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"UNVEIL" Survey Reveals a Life Interrupted by Lupus

Results Show How Disease Takes a Toll on Life for People With Lupus and Lupus Caregivers

WASHINGTON, Sept. 16, 2014 /PRNewswire/ -- The Lupus Foundation of America and Eli Lilly and Company (NYSE: LLY) today released results from UNVEIL: understanding the impact of lupus, a new survey that sheds light on the lupus journey and the challenges not only for those living with lupus, but also for lupus caregivers. The UNVEIL study, which involved over 1,000 people with lupus and lupus caregivers highlights the devastating impact lupus has on all aspects of life including family, work, finances, treatment experiences and overall quality of life.

"Throughout the course of their disease, people with lupus experience significant symptoms such as pain, fatigue, depression, cognitive issues and physical impairment that impact every facet of life," explains Sandra Raymond, president and chief executive officer of the Lupus Foundation of America. "Despite these devastating complications, lupus can be hard for others to see because there may be no visible symptoms. The UNVEIL survey provides the public an opportunity to see how life can be interrupted by lupus and why we need everyone's help to fight this cruel disease."

Survey Findings

The Lupus Journey Often Begins With a Long, Complicated Path to Diagnosis

- On average, it takes nearly six years for people with lupus to be diagnosed from the time they first notice their lupus symptoms.
- A majority of people with lupus surveyed (63 percent) report being incorrectly diagnosed. Of those reporting incorrect diagnosis, more than half of them (55 percent) report seeing four or more different health care providers for their lupus symptoms before being accurately diagnosed.

The Severe Impact of Lupus Proves a Challenge to Treat

- On average, people with lupus surveyed take nearly eight prescription medications to manage all their medical conditions including lupus.
- Of the 23 percent of people with lupus who experience severe lupus flares all or most of the time over the last three months, 40 percent were admitted to the hospital at least once during the past 12 months, with an average stay of 10.5 days.

Lupus Interrupts Every Facet of Life **Work-life**

- For the majority of people with lupus surveyed (89 percent), lupus impacts their work life.
- More than half (55 percent) of people with lupus surveyed whose work is affected are working part-time, intermittently or are unemployed because of lupus.
- Almost three-quarters (74 percent) of caregivers report that caring for someone with lupus has an impact on their work productivity.
- A large proportion (41 percent) of caregivers surveyed are only able to work part-time or intermittently, or are unemployed, with nearly half (45 percent) of those indicating caregiving responsibilities being the reason. In addition, 60 percent note they spend 16 or more hours per week helping loved ones with lupus.

Family-life/Daily Living

- More than 75 percent of caregivers surveyed help a loved one with lupus with daily activities, such as cooking, shopping, household chores and providing financial help.
- Eighty-four percent of people with lupus surveyed indicate they feel they are a burden to their family and friends due to their inability to perform daily activities. In addition, 94 percent indicate that lupus interferes with their ability to enjoy life.
- Nearly three in four people with lupus surveyed (76 percent) said fatigue limits their ability to participate in social activities. For caregivers, nearly half surveyed (49 percent) replied that caregiving responsibilities impact their ability to socialize with friends.

Mental Health

- The majority of people with lupus surveyed feel anxious (90 percent) and depressed (85 percent) due to their lupus.
- More than 94 percent of caregivers surveyed experience increased anxiety and stress in relation to their caregiving, worrying that their loved one with lupus will become sicker.

"Lupus goes well beyond joint pain and fatigue. For me, it has derailed my life and impacted not only me but everyone around me," said Wendy Rodgers, a California woman living with lupus. "Initiatives like this take us one step closer to helping the public better understand the needs of people with lupus, as well as those who care for loved ones with the disease. The more people know about lupus, the better support there will be for those living with the disease and the sooner we can conquer it."

UNVEIL life's interruptions with lupus. To learn more, visit lupus.org/UNVEIL.

About Lupus

Lupus is an unpredictable and misunderstood autoimmune disease that ravages different parts of the body. It is difficult to diagnose, hard to live with and a challenge to treat. Lupus is a cruel mystery because it is hidden from view and undefined, has a range of symptoms, strikes without warning, and has no known cause and no known cure. Its health effects can range from a skin rash to a heart attack. Lupus is debilitating and destructive and can be fatal, yet research on lupus remains underfunded relative to diseases of similar scope and devastation. For more information, visit lupus.org.

About the Survey

The survey was conducted online by ICON Commercialization & Outcomes on behalf of the Lupus Foundation of America and Eli Lilly and Company between February and March 2014. A total of 827 people with lupus and 253 lupus caregivers completed the survey.

About the Lupus Foundation of America

The Lupus Foundation of America is the only national force devoted to solving the mystery of lupus, one of the world's cruelest, most unpredictable and devastating diseases, while giving caring support to those who suffer from its brutal impact. Through a comprehensive program of research, education, and advocacy, the Foundation leads the fight to improve the quality of life for all people affected by lupus. Learn more about lupus, the [Lupus Science & Medicine Journal](http://lupus.org) and the Lupus Foundation of America at lupus.org. For the latest news and updates, follow us on [Twitter](https://twitter.com/lupus) and [Facebook](https://www.facebook.com/lupus).

About Eli Lilly and Company

Lilly is a global healthcare leader that unites caring with discovery to make life better for people around the world. We were founded more than a century ago by a man committed to creating high-quality medicines that meet real needs, and today we remain true to that mission in all our work. Across the globe, Lilly employees work to discover and bring life-changing medicines to those who need them, improve the understanding and management of disease, and give back to communities through philanthropy and volunteerism. To learn more about Lilly, please visit us at www.lilly.com and <http://newsroom.lilly.com/social-channels>.

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