Despite the devastating impact lupus has on more than 1.5 million Americans each year, awareness about the disease remains very low.

We’re on a mission to unveil the lives interrupted by lupus

In partnership with Eli Lilly and Company, we are proud to presents results of a new survey, UNVEIL: UNDERSTANDING THE IMPACT OF LUPUS, focusing on the lupus journey and the challenges faced not only by those living with lupus, but also for lupus caregivers.

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 healthcare 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 3 in 4 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.

The public needs to better understand the challenges people with lupus and caregivers face on a daily basis. The more we know, the better we can support those living with lupus and the sooner we can conquer this mysterious and devastating disease.

Help us UNVEIL life’s interruptions by lupus! Learn more at www.lupus.org/UNVEIL.