Patient Perspective: Christine Sperling

At the age of 19, I experienced debilitating joint pain, severe fatigue, an unexplained rash, and a critically low platelet count. After several months of uncertainty, I was diagnosed with systemic lupus erythematous (lupus) in the 1980s. At that time, information about this complex autoimmune condition was limited, and as a young woman in my first year of university, I had many unanswered questions. I wondered how lupus would affect my education, career aspirations, relationships, and overall quality of life. Sometime later, I was also diagnosed with antiphospholipid syndrome (APS) and immune thrombocytopenia (ITP).

Over the years, I have experienced a wide range of symptoms, from mild flares to life-threatening complications requiring hospitalizations, surgeries, blood transfusions, and ongoing treatments. These experiences have significantly shaped my daily life and long-term decisions about my career and personal life. Although I faced high-risk pregnancies and complications related to this, I was fortunate to have two healthy children. Despite the many challenges of living with lupus, becoming a mother has been the most rewarding and fulfilling part of my life. My family has continually been a source of strength, joy, and purpose, even during the most difficult times in my health journey.

Recognizing the importance of understanding my condition, I actively sought to educate myself about lupus, its treatment options, and emerging research. This led me to participate in various research projects as a patient, which eventually opened the door to a more formal role. About five years ago, I was invited to join a research team as a patient partner. Since then, I have had the privilege of contributing my lived experience to inform and support the development of meaningful, patient-centered research. I am also a member of the Canadian Venous Thromboembolism Research Network (CanVECTOR) Patient Partner Council, which focuses on research related to venous thromboembolism (VTE).

Living with lupus has had a profound impact on my life. As both a patient and a patient partner, I aim to share perspectives on symptoms, treatment, and access to information. Through my collaboration with researchers, I am helping to ensure that research is more reflective of patient realities and supports better awareness, education, and outcomes for individuals living with lupus.

I am thankful to the incredible researchers who have engaged me as a patient partner and recognized the value of my lived experience in informing study design, improving relevance, and helping to guide research that improves outcomes for those living with lupus.

Ultimately, my goal is to contribute to research in a way that advances care and improves the lives of those affected by this challenging disease.

Christine Sperling
Patient Partner in Medical Research
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Christine Sperling pictured here with her children, Natasha and Sasha.