First Results Presented from Study of U.S. Veterans Using a Health Data Sharing Network Show Measurable Improvements in Epilepsy Self-Management

ATLANTA, April 30, 2014 – 7:30 a.m. (EDT) – Today, the U.S. Department of Veterans Affairs’ Epilepsy Centers of Excellence (ECoE), biopharmaceutical company UCB, and health data sharing network PatientsLikeMe® presented the results of the Policy for Optimal Epilepsy Management (POEM) study at the 66th Annual Meeting of the American Academy of Neurology in Philadelphia, Pa.

This first-time, real-world study of an online health management platform demonstrated statistically significant improvements in established epilepsy metrics of patient self-management and self-efficacy in U.S. veterans who participated in the study, which used PatientsLikeMe.

“The results of the POEM study reinforce the potential for an online data sharing network like PatientsLikeMe to positively influence self-management and self-efficacy for veterans with epilepsy. We’re pleased to share these results with the scientific community at AAN and look forward to using what we’ve learned as a foundation for further research into how we can use digital health solutions to improve the care for the broader epilepsy community,” said principal investigator and ECoE’s John Hixson, M.D., Assistant Professor of Clinical Neurology and Deputy Associate Chief of Staff for Clinical Informatics at the San Francisco VA Medical Center.

In January 2013, the POEM study was launched online for veterans living with epilepsy who had not previously used the PatientsLikeMe website. A total of 249 veterans completed an online informed consent and a baseline assessment of two validated scales that measure epilepsy self-management practices, the Epilepsy Self-Management Scale (ESMS) and the Epilepsy Self-Efficacy Scale (ESES). After completing the initial survey, patients were invited to register as PatientsLikeMe members and engage on the site, which offers multiple ways for patients to connect with other patients, condition-specific tracking tools and educational resources. Six weeks later, 92 participants (36.9%) completed the assessment of ESES and ESMS measures again. These veterans reported improvement in epilepsy
self-management and self-efficacy, demonstrated by increases in both the ESMS (140 to 143 points; p=0.02) and ESES (244 to 254 points; p=0.02) total scores over six weeks. The greatest change was observed on the ESMS information management subscale (20 to 22 points; p<0.001).

“UCB is committed to working with leading health care and technology experts like the VA ECoE and PatientsLikeMe to improve the standard of care for people living with epilepsy. The VA provides a unique environment to explore the use of an online health platform to support epilepsy self-management practices,” said Patty Fritz, Vice President of Corporate Affairs for UCB. “We believe that this study follows recommendations from the Institute of Medicine Report on epilepsy to strengthen stakeholder collaboration and increase the power of patient-focused data in the pursuit of better outcomes for people living with epilepsy.”

UCB’s first research utilizing patient communities was in 2010, when it partnered with PatientsLikeMe to conduct a study of the patient-reported benefits of participating in the PatientsLikeMe epilepsy community. This survey revealed that people with epilepsy who joined PatientsLikeMe reported that they better understood their own seizures, enhanced management of side effects and improved adherence to their medications.2,3

“The POEM study was unique in that we were able to design, recruit, engage and close the study all within one year,” said Paul Wicks, PhD, Vice President of Innovation at PatientsLikeMe. “It was gratifying to see veterans with epilepsy coming together online to discuss the challenges of living with seizures. It is this kind of interaction with other patients that is a key ingredient to improving engagement and self-management of chronic conditions.”

About Epilepsy 4,5,6

Epilepsy is a chronic neurological disorder affecting approximately 65 million people worldwide and more than 2 million people in the U.S. It is the fourth most common neurological disorder in the U.S. after migraine, stroke and Alzheimer’s disease. Anyone can develop epilepsy; it occurs across all ages, races and genders and is defined as two or more unprovoked seizures.
Notes to editors

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References
3. De la Loge, C., Massagli, M., Wicks, P. PatientsLikeMe®, a data-sharing online community: benefits for patients with epilepsy. Presented at the 63rd Annual Meeting of the American Academy of Neurology (April 9-16 2011), Honolulu, USA.

About ECoE
The VA has funded the Epilepsy Centers of Excellence (http://www.epilepsy.va.gov/). The Centers of Excellence are charged with: (1) establishing a national system of care to all veterans with epilepsy, (2) educating veterans and others in their lives impacted by epilepsy about high quality epilepsy care, (3) providing health professional education and training in order to deliver the highest quality of standard of care to veterans with epilepsy, (4) utilizing national VA and other databases in order to inform providers and policy makers in Central Office about health care delivery and health policy decisions, (5) conducting state-of-the-art research about epilepsy, and (6) implementing an informatics backbone to meet the above objectives.

About UCB
UCB, Brussels, Belgium (www.ucb.com) is a global biopharmaceutical company focused on the discovery and development of innovative medicines and solutions to transform the lives of people living with severe diseases of the immune system or of the central nervous system. With more than 8500 people in approximately 40 countries, the company generated revenue of € 3.4 billion in 2013. UCB is listed on Euronext Brussels (symbol: UCB). Follow us on Twitter: @UCB_news
About UCB Research Collaborations
UCB has adopted an open innovation model in which internal and external experts collaborate to address unmet needs for people living with severe diseases of the immune system and the central nervous system. As part of its commitment to raising the standard of care for patients, UCB is building these long-term collaborations and super networks with leading researchers and institutions to use cutting-edge scientific research and technology to deliver unique patient solutions.

About PatientsLikeMe
PatientsLikeMe® (www.patientslikeme.com) is a patient network that improves lives and a real-time research platform that advances medicine. Through the network, patients connect with others who have the same disease or condition and track and share their own experiences. In the process, they generate data about the real-world nature of disease that help researchers, pharmaceutical companies, regulators, providers, and nonprofits develop more effective products, services and care. With more than 250,000 members, PatientsLikeMe is a trusted source for real-world disease information and a clinically robust resource that has published more than 40 peer-reviewed research studies. Visit us at www.patientslikeme.com or follow us via our blog, Twitter or Facebook.