



For Immediate Release

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Raise Your Hand to Support People with Rare Diseases

Lundbeck drives rare disease awareness and research with a month-long fundraiser leading up to Rare Disease Day 2012

Generate a big show of hands by visiting www.rarediseaseday.us and clicking the “Raise Your Hand” icon – then share with friends via Facebook and Twitter

DEERFIELD, Ill. February 2, 2012 – Today, Lundbeck announced its third annual *Raise Your Hand to Fight Rare Diseases* campaign in support of Rare Disease Day, a worldwide observance on February 29 to increase awareness of rare diseases. When an individual clicks the *Raise Your Hand* icon posted on the National Organization for Rare Disorders (NORD) Rare Disease Day website (www.rarediseaseday.us), Lundbeck will make an unrestricted donation to NORD’s general research fund.

“There is limited funding available to support research on the nearly 7,000 rare diseases affecting nearly 30 million Americans,”¹ said Peter L. Saltonstall, NORD president and CEO. “We are very pleased to partner with Lundbeck for the third year of the *Raise Your Hand* campaign. With Lundbeck’s donations to our general research fund over the past two years, we’ve been able to initiate studies for Stiff-Person Syndrome and Systemic Sclerosis, two severe and very rare disorders.”

Lundbeck’s 2010 donation supported a study by Eric Lancaster, MD, for Stiff-Person Syndrome (SPS), a rare, acquired neurological disorder² believed to affect fewer than one in 1 million people.³ Results are expected to be released early this year with the hope of decreasing the time to reach a diagnosis of SPS. Lundbeck’s 2011 donation supports a study of systemic sclerosis, a rare autoimmune disorder affecting an estimated 49,000 people in the U.S.⁴ This disease causes damage to the skin, but also involves the tissues beneath, blood vessels, and major organs such as the intestines, lungs, heart, and kidneys.⁴ Led by Silvia Laura Bosello, MD, the study is aimed at improving the identification of abnormal B-cells and administering medications that are known to positively affect the production of B-cells.

“Lundbeck is proud to contribute funding to help advance this important research. Our focus on making a difference for patients, no matter how complex the condition, is what drives us at Lundbeck every day,” said Staffan Schüberg, president of Lundbeck. “Our continued partnership with NORD reflects our overall efforts to push forward research and innovation that can have a positive impact on patients, families and caregivers.”

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Lundbeck is doing all it can to provide support today while driving research and innovation for patients with challenging neurologic and psychiatric conditions. In the last three years, Lundbeck has introduced three therapies for rare central nervous system (CNS) disorders, including ONFI™ (clobazam), which became available in January and is approved as add-on treatment of seizures associated with Lennox-Gastaut Syndrome (LGS) in people 2 years of age and older. Currently, the company has numerous CNS compounds in development, including several in late-stage clinical trials.

In addition to epilepsy, Lundbeck has invested significant resources toward Huntington's disease (HD), another rare CNS disorder, through community-based programs and its HD Research Initiative. This research is driven by collaborations with academic institutions and companies, with the goal of identifying and ultimately commercializing therapies that may slow or halt the progression of HD.

About Rare Diseases

There are approximately 7,000 rare diseases or conditions affecting an estimated 30 million Americans,¹ though the number of individuals confronting any one of these disorders can be quite small. In the United States, rare diseases, also referred to as "orphan conditions," are generally defined as diseases that affect fewer than 200,000 Americans.¹ Compared to individuals with more common disorders, those with rare diseases often face greater challenges such as difficulty in finding medical experts, delay in receiving an accurate diagnosis, and access to few, if any, treatment options.¹

About Rare Disease Day

Rare Disease Day is an annual event observed worldwide on the last day of February each year. The purpose of the day is to raise awareness of rare diseases as a public health issue and bring together patients and families with rare diseases to discuss the need for greater awareness, more research, and better access to diagnosis and treatment.¹ Rare Disease Day was first launched in 2008 in Europe by the European Rare Disease Organization, EURORDIS, a sister organization to NORD. In 2009, other countries throughout the world joined EURORDIS to observe the day.⁵ NORD, which represents the nearly 30 million Americans affected by rare diseases,¹ is the sponsor of Rare Disease Day in the United States. To learn more about Rare Disease Day 2012, please visit www.rarediseaseday.us, or visit Facebook and become a fan of Rare Disease Day US.

About ONFI™ (clobazam)

ONFI is an oral antiepileptic drug developed in the United States by Lundbeck, and is available at retail pharmacies in 5 mg, 10 mg, and 20 mg tablets. ONFI (pronounced "ON-fē") is a federally controlled schedule four substance (C-IV). ONFI is a 1,5 benzodiazepine. The exact mechanism of action for ONFI is not fully understood, but is thought to involve potentiation of GABAergic neurotransmission resulting from binding at the benzodiazepine site of the GABA_A receptor.⁶

For more information, please visit www.onfi.com.

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Important Safety Information⁶

- **ONFI can make you sleepy or dizzy and can slow your thinking and make you clumsy which may get better over time.** Do not drive, operate heavy machinery, or other dangerous activities until you know how ONFI affects you. Do not drink alcohol or take other drugs that may make you sleepy or dizzy while taking ONFI without first talking to your healthcare provider as your sleepiness or dizziness may get much worse.
- **ONFI can cause withdrawal symptoms.** Do not suddenly stop taking ONFI without first talking to a healthcare provider. Stopping ONFI suddenly can cause seizures that will not stop (status epilepticus), hearing or seeing things that are not there (hallucinations), shaking, nervousness, and stomach and muscle cramps.
- **ONFI can be abused and cause dependence.** Physical dependence is not the same as drug addiction. Talk to your healthcare provider about the differences. **ONFI is a federally controlled substance (C-IV) because it can be abused or lead to dependence.**
- **Like other antiepileptic drugs, ONFI may cause suicidal thoughts or actions in a very small number of people, about 1 in 500.** Call your healthcare provider right away if you have any symptoms, especially sudden changes in mood, behaviors, thoughts, or feelings, and especially if they are new, worse, or worry you.
- Tell your healthcare provider about all of your medical conditions including liver or kidney problems, lung problems (respiratory disease), depression, mood problems, or suicidal thoughts or behavior.
- If you are pregnant or plan to become pregnant, ONFI may harm your unborn baby. You and your healthcare provider will have to decide if you should take ONFI while you are pregnant.
- ONFI can pass into breast milk. You and your healthcare provider should decide if you should take ONFI or breast feed. You should not do both.
- Tell your healthcare provider about all the medicines you take including prescription and nonprescription medicines, vitamins and herbal supplements as taking ONFI with certain other medicines can cause side effects or affect how well they work. ONFI may make your birth control medicine less effective. Talk to your healthcare provider about the best method to use.
- The most common side effects seen in ONFI patients include: sleepiness; drooling; constipation; cough; pain with urination; fever; acting aggressive, being angry or violent; difficulty sleeping; slurred speech; tiredness; and problems with breathing.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

For more information, please see the [ONFI Medication Guide](#) and [Full Prescribing Information](#).

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About Lundbeck in the U.S.

Lundbeck in the U.S., headquartered in Deerfield, Illinois, is a wholly-owned subsidiary of H. Lundbeck A/S in Denmark. Lundbeck is dedicated to providing innovative specialty therapies that fulfill unmet medical needs of people with central nervous system (CNS) disorders, including rare diseases. Lundbeck is a member of the National Organization for Rare Disorders Corporate Council.⁷

For more information, visit www.lundbeckus.com or follow us on Twitter at [@LundbeckInc](https://twitter.com/LundbeckInc).

About Lundbeck

H. Lundbeck A/S (LUN.CO, LUN DC, HLUKY) is an international pharmaceutical company highly committed to improving the quality of life for people suffering from brain disorders. For this purpose, Lundbeck is engaged in the research, development, production, marketing and sale of pharmaceuticals across the world. The company's products are targeted at disorders such as depression and anxiety, schizophrenia, insomnia, epilepsy, and Huntington's, Alzheimer's and Parkinson's diseases.

Lundbeck was founded in 1915 by Hans Lundbeck in Copenhagen, Denmark. Today Lundbeck employs approximately 5,900 people worldwide. Lundbeck is one of the world's leading pharmaceutical companies working with brain disorders. In 2010, the company's revenue was DKK 14.8 billion (approximately EUR 2.0 billion or USD 2.6 billion). For more information, please visit www.lundbeck.com.

ONFI is a trademark of Lundbeck.

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Sources

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