The Johns Hopkins Stiff Person Syndrome Center

Stiff Person Syndrome Research Foundation Philanthropic Impact Report

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The **Johns Hopkins Stiff Person Syndrome Center**, led by Dr. Scott Newsome, offers patient education, symptom management and hope for the future for people with this rare disorder. Our multi-specialty team includes experts in neurology, immunology, ophthalmology, neuromuscular disease and related fields. With access to one of the largest databases of stiff person syndrome (SPS) biomarkers, our team works to advance the understanding of this disease and leads the way toward more effective treatments.

As defined by the National Institutes of Health, **biomarkers** are characteristics that can be objectively measured and used as an indicator of normal biological processes, disease processes, or pharmacologic responses to a therapy. Biomarkers are important for the clinical management of a disease, as well as the development of therapeutic interventions, and can be detected through a variety of tests and procedures. There are a variety of types, including susceptibility/risk, diagnostic, monitoring, prognostic, predictive, pharmacodynamic (response), and safety biomarkers.

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The generosity of the **Stiff Person Syndrome Research Foundation** (SPSRF), along with grateful patients and other individuals, has facilitated our work investigating which parts of the immune system are abnormal in SPS and exploring markers of neurological injury.

Early evaluations have found evidence of an elevated protein - B-cell activating factor (BAFF) - that is important for select immune cell survival and activation. In a separate study, a marker of central nervous system injury was detected. Taken together, these studies have identified biomarkers that provide insight into the abnormal immune system in SPS as well as the downstream effect with neuronal injury. These biomarkers could be used in a clinical trial to assess response to treatment.

Preliminary data from these investigations are currently being analyzed, and one or more manuscript will be prepared. When published, we look forward to sharing these articles with the SPSRF. Furthermore, we are currently discussing how we might leverage this important information in future studies. Philanthropy will continue to play a critical role in this work, and could accelerate its pace with the addition of a member of the research team in a research coordinator, laboratory tech, or SPS-focused clinical and research fellow.

THANK YOU for your loyal support of our work!