



## UCB Partners in Health Economics and Outcomes Research to Evolve Solutions for Seizure Clusters

- Through collaborations with Le Bonheur Children’s Hospital, the Wisconsin Health Information Organization, and Yale University, UCB seeks to further understand the economic and clinical impacts of undertreating seizure clusters and explore drivers of better outcomes
- The impact of seizure clusters on patient and caregiver quality of life is an understudied area of epilepsy research
- The goal of the collaborations is to positively impact patients with unmet needs in uncontrolled epilepsy, including patients in need of rescue therapy

**Atlanta, Ga. August 17, 2022 – 7:00a (EST)** - UCB today announced three collaborations aimed at examining the impact of seizure clusters on patient and caregiver quality of life. The collaborations with Le Bonheur Children’s Hospital, the Wisconsin Health Information Organization (WHIO), and Yale University will uncover and leverage the power of education and real-world evidence (RWE) to address this research gap, expand awareness, and enact positive change in the health outcomes of individuals with seizure clusters.

Seizure clusters are episodes of increased seizure activity, during which two or more seizures occur within a 24-hour period. It is estimated that more than 150,000 people in the U.S. with uncontrolled epilepsy also experience seizure clusters. Due to their unpredictable nature, these disruptive events can leave those living with epilepsy feeling anxious, worried, frustrated, or isolated – further fueling a decline in mental health for this patient population.

“Our real-world evidence and educational collaborations with Le Bonheur Children’s Hospital, the Wisconsin Health Information Organization, and Yale University illustrate our desire to meaningfully contribute to how physicians, patients, and the overall care system think about and treat seizure clusters. This includes how we frame and account for the value of treatments within the healthcare ecosystem,” said Brad Chapman, Head, U.S. Epilepsy and Rare Syndromes at UCB. “We know that rescue medications that allow adults and adolescents to get back to their daily activities quickly is especially important, whether it’s in the classroom or in day-to-day life, and we are committed to delivering solutions that further this ambition.”

The project with Le Bonheur Children’s Hospital focuses on improving the lived epilepsy patient experience by developing resources designed specifically for patients and caregivers that address the importance of the proper use of rescue medications outside the hospital. This "Ask the Experts" project seeks to combat identified gaps in patient and caregiver education and information as it relates to epilepsy and more specifically seizure clusters through the development of an educational resource and a video.

"We know most seizure clusters happen at home or during other daily activities; treating seizure clusters where and when they happen is critical for better patient outcomes," said Dr. James Wheless, BScPharm, MD, FAAP, FAAN, FAES, Co-Director of the Neuroscience Institute, Le Bonheur Children’s Hospital. "As school starts





and with COVID-19 still a medical concern, it's of the utmost importance that we prepare students to successfully start their school year with a seizure action plan and appropriate rescue medications so they can prepare their teachers and school nurses to act when the cluster starts."

The collaboration with WHIO aims to understand the economic and clinical impact of undertreating seizure clusters and to explore drivers of better outcomes. This project will analyze retrospective claims at a state level to examine prescribing trends, healthcare utilization, costs, access barriers, and disease prevalence.

Dr. George Morris, MD, MPH, FAAN, FAES, epileptologist in the Milwaukee-area, and valued partner in the WHIO Project, explains, "Epilepsy's impact on a person's health and their quality of life is significantly affected by seizure clusters. The health risk from aspiration and terrifying experience of the patient, family, and friends is unique to epilepsy. This project uses a unique data source to see the comprehensive effects across nearly all Wisconsin patients. We are excited to know what factors may help reduce seizure clusters to inform providers and patients about best practices."

The Yale University Project, Reduction of Seizures through Education and Support (ROSES), aims to increase understanding of seizure cluster management, to contribute new insights to clinical management and patient-centric care, and improve overall epilepsy quality care. Specifically, this study is designed to assess the impact of seizure rescue medications, treatment patterns, healthcare resource utilization, clinic quality improvement tools (i.e., Seizure Action Plans), and the patient/caregiver experience.

### **About Epilepsy<sup>1-4</sup>**

Epilepsy is a chronic neurological disorder of the brain. It is the fourth most common neurological condition worldwide and affects approximately 65 million people. In the U.S. more than 3.4 million people have epilepsy. Anyone can develop epilepsy; it occurs across all ages, races and genders, and is defined as one or more unprovoked seizures with a risk of further seizures.

### **About Seizure Clusters<sup>5-10</sup>**

Of the one third of patients living with uncontrolled epilepsy, it is estimated that more than 150,000 people in the U.S. with refractory epilepsy also experience seizure clusters. Seizure clusters are broadly defined as acute episodes of consecutive seizures that occur within a short period of time with a patient regaining consciousness during the interictal period. These clusters are also distinguishable from a person's typical seizure pattern. Other names for seizure clusters include acute-repetitive seizures (ARS), serial seizures, crescendo seizures, and seizure flurries, which highlight the repetitive nature of the seizures. Seizure clusters are a form of seizure emergency that can evolve into prolonged seizures or status epilepticus.

### **About UCB in Epilepsy**

UCB has a rich heritage in epilepsy with over 20 years of experience in the research and development of anti-epileptic drugs. As a company with a long-term commitment to epilepsy research, our goal is to address unmet medical needs. Our scientists are proud to contribute to advances in the understanding of epilepsy and its treatment. We partner and create super-networks with world-leading scientists and clinicians in academic institutions, pharmaceutical companies, and other organizations who share our goals. At UCB, we are inspired by patients, and driven by science in our commitment to support patients with epilepsy.

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## About UCB

UCB, Brussels, Belgium ([www.ucb.com](http://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 approximately 8,600 people in approximately 40 countries, the company generated revenue of €5.8 billion in 2021. UCB is listed on Euronext Brussels (symbol: UCB). Follow us on Twitter: @UCBUS.A.

## Forward looking statements

This press release may contain forward-looking statements including, without limitation, statements containing the words “believes”, “anticipates”, “expects”, “intends”, “plans”, “seeks”, “estimates”, “may”, “will”, “continue” and similar expressions. These forward-looking statements are based on current plans, estimates and beliefs of management. All statements, other than statements of historical facts, are statements that could be deemed forward-looking statements, including estimates of revenues, operating margins, capital expenditures, cash, other financial information, expected legal, arbitration, political, regulatory or clinical results or practices and other such estimates and results. By their nature, such forward-looking statements are not guarantees of future performance and are subject to known and unknown risks, uncertainties and assumptions which might cause the actual results, financial condition, performance or achievements of UCB, or industry results, to differ materially from those that may be expressed or implied by such forward-looking statements contained in this press release. Important factors that could result in such differences include: the global spread and impact of COVID-19, changes in general economic, business and competitive conditions, the inability to obtain necessary regulatory approvals or to obtain them on acceptable terms or within expected timing, 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, safety, quality, data integrity or manufacturing issues; potential or actual data security and data privacy breaches, or disruptions of our information technology systems, product liability claims, challenges to patent protection for products or product candidates, competition from other products including biosimilars, 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. There is no guarantee that new product candidates will be discovered or identified in the pipeline, will progress to product approval or that new indications for existing products will be developed and approved. Movement from concept to commercial product is uncertain; preclinical results do not guarantee safety and efficacy of product candidates in humans. So far, the complexity of the human body cannot be reproduced in computer models, cell culture systems or animal models. The length of the timing to complete clinical trials and to get regulatory approval for product marketing has varied in the past and UCB expects similar unpredictability going forward. Products or potential products, which are the subject of partnerships, joint ventures or licensing collaborations may be subject to differences disputes between the partners or may prove to be not as safe, effective or commercially successful as UCB may have believed at the start of such partnership. UCB’s efforts to acquire other products or companies and to integrate the operations of such acquired companies may not be as successful as UCB may have believed at the moment of acquisition. Also, UCB or others could discover safety, side effects or manufacturing problems with its products and/or devices after they are marketed. The discovery of significant problems with a product similar to one of UCB’s products that implicate an entire class of products may have a material adverse effect on sales of the entire class of affected products. Moreover, sales may be impacted by international and domestic trends toward managed care and health care cost containment, including pricing pressure, political and public scrutiny, customer and prescriber patterns or practices, and the reimbursement policies imposed by third-party payers as well as legislation affecting biopharmaceutical pricing and reimbursement activities and outcomes. Finally, a breakdown, cyberattack or information security breach could compromise the confidentiality, integrity and availability of UCB’s data and systems.

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