

Spastic Paraplegia Foundation 6952 Clayborne Drive O'Fallon, MO 63368-6202

> Phone: (877) 773-4483 SP-Foundation.org

> > November 7, 2023

Dear SPF Supporter

We have much EXCITING NEWS to share with you! First, our anonymous donors will match your gift to the Spastic Paraplegia Foundation, dollar for dollar up to \$300,000, for donations received before January 15, 2024!

Your donation is <u>appreciated</u>, <u>important</u>, and <u>vital</u> because the research you are sponsoring is making amazing progress! As you may have heard, nine Spastic Paraplegia - Centers of Excellence are being set up all over the United States. A large group of expert neurologists, collaborating with the Spastic Paraplegia Foundation, are working together with HSP and PLS patients all over the US. They will collect information and samples from patients to get us closer to beginning clinical trials on several very promising new drugs.

The Spastic Paraplegia Foundation uses your donations to support the top-ranked research proposals by awarding grants to help research HSP and PLS. We are receiving more and more research proposals that our expert Scientific Advisory Board objectively rank. However, there are proposals that are not funded because of our lack of funds to support them. With every proposal, scientists and investigators continue to search for knowledge and advancements. As researchers make new discoveries or learn more about the possible causes of our diseases, it is vitally important to continue that research to the next discovery, until we find that treatment or cure that significantly improves our lives.

Several researchers are working on genetic engineering, using new, exciting, state of the art techniques. One is generating nerve cells from children with HSP. Another is discovering how regulating mitochondria can benefit people with HSP. Many are working on specific HSP genes so people with those gene mutations will be able to see relief.

Another scientist is specifically studying how HSP nerve damage takes place with the hopes of preventing or reversing that process. Another scientist has put together a thorough group of PLS biomarkers which is imperative for the Clinical Trial process that could soon begin for other very promising drugs.

Your tax-deductible gift is being multiplied in other ways too. First, the Spastic Paraplegia Foundation is a 21-year-old, well respected, patient advocacy organization that carefully scrutinizes how we spend your donations. Our volunteer Scientific Advisory

Board of world-renowned neurological experts compassionately donate their time and expertise to rank the many outstanding research proposals. Only the top ranked "Excellent and Very Promising" proposals are funded. Second, when the U.S. National Institute of Health (NIH) discovers that SPF has sponsored a particular researcher, that researcher's credentials will garner more respect for future work with NIH. The NIH may then sponsor them in ways that far exceed the funded proposals for SPF. Third, there are many people that put in countless hours working for the Spastic Paraplegia Foundation as volunteers. That's right, they don't cost you a dime. We have a first-rate attorney and a CPA working probono. We also have a professional writer, a PhD in genetics, a judge, plus many more well educated, experienced volunteers - all donating their time and talents so your donation can work even harder for what you believe in - finding a cure or treatment for HSP and PLS.

During the past year, scientific discoveries concerning HSP and PLS were being announced every three days. That's right - twice weekly! The pace is very exciting, keeps us on the edge of our seats and it demands to be paid for. We are getting ever closer to the day when the focus will change from finding the cause of these disorders to having real life ways that our friends and loved ones with HSP and PLS can be free of pain and stiffness and actually WALK NORMAL!

Like me, I know you must feel disheartened that SPF can't afford to support all of the highly ranked research. Scientists are then forced to work on research in other diseases since we cannot afford to support their proposals. Think of what could happen if we could fund more of these highly ranked proposals. What doors could we open? How much suffering could we stop? Every donation is vitally important. Your donation of just the cost of going out to the movies - \$25 - will be doubled to \$50. \$250 will be doubled to \$500, \$500 to \$1,000, and \$10,000 to \$20,000. I challenge you to use every nickel of this match! Our anonymous donors are asking you to stretch your gift this year. What power for good this gives you! You really will make a difference!

There has never been a better time, but time is of the essence. Our anonymous donors have understandably set a deadline of January 15th, 2024. I can't thank you enough for your generosity. Please send your tax-deductible contribution today!

Sincerely,

Gree Pruitt

President, Spastic Paraplegia Foundation

P.S. Please take time to review the enclosed *Synapse*, which includes important information and photos from the 2023 Annual Conference, the Year-Giving Campaign, and Giving Tuesday November 28, 2023.