



Survey reveals PatientsLikeMe® helps people with epilepsy improve seizure understanding and medication adherence

Brussels (Belgium) and Cambridge, MA (US) April 12th 2011 – 1930 CET – In a survey amongst people with epilepsy in the U.S. who have joined PatientsLikeMe®, the leading health data-sharing website for patients, respondents indicate that better seizure understanding and improved adherence are key benefits of using the site. The majority of respondents (55%) indicate a better understanding of their seizures, while one in four (27%) report improved adherence to treatment as a result of joining the PatientsLikeMe epilepsy community. When asked about their social interactions with other patients, one in three respondents (30%) said they did not know a single other person with epilepsy before joining the site; 63% of these said they were now communicating with one or more patients on the site.

The complete results from this survey of 221 epilepsy patients are being presented this week at the annual meeting of the American Academy of Neurology, in Hawaii, US (April 9th-16th). In early 2010, PatientsLikeMe and UCB first invited U.S. epilepsy patients to share their seizure experiences, symptoms and treatments through the website; there are more than 3,600 members to date. UCB receives anonymized, aggregated data from the PatientsLikeMe epilepsy community.

“The survey demonstrated that there’s a clear unmet need and that people with epilepsy want to be able to share and learn from others just like them. Having demonstrated the key benefits of the community for learning about seizures, improving social interactions and quality of life, we are pleased to support the expansion of the epilepsy community to patients outside of the U.S. and help patients find one another in the online world,” says Prof. Iris Loew-Friedrich, Chief Medical Officer, UCB.

Adds Ben Heywood, co-founder and president of PatientsLikeMe, “It’s exciting to work with a patient-centric company like UCB to help more and more patients benefit from one another. The patient voice drives much of our decision-making, such as the recent opening of the site to *all* patients with *any* condition.”



As a part of this endeavor, a safety surveillance program was established that enables UCB to collect reports of adverse events that have been associated with the use of its antiepileptic products and communicate those adverse events to the FDA. This allows UCB to better monitor its antiepileptic medicines with the overall goal of improving patient safety and compliance.

The Value of Finding “Patients Like Me”

Findings from the PatientsLikeMe and UCB research study, being presented today at the 2011 American Academy of Neurology (AAN) annual meeting, included:

- One of the greatest benefits reported by more than half (55%) of respondents was the site being considered ‘moderately’ or ‘very’ helpful for learning about their seizures*
- Nearly half (45%) of respondents found the site useful for helping them chart their seizures and 30% felt they received better healthcare from their providers as a result of recording their symptoms
- Approximately one in four respondents (27%) said the site was useful in helping them to manage a reduction in their treatment side effects. Improved recognition of side effects, better use of coping strategies, and improved reporting to clinicians were cited as possible mechanisms
- Another quarter of respondents (27%) reported improved adherence as a result of using PatientsLikeMe®, with open text responses suggesting that awareness of the consequences of non-adherence on other patients helped them to adhere to their own treatment regimen

For more information about the expansion of conditions at PatientsLikeMe®, including opening membership for people with epilepsy outside of the U.S., please go to www.patientslikeme.com.

About the Survey

Data from 221 completed questionnaires are presented. Mean age of respondents was 40 years (SD 12, range 17–72) and most were female (67%). The largest proportion of respondents had temporal lobe epilepsy (32%). Initially, 86% of users were ‘comfortable’ or ‘very comfortable’ sharing their health data online, rising to 93% at time of survey.

** Scale spanned five descriptors: very helpful; moderately helpful; a little helpful; not at all helpful and not applicable*



Reference

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.

Other PatientsLikeMe® data presented at AAN

De la Loge C, Keininger D, Isoljarvi J, Massagli MP, Wicks P. Characteristics of users of the epilepsy community PatientsLikeMe.com and comparison with a representative claims database. Presented at the 63rd Annual Meeting of the American Academy of Neurology (April 9-16 2011), Honolulu, USA.

For Further information

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About PatientsLikeMe®

PatientsLikeMe® (www.patientslikeme.com) is the world's leading online health data sharing platform. PatientsLikeMe® creates new knowledge by charting the real-world course of disease through the shared experiences of patients. While patients interact to help improve their outcomes, the data they provide helps researchers learn how these diseases act in the real world and accelerate the discovery of new, more effective treatments.

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 8 500 people in about 40 countries, the company generated revenue of EUR 3.2 billion in 2010. UCB is listed on Euronext Brussels (symbol: UCB).



Forward looking statement

This press release contains forward-looking statements based on current plans, estimates and beliefs of management. Such statements are subject to risks and uncertainties that may cause actual results to be materially different from those that may be implied by such forward-looking statements contained in this press release. Important factors that could result in such differences include: changes in general economic, business and competitive conditions, effects of future judicial decisions, changes in regulation, exchange rate fluctuations and hiring and retention of its employees.