



Special Communication

Improving understanding, promoting social inclusion, and fostering empowerment related to epilepsy: Epilepsy Foundation public awareness campaigns – 2001 through 2013 [☆]



P. Price ^a, R. Kobau ^{b,*}, J. Buelow ^c, J. Austin ^{d,1}, K. Lowenberg ^c

^a McKing and Associates, Atlanta, GA, USA

^b Centers for Disease Control and Prevention, Division of Population Health, Epilepsy Program, USA

^c National Epilepsy Foundation, Landover, MD, USA

^d Carlsbad, CA, USA

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ABSTRACT

It is a significant public health concern that epilepsy, the fourth most common neurological disorder in the United States, is generally poorly understood by both the public and those living with the condition. Lack of understanding may magnify the challenges faced by those with epilepsy, including limiting treatment opportunities, effective management of symptoms, and full participation in daily life activities. Insufficient awareness of epilepsy and appropriate seizure first aid among the public and professionals can result in insufficient treatment, inappropriate seizure response, physical restraint, social exclusion, or other negative consequences. To address the need for increased public education and awareness about epilepsy, the national Epilepsy Foundation, supported by the Centers for Disease Control and Prevention, has conducted yearly multifaceted public education and awareness campaigns designed to reach the broad population and targeted segments of the population including youth, young adults, racial/ethnic groups (i.e., African-, Hispanic-, and Asian-Americans), and people with epilepsy and their caregivers. Campaign channels have included traditional media, social media, and community opinion leaders and celebrity spokespersons. The key activities of these campaigns, conducted from 2001 to 2013, are summarized in this report.

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1. Introduction

While people may readily recognize seizure activity associated with epilepsy when they see it in real life or on the screen, epilepsy – the fourth most common neurological disorder in the United States [1] – is generally poorly understood by the public, even among people who know someone with the disorder [2–4]. This raises a significant public health concern given that epilepsy is not rare: about 1 in 26 people will develop epilepsy at some point in their lives [5]. In addition, research has shown that people who have epilepsy themselves often do not have an adequate understanding of their condition, including their diagnosis, the nature of seizures that they experience, what precipitates or triggers their seizures, the possible side effects of the treatment that they receive, the safety issues that they face, and the risks and

potential consequences of their condition [6]. This lack of understanding may also intensify the challenges faced by those with epilepsy, especially in regard to managing medication schedules, symptoms, disability, lifestyle limitations, emotional stress, and stigma [7,8].

Misunderstanding, misinformation, and misperceptions about epilepsy and seizures, passed down through the centuries, have resulted in stigma – negative attitudes and beliefs related to those living with the disorder that can result in social-distancing behaviors, social exclusion, and discrimination. This has appeared in the workplace, in schools, and in the community because of the public's inexperience with appropriate seizure response, persistent myths about epilepsy, and their lack of understanding about the abilities of people with epilepsy [4,5]. In addition, people with epilepsy may experience “felt” stigma, being ashamed of their condition and afraid to be open about it because of the fear of prejudice and discrimination [9].

Over the years, studies have supported the belief that education and awareness campaigns can influence large numbers of people to change or avoid behavior that leads to disability and stigmatization [10,11]. In addition, participants from the epilepsy community, health care, public health, and organized systems of care have come together to address optimal health for people with epilepsy. These meetings have resulted in recommendations related to programs, services, and communication

[☆] Disclaimer: The findings and conclusions in this study are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

* Corresponding author at: Centers for Disease Control and Prevention, Division of Population Health, Epilepsy Program, 4770 Buford Highway NE, MS F-78, Atlanta, GA 30341, USA. Tel.: +1 770 488 6087; fax: +1 770 488 5486.

E-mail address: rkobau@cdc.gov (R. Kobau).

¹ Self-employed consultant.

strategies for epilepsy stakeholders and the public health community to better support people with epilepsy [4,12,13]. As a result of these recommendations, as well as contributions from the Living with Epilepsy Task Force [14] and the Vision 20–20 coalition [5], the Institute of Medicine (IOM) was asked to address the public health dimensions of epilepsy. The consensus report that followed, *Epilepsy across the Spectrum*, has further clarified the complex nature of epilepsy and the role of public health in addressing this disorder, and underlined the importance of comprehensive educational efforts for people with epilepsy and their families, including health literacy and cultural considerations, and the need to eliminate the stigma of epilepsy [4,5]. In this overview, we summarize select public awareness activities on epilepsy to highlight target populations, themes, communication channels, and impacts.

2. Epilepsy Foundation awareness campaigns: 2001–2013

To address the gap in public awareness, the national Epilepsy Foundation (EF), supported by the Centers for Disease Control and Prevention (CDC), has conducted yearly multifaceted public education and awareness campaigns about epilepsy for more than a decade. Campaigns have been tailored to reach targeted segments of the population including youth, young adults, African-Americans, Hispanic-Americans, and Asian-Americans. Communication of key campaign messages has evolved over the years to include not only mass media channels such as television, radio, and print but also other media

including DVDs, the Internet, and, most recently, a full array of social media. In addition, public personalities, celebrities, and trusted medical professionals have been recruited to increase understanding and promote greater acceptance of epilepsy by serving as advocates for those with the disorder. Partnerships have grown to include, in addition to affiliates of the national Epilepsy Foundation, companies and corporations; churches; community centers; clinics; local community groups; and national associations, networks, forums, councils, and academic institutions. Table 1 provides a brief outline of the yearly campaigns. Key activities composing each campaign year are described below. With the exception of one year (2004/2005), measurement of campaign effects was limited to estimated audience reach and, later, audience involvement via social media.

Before the first national epilepsy public awareness campaign launched in November 2001, a survey on attitudes and beliefs about epilepsy was distributed to high school students in multiple states. Baseline data from 20,000 students revealed that about half of youth were not sure whether seizures were contagious, and about two-thirds would not know what to do in the presence of someone having a seizure [15]. This led to the launch of the 2001 *Entitled to Respect (E2R)* campaign, which focused on outreach through teen media channels and the support of the popular musical group *NSYNC. The main objectives of this campaign were to increase teens' awareness of epilepsy and increase self-esteem among teens with epilepsy. The message was straightforward: youth with epilepsy are entitled to respect just like everybody else. Through the Internet and radio stations and by television,

Table 1
Summary of Epilepsy Foundation awareness campaigns: 2001–2013.

Year	Target group	Theme	Methods	Key partners
2001–2002	Teens	Entitled to Respect	Celebrity endorsement, Internet, radio PSAs, audio and video news releases, newspapers, posters, brochures	*NSYNC, epilepsy clinical specialists
2002–2003	Tweens	Entitled to Respect	Celebrity endorsement; Internet; PSAs; ads to youth magazines, high school newspapers, local and national print media	Ashton Kutcher, Triple Image, Clear Channel affiliates
2003–2004	African-American youth	Entitled to Respect/Get the Word Out	Celebrity endorsement, Internet, contest, PSAs, news releases, brochure, posters, campaign microsite	Monica (Arnold), EF affiliates, Clear Channel Worldwide, National Peer Helpers Association, National Association of Police Athletic Leagues
2004–2005	African-American community	Get the Word Out	Celebrity endorsement, audio and video PSAs, radio media tours, Internet, print media, broadcasts, brochures, seizure first aid bookmarks, fact sheets, planned events	Garcelle Beauvais-Nilon, EF affiliates, beauty salons, churches, community centers, health clinics
2005–2006	Hispanic-American community	Epilepsy: It's More Common Than You Think	Radio interviews and PSAs, celebrity endorsement, magazine and newspaper articles, exhibits, handouts, community health worker in-home visits	"Prevenir es Salud" with Dr. Elmer Huerta, EF affiliates, National Association of Hispanic Journalists, National Council of La Raza, Lay Health Workers National Network
2006–2007	Hispanic-American community	Not Another Moment Lost to Seizures	Radio PSAs, newspaper articles, Internet, curriculum development, community workshops, conference exhibits and presentations, telephone information service line	Hispanic Leadership Council, EF affiliates, National Council of La Raza, Lay Health Workers National Network, United States Hispanic Chamber of Commerce
2007–2008	Hispanic-American community, African-American community	Not Another Moment Lost to Seizures, Know the Difference	Radio PSAs, newspaper articles, Internet, curriculum pilot, magazine ads, educational materials, community workshops, forums, conference exhibits	EF affiliates, Community Health Workers – Promotores, East Coast Migrant Stream Forum, Midwest Stream Farmworker Health Forum, NAACP, National Urban League, Congressional Black Caucus
2008–2009	Hispanic-American community, African-American community	No More Seizures, Know the Difference	Radio PSAs, Internet, magazine ads, curriculum, toll-free telephone, educational materials, community presentations, conferences, forums	EF affiliates, Promotores National Network Association, National Center for Farmworker Health, Urban League affiliates, EEOC
2009–2010	Hispanic community, African-American community	Know the Difference	Radio PSAs, Internet, magazine ads, toll-free telephone, educational materials, community presentations, social media	EF affiliates, Promotores National Network Association, National Center for Farmworker Health, historically black colleges and universities
2010–2011	Hispanic-American community, African-American community	Get Seizure Smart, Know the Difference	Internet, videos, curriculum, toll-free telephone, social media, brochures, ads, flyers, posters, bookmarks, hangers	International Medical Interpreters Association, EF affiliates, National Center for Farmworker Health, historically black colleges and universities, predominantly black institutions
2011–2012	Hispanic-American community, African-American community	Get Seizure Smart	Internet, social media, community events, educational materials, ads, video, DVD	EF affiliates, National Center for Farmworker Health, historically black colleges universities, Predominantly Black Institutions, Hispanic Serving Institutions
2012–2013	Asian-American youth and young adults	26 Days of Epilepsy Awareness and Action	Internet, video, social media, community events, physician outreach, celebrity endorsement	Richard Lui and James Kyson, EF affiliates, Asian-American physicians

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