2006 (African Americans)
- La Epilepsia - Hispanic Outreach
- TalkAboutIt!org
- Get Seizure Smart
New Tools & Approaches

- Social Media – websites, twitter, facebook
- Partnerships with Other Organizations
- Peer to Peer Programs & Networks
- Campaigns are multi-year, multi-faceted, and are evaluated with pre- and post – campaign data
Two Current Campaigns

Teens Get Seizure Smart
ENTITLED TO RESPECT/SEIZURES AND YOU:
TAKE CHARGE OF THE FACTS

CORE MESSAGE

Teens with epilepsy should be treated with the same consideration as anyone else
2001 Teen Survey

- 19,441 valid surveys conducted of teens reached over 4 months through 20 affiliates, and evaluated by Mathew Greenwald & Associates
- Survey showed that 2/3 of teens were not familiar with epilepsy, did not fear it, did not know how someone would be affected by epilepsy. Fewer than 8% were very familiar with epilepsy.
2001 Teen Survey

- In addition to awareness being low, only a little more than ½ had heard or read about epilepsy, and knew it was not contagious.
- Only 28% knew epilepsy is not a form of mental illness, the rest weren’t sure or thought it was.
- Most teens did not know or were not sure what to do if they saw someone have a seizure.
2001 Teen Survey

• Many teens recognized there are social stigmas connected to epilepsy. Fewer than half would tell their friends if they had epilepsy.

• Most significantly, only 3 in 10 teens said they would date someone with epilepsy, most were not sure, and 11% said they would not.
ENTITLED TO RESPECT/SEIZURES AND YOU:
TAKE CHARGE OF THE FACTS

- Media campaign started in 2002 generating over 1.5 million impressions through print, television and radio
- Actor Ashton Kutcher (*That 70’s Show*) and the band N’Sync served as celebrity spokespersons
- Teen Review Panel and Teen Ambassadors helped create and distribute information
- Campaign updated in 2006 with *Seizures and You: Take Charge of the Facts*, an depth educational campaign for teens that focused on reducing stigma, dispelling myths, and seizure first aid.
ENTITLED TO RESPECT/SEIZURES AND YOU: TAKE CHARGE OF THE FACTS

Assessing Attitudes and Awareness Regarding Epilepsy among Youth: Results of a 2007 National Study

• Study to measure teen knowledge of epilepsy over a six-year period by conducting and comparing the 2001 National Teen Survey on Epilepsy and the 2007 National Study on Teen Attitudes and Awareness of Epilepsy.
ENTITLED TO RESPECT/SEIZURES AND YOU: TAKE CHARGE OF THE FACTS

• Between 2001 & 2007, teens unfamiliar with epilepsy decreased from close to 70% to fewer than 25%. Chronic conditions such as HIV, asthma, or diabetes, averaged only an 8% increase in familiarity.

• From 2001-2007, teens who believed that other teens with epilepsy lived normal lives increased from 53% to 71%, and misperceptions about epilepsy being contagious decreased from 68% to 51%.

• Teens who reported that they would date someone with epilepsy increased by 22%.

• Despite programs, in 2007 first aid knowledge decreased from 2001.
Results of 2007 Study

• Following participation in the Seizures and You: Take Charge of the Facts program, students’ self-reported preparedness regarding seizure first aid increased from 40% to 87%.

• The decrease in the 2007 may be a result of the limited reach of the curriculum of the programs as results also showed that only 11% of teens had ever seen or had a presentation on epilepsy.
Results of 2007 Study

- Fear of epilepsy increased when someone saw a seizure.
- But increased familiarity with seizures, seeing more than 3, knowing someone with epilepsy, or attending a presentation on epilepsy increased comfort and reduced fear.
- High levels of uncertainty and misinformation about epilepsy still exist.
GET SEIZURE SMART
2010 National Epilepsy Awareness Month

- An online campaign, using social and print media
- Asked supporters to distribute 1 page *Get Seizure Smart!* quiz.
- At least 1 million quizzes distributed in 30 days. 30% of people distributed 100+ flyers
- 95% of participants surveyed considered it a success and 90%+ said they’d participate again.
Challenges, Lessons Learned

- Costs of campaigns are extremely high
- Epilepsy directly affects 1% of the population
- Epilepsy is a complex condition with a complex message – goals can vary and messages can appear to conflict
- Public awareness campaigns must take place over extended period of time
- Crowded market of public awareness messages ("With so much message “noise” in the market” ….it takes a fresh look and new creative platforms. (Goldsmith, VP, Creative and Brand Strategy/ ACS)
Challenges, Lessons Learned

- Campaigns may need to be continuous.
- Targeting message, audience, using multi-faceted tools, peer to peer, personal stories need to occur, but not at expense of broad based educational awareness.
- Evaluate behavioral change, engagement & actions as a result of campaigns, not only survey responses.
Recommendations

• Conduct new Gallup-type poll on broad based attitudes & knowledge about epilepsy – better today than in the last century?
• Broad public awareness campaigns desperately needed on epilepsy, proper first aid, seizure recognition
• Improve dissemination of consistent message and information about current treatment
• Messages must promote behavioral change
Recommendations

- Expand reach of education and awareness campaigns to targeted groups – children, teens, educators, police & public responders, employers
- Expand programs to engage targeted groups to promote behavioral change
- Conduct outcomes evaluation – what people say is not enough.