



Anna - UCB

New survey suggests workplace stigma over epilepsy could be overcome if employers provided information and training on the world's most common chronic neurological disorder¹

- YouGov survey reveals more than one in four UK employees would be concerned about working with a colleague who had epilepsy²
- Lack of understanding and knowledge by employers and employees about how to cope with a seizure is major worry²

Slough, UK, 17 May 2016: Over a quarter (26%) of workers in Great Britain would be concerned about working with a colleague with epilepsy, according to a new nationwide YouGov survey of over 2,000 people. The majority of workers who would be concerned (63%) stated that their worry was due to having no idea about what to do to help a co-worker suffering a seizure.²

Dr Dominic Heaney, Consultant Neurologist University College London: *"I speak to patients with epilepsy every day. Apart from the challenges of finding the right anti-epileptic treatment, another important task is to preserve as far as possible the normality of their lives after epilepsy diagnosis. That means maintaining relationships with family and friends, but also their jobs and importantly, income. These survey results reinforce what I have heard from patients: discrimination in the workplace is common and often unwitting - with a lack of knowledge about epilepsy amongst the general public, what epilepsy means and doesn't mean - with people being unaware of the right actions if somebody has a seizure, or even what a seizure may look like. Much could be done. Seizures can present in many different ways, so it is important that people know how to recognise them and what to do to give the best help possible."*

Lack of awareness around epilepsy, the world's most common chronic neurological condition, is reinforced in the other survey responses, which reveal that 76% of those questioned have not been offered training on what to do if someone were to have an epileptic seizure at work.² This is despite current UK regulations stating that employers must provide their staff with the required information, instruction and training to ensure their health, and the safety of their colleagues at work.³ Further, over one in five (21%) of adults in Great Britain are unaware that epilepsy can be fatal, with only 17% claiming that they would definitely know what to do to help someone having a seizure.²

Matthew Sowemimo, Epilepsy Society Director of External Affairs and Fundraising said: *"People with epilepsy are up to twice as likely to be at risk of unemployment compared with those who don't have the condition. This problem would be reduced if there was training in place to inform people about what to do if someone had a seizure at work. People with epilepsy will feel safer and more supported within the workplace if they know that their colleagues are better informed about epilepsy. Employers may also be more confident in hiring someone with epilepsy if they had a better understanding of the condition."*

There are currently 600,000 (or one in 100) people with epilepsy in the UK⁴ and the number of cases is continuing to rise, with a prediction of a 5.8% increase by 2022.⁵ Seizures, which often occur without warning, make it difficult for patients to lead a normal life, as well as hold down a job and relationships. The economic cost of epilepsy in England & Wales is estimated at £2 billion annually, 69% of which is due to indirect costs such as unemployment and mortality.⁶

Johnny McClue, a patient who began having 'absence' seizure (short lapses of awareness lasting a few seconds) at the age of 27 said: "A lot of the seizures happened at work and that is the point at which it became difficult for my boss and other employees to deal with it. It was not that I was unconscious I would just zone out for a few minutes. I felt isolated in the workplace with no one to speak to. I was coming home from work absolutely exhausted as a result of the seizures". Over the course of the next year Johnny continued to have seizures, despite his medication. He was also made redundant from his job.

Another patient, Jasmine Smith, was 17 years-old when she was diagnosed with a brain tumour which triggered epileptic seizures. She had hoped to become a ballet dancer but was asked to leave the university where she was studying dancing. The same happened with several jobs, including cleaning, waitressing and working in a shop. Jasmine, now 25, is seizure free, and as a result of her experiences has become a nurse and is training to become an epilepsy specialist. She said: "What happened to me with epilepsy has really opened my eyes and made me appreciate being healthy and not having seizures. Being asked to leave university and losing jobs has also made me want to fight harder and to stop it happening to other people. I stumbled upon nursing by accident and epilepsy made me want to become a nurse and as it turns out I love nursing."

National Epilepsy Week takes place between 15th and 21st May 2016. It aims to help raise awareness of epilepsy and improve the lives of those affected by the condition.

For further information

Scott Fleming, Communications Director
UCB, British & Irish Isles
T: +44 770.277.7378
E: scott.fleming@ucb.com

Avril O'Connor, Brand Communications Manager
UCB, British & Irish Isles
T: 07736 120044
E: avril.oconnor@ucb.com

Hannah Stokell, Account Director
RM Eclipse
T: +44 (0)207 861 3957
E: hannah@rmeclipse.com

About epilepsy

Epilepsy is a chronic neurological disorder affecting approximately 600,000 people in the UK. Although epilepsy may be linked to factors such as health conditions, race and age, it can develop in anyone at any age.⁴

Epilepsy is considered to be a disease of the brain defined by any of the following conditions:⁷ (1) at least two unprovoked (or reflex) seizures occurring more than 24 hours apart; (2) one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years; (3) diagnosis of an epilepsy syndrome.

Partial-onset seizures (POS) specifically affect only part of the brain instead of both sides of the brain at once. Types of POS include:

- Simple partial seizures – people remain conscious and alert but may feel sensations such as tingling in the fingers
- Complex partial seizures – people lose consciousness and experience automatic dramatic movement for 15 seconds to three minutes

Secondary generalised seizures occur when both sides of the brain are affected after the initial event (a partial seizure) has already begun. These seizures generally last 1 to 3 minutes and involve the stiffening of the muscles, loss of consciousness and rapid jerking.

About the survey

A nationwide survey of 2,000 respondents was carried out by YouGov and funded by UCB. A series of 10 questions were asked that focused on general public awareness of epilepsy, as well as perceptions of the condition within the workplace. Total sample size was 2,043 adults, of which 1,159 were workers. Fieldwork was undertaken between 19th - 20th April 2016. The survey was carried out online. The figures have been weighted and are representative of all GB adults (aged 18+).

About UCB in Epilepsy

UCB has made a major contribution to improving epilepsy care and continues to work on addressing key unmet needs in epilepsy, notably drug-resistant epilepsy and disease modification. UCB aim to contribute to cutting-edge research leading to the identification of novel AED targets,⁸ and validation of mechanisms that will pave the way for future therapeutic solutions for epilepsy patients.⁹

UCB's Brivaracetam was granted European Medicines Agency (EMA) authorisation for use within Europe and the UK on 14th January 2016, specifically for the treatment of POS, with or without generalised seizures. Brivaracetam was also launched in the UK on 29th February 2016.¹⁰

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 7,700 people in approximately 40 countries, the company generated revenue of € 3.9 billion in 2015. UCB is listed on Euronext Brussels (symbol: UCB).

Forward looking statements

This press release contains forward-looking statements based on current plans, estimates and beliefs of management. All statements, other than statements of historical fact, are statements that could be deemed forward-looking statements, including estimates of revenues, operating margins, capital expenditures, cash, other financial information, expected legal, political, regulatory or clinical results and other such estimates and results. By their nature, such forward-looking statements are not guarantees of future performance and are subject to risks, uncertainties and assumptions which could cause actual results to differ materially 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, the inability to obtain necessary regulatory approvals or to obtain them on acceptable terms, costs associated with research and development, changes in the prospects for products in the pipeline or under development by UCB, effects of future judicial decisions or governmental investigations, product liability claims, challenges to patent protection for products or product candidates, changes in laws or regulations, exchange rate fluctuations, changes or uncertainties in tax laws or the administration of such laws and hiring and retention of its employees. UCB is providing this information as of the date of this press release and expressly disclaims any duty to update any information contained in this press release, either to confirm the actual results or to report a change in its expectations.

There is no guarantee that new product candidates in the pipeline will progress to product approval or that new indications for existing products will be developed and approved. Products or potential products which are the subject of partnerships, joint ventures or licensing collaborations may be subject to differences between the partners. Also, UCB or others could discover safety, side effects or manufacturing problems with its products after they are marketed.

Moreover, sales may be impacted by international and domestic trends toward managed care and health care cost containment and the reimbursement policies imposed by third-party payers as well as legislation affecting biopharmaceutical pricing and reimbursement.

References

1. World Health Organisation Media Fact Sheet. Available at: http://www.who.int/mental_health/neurology/epilepsy/en/. Accessed May 2016.
2. YouGov survey – Epilepsy in the Workplace April 2016.
3. HSE. Health and safety training for people and their employers. Available at: <http://www.hse.gov.uk/pubns/indg345.pdf>. Accessed May 2016
4. Epilepsy Action. Epilepsy facts, figures and terminology. Available at: <https://www.epilepsy.org.uk/press/facts> . Accessed May 2016.
5. Epilepsy Research UK. Number of Epilepsy Cases Predicted to Rise. Available at: <http://www.epilepsyresearch.org.uk/number-of-epilepsy-cases-predicted-to-rise/>. Accessed May 2016.
6. The Costs of Epilepsy Misdiagnosis in England & Wales. Available at: <http://www.sciencedirect.com/science/article/pii/S1059131106001634>. Accessed May 2016.
7. Bromfield EB, Cavazos JE, Sirven JI. An Introduction to Epilepsy. US National Library of Medicine. Available at: <http://www.ncbi.nlm.nih.gov/books/NBK2508/> Accessed May 2016.
8. Kaminski R.M., Gillard M. & Klitgaard H. Targeting SV2A for Discovery of Antiepileptic Drugs. Jasper's Basic Mechanisms of The Epilepsies. 4th Edition, 2012:1-12

9. Mazzuferi M., Kumar G., van Eyll J., Danis B., Foerch P. & Kaminski R.M. Nrf2 defense pathway: Experimental evidence for its protective role in epilepsy. *Ann Neurol.* 2013 74(4):560-568
10. EMA. Briviact. Available at: http://www.ema.europa.eu/ema/index.jsp?curl=pages/medicines/human/medicines/003898/human_med_001945.jsp&mid=WC0b01ac058001d124. Accessed May 2016.