

<u>https://sp-foundation.org</u> jowestbrook@gmail.com ● john.cobb@sp-foundation.org

Who We Are

The Spastic Paraplegia Foundation (SPF) was created in 2002 as a non-profit health organization. Our goals are:

- to fund research into the causes, therapies, and cures for hereditary spastic paraplegia (HSP) and primary lateral sclerosis (PLS),
- to provide educational materials, conferences and gatherings for people affected by these disorders, and
- to foster support among the patients and families affected by these disorders.

Our goal will be reached when all those with HSP and PLS are diagnosed, treated, and cured. With our research grant program, we strive to help make that day a reality.

Research Grants

Grants up to \$75,000 per year will be awarded for one and two-year proposals. (Maximum grant of \$150,000 over two years.) Proposals on any aspect of hereditary spastic paraplegia (HSP) or primary lateral sclerosis (PLS) will be considered.

Research grants may provide "seed monies" to assist investigators with new ideas, early or pilot phases of studies, or as supplemental support in ongoing investigations. We anticipate that early studies funded by the SPF will develop into projects that can successfully attract future funding from other sources.

We encourage everyone who may apply for a grant to examine the list of previously funded proposals at https://sp-foundation.org/research/research-impact.html.

Separate PLS and HSP Grants

The SPF intends to invest approximately the same amount of money in funding PLS proposals as we will on HSP proposals. Proposals dealing with PLS will therefore not compete with proposals for HSP. As a result, the SPF could fund a PLS proposal even though it is ranked lower than an HSP proposal that did not receive funding (and visa versa).

Publicity and Confidentiality

Your grant application is considered confidential and will be released only to members of the SPF Scientific Advisory Board, the Research Grant Committee, and the Board of Directors.

If your grant is selected to receive funding, the title and the name of the principal investigator and his/her institution will be published on our website, newsletter, annual report and wherever else the SPF feels is appropriate. We request that each grant application include a title understandable by the lay public. We may also contact the recipients of funding to solicit more information about their research that can be communicated to the foundation's community of patients and families. Communicating the impact of the research that is funded is critical to our fundraising efforts and community engagement.

Grant recipients are highly encouraged to provide information and patient samples collaboratively to other researchers in the field.

Application Procedure

Proposal Contents:

- 1. The formal title of the proposal, and a second, modified title that is understandable to the lay public and will be used by the SPF for public relations and publicity purposes.
- 2. Research target (HSP, PLS or both). Note that a proposal concerning the genetic aspects of PLS will be considered a PLS proposal, not a complicated HSP proposal.
- 3. Specific goals. Briefly indicate what specific aim(s) the research proposed in the application intends to accomplish.
- 4. Background and significance.
- Research design and methods. Describe techniques and scientific approach. Include a brief description of the statistical approach, and if applicable, power or sample size calculations.
- 6. Facilities available and budget. Do not include indirect costs, equipment or conference expenses, or PI salary. All amounts must be in US dollars.
- 7. Criticality of SPF funding for your proposed project.
- 8. SPF grant recipients are encouraged to collaborate and share data and/or patient samples with other SPF grant recipients. Your proposal should state if, when and how the knowledge gained in the performance of research under the proposed grant will be shared.
- 9. Curriculum vitae/biographical sketch and bibliography.

Proposal Page Limit

Proposals shall be no more than 8 pages long (excluding CV/ bio sketch and bibliography).

Proposal submission

Please email it to jowestbrook@gmail.com and john.cobb@sp-foundation.org. You will receive an acknowledgment of your submission in one to two business days. If you do not receive a confirmation, please re-submit the proposal with a note that it was previously sent.

All applications will be reviewed by the SPF's Scientific Advisory Board (SAB), which will evaluate and rank all proposals. The Board of Directors will be guided by the recommendations of its SAB in making its final funding decisions.

Funding decisions will be based on the ranking assigned to each proposal, and the amount of available funds. HSP and PLS proposals will not compete against each other.

Funding decisions will be announced to applicants by approximately May 30, Researchers awarded a grant will sign a contract with the SPF and will be asked to provide a short progress report every six months.

Publications

When a paper or poster by an SPF Research Grant recipient, based on work supported by an SPF grant, is published or presented before a scientific organization, a copy of the paper or poster must be emailed to the SPF.

All papers, posters, and exhibits by an SPF Research Grant recipient, based on work supported by an SPF grant, must carry a credit line to the Spastic Paraplegia Foundation, Inc.

A short, final report must be submitted to the SPF within four months of the end of the grant period. The SPF will publish this report on its website, in its annual report, and wherever else it deems appropriate. It must be written so that the average layperson can understand it. The SPF takes seriously its responsibility to its contributors to report to them on the use of their donations.

Further Information

- Funding can be used to cover expenses such as technical assistance, supplies, and small equipment.
- Funding cannot be used to cover overhead, equipment or conference expenses, or other indirect costs.
- The SPF Scientific Advisory Board will review all applications for scientific merit.
- Clinical drug trials must meet the requirements established by the Food and Drug Administration (FDA).

- If a study involves humans, copies of the Informed Consent and the Institutional Review Board (Ethics Committee) approvals are required from each site involved in the study before payment.
- If a study involves human gene therapy, please submit a copy of the NIH Recombinant DNA Advisory Committee (RAC) review or waiver of review.
- Grant recipients may be asked to serve on our Scientific Advisory Board and will be expected to do so if asked.
- These two-year grants are intended to help an investigator explore a new idea, or to collect preliminary data that can lead to a larger-scale proposal. Proposals from new, young investigators are encouraged.
- Proposals should explore no more than one or two Aims, as the scope (time and funding amount) does not realistically permit more.
- Proposals should indicate, briefly, what the investigator thinks will come next after this Aim is accomplished.
- Proposals that demonstrate an awareness that experimental results sometimes do not turn out as expected—and a fallback plan—are encouraged.
- Novel ideas and approaches, and a high degree of relevance or applicability to HSP/PLS are preferred.
- Questions or inquiries may be directed to <u>jowestbrook@gmail.com</u> and <u>john.cobb@sp-foundation.org</u>.