



## ▶ *Pharma Helps Fund Revamped* **Patient Portal for Epilepsy**

**TRENDWATCH: Patients drive industry's social media use.**

**T**he Epilepsy Foundation has revamped its website — epilepsy.com — to help improve treatment and care and to position itself as a community hub accessible from any device with access to the Internet.

In developing the new site, the foundation sought to create a centralized source for all epilepsy-related information and support services, one of the recommendations presented by the Institutes of Medicine in its seminal 2012 report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*.

Users will find updated facts and figures about epilepsy and seizure causes, diagnosis, treatments, and research, as well as the resources to support those living with epilepsy and their caregivers. The new site combines two websites for epilepsy-related content — epilepsyfoundation.org and the previous epilepsy.com — into one site. The previous sites averaged more than 500,000 unique visitors per month.

Fully integrated with social media, the new site encourages visitors to become ambassadors for epilepsy and seizure awareness. Users can log in or register with their social identity from Facebook, Google Plus, or Twitter to comment on content, ask questions, participate in conversations, and easily share pages to their social media profiles.

Sunovion Pharmaceuticals is the lead sponsor for funding of the upgrade. Additional support came from the American Epilepsy Society, Cyberonics, Lundbeck, the McGrath Abrams Family Foundation, UCB Pharma, and Upsher-Smith Laboratories.

▼ *For additional information, visit [epilepsy.com](http://epilepsy.com), or [facebook.com/epilepsyfoundationofamerica](https://facebook.com/epilepsyfoundationofamerica), or [@epilepsyfdn](https://twitter.com/epilepsyfdn).*



broader discovery of patient insights; enhanced customized research services and capabilities; focused research projects to evaluate and develop new medical evidence, measures and standards of health; and access to PatientsLikeMe's clinical trial awareness tool, which allows patients to learn about clinical trials.

▼ *For more information, visit [patientslikeme.com](http://patientslikeme.com).*

### **Documentary Increases Awareness of Huntington's Disease**

At a very young age, Kristen Powers watched her mom's life shrink away and eventually end as a result of Huntington's Disease. She was determined to be tested for the genetic disease as soon as she turned 18 in order to plan her life accordingly. In the meantime, she filmed a documentary of her life before the testing, and ended up raising more than \$18,000 on the crowd-funding website Indiegogo to hire a video crew.



Since 2012, her efforts have appeared on national television, garnered her speaking engagements at conferences, including TEDxTeen, and articles about her have been published in USA Today, The Stanford Daily, as well as many other publications.

Twitch is the first documentary to follow the life of an individual going through genetic testing for Huntington's Disease (HD), a genetic neurological brain disorder that destroys the victim's ability to walk, talk, think, and reason, eventually leading to death. The documentary explains the science through interviews with major Huntington's Disease experts and activists provide deeper insight into the complexities and hopes buried in the disease.

This documentary highlights the pressures people, especially young adults, face when given the chance to be handed their medical fate.

Spoiler alert: Kristen tested negative for Huntington's Disease. Neither she nor her children will have the disease.

▼ *For more information, visit [twitchdocumentary.com](http://twitchdocumentary.com).* **PV**

### **Women of Social Media in North America**

Communications firm Weber Shandwick partnered with KRC Research to conduct Digital Women Influencers, an online survey of 2,000 North American women to identify segments of women who are influential in social media.

The research concluded that women are the "low-hanging fruit" of social media today and deserve closer attention from marketers.

#### **Survey findings include:**

- » 82 million women in North America are on social media.
- » Women on social media have an average of 1,600 social connections.

- » 86% of North American women have a social media account.
- » 68% of women spend one hour or more each week on social networks.

▼ *For more information, visit [webershandwick.com](http://webershandwick.com).*

### **PatientsLikeMe and Genentech Collaborate to Boost Oncology Network**

PatientsLikeMe has partnered with Genentech to explore use of PatientsLikeMe's global online patient network to develop innovative ways of researching patients' real-world experience with disease and treatment. The five-year agreement is the first broad research collaboration between PatientsLikeMe and a pharmaceutical company and provides PatientsLikeMe the opportunity to expand its patient network in oncology.

The agreement provides Genentech the opportunity to use PatientsLikeMe's Global Network Access, a service for pharmaceutical companies that delivers a range of data, research, and tools. The service includes: access to PatientsLikeMe's network to enable cross-sectional research and

