**SPF SPASTIC PARAPLEGIA FOUNDATION, INC.**

*Research / Education / Support*

# 2012
## ANNUAL REPORT

Dear Friends,

2012 was a great year for The Spastic Paraplegia Foundation and 2013 portends to be even more promising. Our sincere and heartfelt thanks go out to the community at large and to all our generous supporters (page 4) for making this possible.

An update on the research we have supported was given at our Annual Conference last June in McLean, Va., where over 150 people attended. Dr. Nazem Atassi spoke about Therapy Development, Stem Cell Research and The Northeast ALS Consortium (NEALS) collaboration with SPF that began in 2010. He spoke about the stem cell ALS clinical trial at Emory University. Dr. Craig Blackstone talked about research inflection points or times when real significant progress in research comes to fruition. This is what we are experiencing now. Dr. Hiroshi Mitsumoto talked about the strides they are making in PLS Research and Dr. John Fink spoke about all the advances that are taking place in both HSP and PLS research. Dr. Fink said: "there is a lot to be excited about!" The HSP and PLS research we are sponsoring does make us ever more excited to take the next step toward that day when a treatment can be announced.

*"There is a lot to be excited about!"*

Some examples of the progress that has been taking place are Dr. Paola Arlotta, associate professor of stem cell and regenerative biology at Harvard University has discovered that parts of the brain previously thought to be immutable, can be corrected. The implications for the treatment of neurodegenerative disorders like PLS, HSP and ALS could be enormous. Dr. Arlotta said that her achievements with cerebral cortex research "opens the door to reprogramming in other areas of the central nervous system."

What's more, a gene associated with regeneration of injured nerve cells has been identified by scientists at Penn State and Duke Universities. The team leader, Dr. Melissa Rolls, reported their discovery that a mutation in a single gene can keep a cell axon, or the part of the cell used to communicate with other cells, from being able to heal itself. This discovery opens the door to new discoveries with spinal cord and neurological disorders.

It is because of the generosity of our supporters that we are able to announce $200,000 for a PLS Research Training Fellowship plus $370,000 for a Research Grant Program. Each year, as our knowledge progresses, the research proposals we receive are ever more encouraging. Although the size of our research budget always prevents us from being able to support all of the top proposals, with the help and hard work of our Scientific Advisory Board (page 2), we are able to support the most outstanding research possible.

The Virginia Freer-Sweeney Clinical Research Training Fellowship is a joint project with NEALS and offers two years of very significant salary and educational support to train exceptional junior clinical researchers to translate advances in neuroscience into treatments for people with PLS. Dr. Christina Fournier at Emory University, Atlanta Ga. has been selected for this support. She has already trained under two of the most respected ALS/PLS Clinician/Scientists in the world, Drs. James Russell and Jonathan Glass. She plans to continue to work collaboratively with Dr. Glass and develop a longitudinal PLS biomarker study.

Hiroshi Mitsumoto, MD, DSC is continuing his SPF funded ground-breaking study with PLS but the next phase of this study is even more compelling than the first. In this new phase, he will be analyzing patient samples for biomarkers and genetic signatures unique to PLS.

In HSP research, we funded two teams. Both are working on treatments. Tina H. Lee Ph.D. with Carnegie Mellon Univ., Pittsburgh Pa., will identify compounds to treat SPG3a associated HSP. Andrew Grierson, Ph.D., Kurt De Vos, Ph.D. Univ of Sheffield, UK and Ludo VanDen Bosch, Ph.D. Univ of Leuven, Belgium are all focusing their work on a new therapeutic approach to treat HSP.

Thanks so much to everyone who has helped fund research that will lead to treatment and eventually to a cure for HSP and PLS!

Sincerely,

Frank Davis

SPF President

CHASING A CURE

# Would you like more information about us?

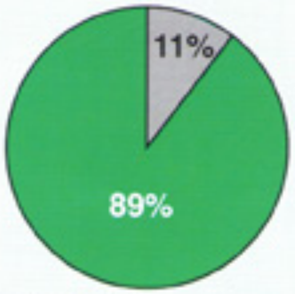
The Spastic Paraplegia Foundation, Inc. ("SPF") is a Massachusetts not-for-profit corporation that is a nationwide, volunteer-run, health organization dedicated to funding cutting-edge scientific research to discover the causes and cures for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis, and to diminishing suffering by education and support.

The SPF home corporate office is located at 4 Couture Rd., Southampton, Ma 01073. A copy of our latest annual report or financial statement may be obtained by writing to the SPF at 4 Couture Rd., Southampton, Ma 01073, or calling 877-773-4483.

## Financial Activities

| REVENUE | 2012 | 2011 | 2010 |
|---|---|---|---|
| Donations | $569,558 | $232,424 | $214,937 |
| Team *Walk* | 112,710 | 45,575 | 164,364 |
| Special Events | 130,269 | 174,555 | 404,531 |
| Program Fees & Products | 16,795 | 11,066 | 33,911 |
| Investment Income | 143 | 11 | 74 |
| **Total Support and Revenue** | **$829,475** | **$463,631** | **$817,817** |
| **DIRECT EXPENSES** | | | |
| Fundraising | $50,646 | $66,688 | $72,274 |
| Management and Administration | 39,408 | 39,943 | 59,931 |
| Program Expense | 39,040 | 17,449 | 33,874 |
| **Total Expenses** | **129,094** | **$124,080** | **$166,079** |
| **GRANTS PLEDGED** | **$370,000** | **$600,000** | **$432,952** |
| **FELLOWSHIP** | **$200,000** | **N/A** | **N/A** |
| **NET ASSETS** *(as of December 31)* | **$889,186** | **$430,341** | **$690,716** |

### Where your dollars go



**89% Mission**
**11% Management and Fundraising Support**

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**John K. Fink, MD**
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