



**For Immediate Release**

**CONTACT:**

NORD: Mary Dunkle  
(203) 744-0100

Lundbeck Inc.: Sally Benjamin Young  
(847) 282-5770

**National Organization for Rare Disorders Awards Grant to  
Support Research in Stiff-Person Syndrome**

*Research funding for this rare neurological disorder is made possible  
through Lundbeck Inc.'s "Raise Your Hand to Support Rare Diseases" campaign*

Danbury, Conn., January 11, 2011 – The National Organization for Rare Disorders (NORD) has awarded a research grant for the study of stiff-person syndrome, a rare acquired neurological disorder,<sup>1</sup> to Eric Lancaster, MD, PhD of the University of Pennsylvania. The study is titled, "Auto-Antigen Profiling in Stiff-Person Syndrome." This grant is made possible through funds contributed by Lundbeck Inc. in connection with a special program conducted in the month leading up to Rare Disease Day in 2010. Specifically, Lundbeck conducted a web-based campaign, "*Raise Your Hand to Fight Rare Diseases*," an initiative for Rare Disease Day 2010 that led the company to donate \$10,000 to NORD's general research fund.

Stiff-person syndrome (SPS) is characterized by fluctuating muscle rigidity in the trunk and limbs and a heightened sensitivity to stimuli such as noise, touch, and emotional distress, which can set off muscle spasms.<sup>2</sup> The exact prevalence of SPS is unknown, although the incidence is believed to be approximately 1 in 1,000,000 individuals in the general population.<sup>1</sup> Women are affected twice as often as men.<sup>2</sup> Scientists don't yet understand what causes SPS, but research indicates that it is the result of an autoimmune response gone awry in the brain and spinal cord.<sup>2</sup>

"Imagine being afraid for your child to spontaneously hug you, or to be greeted by a neighbor, step from a curb, or even leave your house, because of the fear of painful muscle spasms and potentially serious falls. Paralyzing fear and self-induced isolation become your constant companions," said Debra Richardson. "I was diagnosed with SPS in 1994. NORD was my first contact. I am encouraged to know that there are scientists who are interested in this very rare disease and that NORD is able to fund the research."

"There has been limited research on stiff-person syndrome so we were quite pleased when our medical advisory committee granted Dr. Lancaster the award," said Peter L. Saltonstall, NORD president and CEO. "Lundbeck's contribution towards our general research fund was much appreciated and made possible this award that supports a very worthy cause."

Lundbeck introduced the *Raise Your Hand to Fight Rare Diseases* campaign in February 2010 in recognition of National Rare Disease Day. The web-based initiative was designed to generate support for people with rare disorders and engage the community in raising awareness and research support. In response to individuals clicking an icon on NORD's Rare Disease Day website ([www.rarediseaseday.us](http://www.rarediseaseday.us)), Lundbeck made a donation to a general research fund managed by NORD. During the 21-day campaign, more than 4,100 people clicked the icon and hundreds encouraged others to participate in Rare Disease Day by sharing the information through Facebook and Twitter.

"Lundbeck is very pleased to know that our donation through the *Raise Your Hand* campaign will fund research for this very challenging disease," said Mark Weinberg, vice president in medical affairs at Lundbeck Inc. "Through our work in rare diseases, we've come to appreciate the hardships faced by these communities of patients and the value of research for even the rarest diseases. With Rare Disease Day 2011 around the corner, we look forward to making another meaningful donation through this same campaign."

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#### About Rare Diseases

There are approximately 7,000 rare diseases or conditions affecting an estimated 30 million Americans, though the number of individuals confronting any one of these disorders can be quite small. Individuals with rare diseases often face challenges that occur less frequently with more common disorders, including difficulty in finding medical experts, delay in receiving an accurate diagnosis, and access to few, if any, treatment options. In the United States, rare diseases, also referred to as "orphan diseases", are generally defined as diseases that affect fewer than 200,000 individuals in the United States. To learn more about SPS, visit [www.rarediseases.org](http://www.rarediseases.org).

#### 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. 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. NORD is the sponsor of Rare Disease Day in the United States. To learn more about Rare Disease Day 2010 in the United States, please visit [www.rarediseaseday.us](http://www.rarediseaseday.us), or visit Facebook and become a fan of Rare Disease Day US.

#### About NORD

The National Organization for Rare Disorders (NORD) represents the nearly 30 million Americans affected by rare diseases. Founded in 1983, NORD is a non-profit organization providing programs of education, advocacy, research, and patient services. NORD administers patient assistance programs to help uninsured or under-insured individuals obtain medications they could not otherwise afford. It also provides information to patients and their families, research grants and fellowships, and advocacy on important public policy issues. Follow NORD at [www.rarediseases.org](http://www.rarediseases.org) and on Twitter at @RareDiseases.

#### About Lundbeck Inc.

Headquartered in Deerfield, Illinois, Lundbeck Inc., a wholly-owned subsidiary of H. Lundbeck A/S, is committed to providing innovative specialty therapies that fulfill unmet medical needs of people with central nervous system (CNS) disorders, including rare diseases for which few, if any, effective treatments are available. For more information, please visit [www.lundbeckinc.com](http://www.lundbeckinc.com).

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#### Sources

1. Stiff-person syndrome.

[http://www.rarediseases.org/search/rdbdetail\\_abstract.html?disname=Stiff%20Person%20Syndrome](http://www.rarediseases.org/search/rdbdetail_abstract.html?disname=Stiff%20Person%20Syndrome) Last accessed 12/20/2010.

2. Stiff-Person Syndrome. <http://www.ninds.nih.gov/disorders/stiffperson/stiffperson.htm> Last accessed 12/20/2010