### What is

## the Spastic Paraplegia Foundation?

The Spastic Paraplegia Foundation was born out of the growth and partnership of grassroots, HSP and PLS online patient communities. These communities began when people affected by the disorders created email groups so that people could connect with and help one another.

The SPF is a national, volunteer managed and operated, tax exempt non-profit organization #04-3594491.

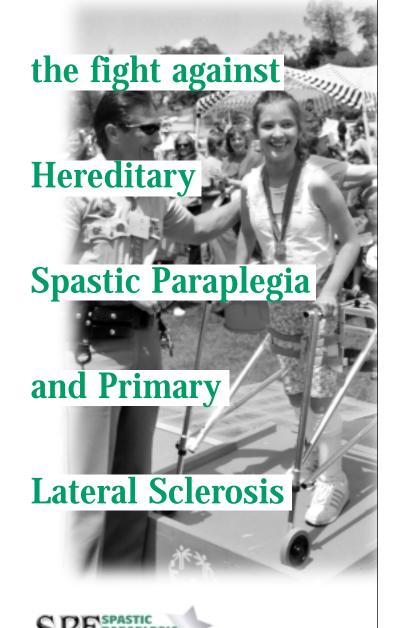
### **Our Mission**

We are committed to discovering the cures for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis by funding research, providing information about these disorders and creating opportunities for mutual support and sharing.



# SPASTIC PARAPLEGIA FOUNDATION, INC.

# **Dedicated** to



### The Disorders

### Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS)

are closely related, rare, neurologic disorders that are caused by degeneration in the brain and spinal cord.

The diseases attack one's ability to walk, often leaving their victims in wheelchairs. They can also rob people of their ability to use their hands and arms, and even to speak. Pain and bladder problems are common. In very rare cases, HSP also causes mental retardation, dementia, epilepsy or other problems.

The diseases can strike at any age--from infancy to late adulthood.

HSP is hereditary. Generally, a child has a 50-50 chance of inheriting the condition from an affected parent. The disorder can also strike randomly and without any apparent family history. PLS is only rarely hereditary.

There are currently no cures for these devastating conditions.



.. Find the Cures Lateral Sclerosis **SPF:** Share Knowledge... Provide Hereditary Spastic Paraplegia and

# SPF Mission Finding The Cures



There is currently no cure for these devastating conditions. Because the disorders are rare, research funding has been very limited.

But now there is realistic hope. SPF was founded to raise money to support cutting edge research specifically on these diseases. No other organization has this focus.

Across the country, our community and friends are joining the fight. Volunteers organize our annual TeamWalk For our Cures signature event, golf tournaments and other special events; work to form valuable partnerships and join our fight by becoming members of the Spastic Paraplegia Foundation.

SPF's expert Scientific Advisory Board, comprised of leading neurologists from across the country, ensures that we fund only the very best science to meet our goals.

Scientists are coming ever closer to finding the answers. The time to close the gap is now.

# **Sharing Information**

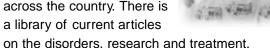
HSP and PLS are rare. There have been few resources to help people understand their disease, treatment, inheritance risk and how to manage life-changing disability issues.

Additionally, many medical professionals aren't knowledgeable enough about the conditions or up-to-date on current research findings.

Lengthy diagnosis periods are common and misdiagnosis is frequent.

The SPF fills critical needs for information. There is a comprehensive, medically reviewed website. An E-News bulletin reaches thousands of subscribers, delivering news about treatment and research as well as helpful resource information.

Conferences featuring leading experts are organized across the country. There is a library of current articles



This is a good start, but more needs to be done to

get critical information in the hands of those who need it most.

# **Providing Support**

Having a disabling condition is tough enough, but having a rare condition is even more frightening. Families have never heard of their disease and wonder how to face the challenges that lie ahead. They wonder how fast their symptoms will progress, what portions of their bodies will be affected and whether their children will develop the disorder.

Establishing opportunities for people to help one another is an SPF focus. There are internet email support groups and a Chat Program.



Support group meetings are held in many areas. Outreach efforts include listings in medical resources, partnerships with related organizations and awareness campaigns.

These programs have made a big difference for many people, but more needs to be done so that no person or family struggles alone in fear.

Through SPF, there is a community that understands, cares and provides a lifeline of support.

# **Investing Your Support Wisely**

It is our intent to send as much money as possible to research--and spend as little as possible on management and fundraising. A portion of our funds is also spent for our education and support programs.

85%

pport programs.

85% of funds go to the SPF mission and 15% to management/fundraising.

100% of your donation is tax-deductible. A copy of the SPF's latest annual filing may be obtained, upon request, from the Foundation:



**SPF**, 209 Park Road, Chelmsford, MA 01824 or at **info@sp-foundation.org** 

### SPF Membership/ Contribution

I want to join the effort to conquer these diseases

want to join the enort to conquer these diseases
General Membership
☐ Friend \$20 - \$99
☐ <i>Stroller</i> \$100 - \$499
☐ <i>Race Walker</i> \$500 - \$999
☐ <i>Runner</i> \$1,000
Pioneer Membership – 5-year Honorary Program
The Pioneer Club honors leadership-level
individual, corporate and foundation donors
during our inaugural five years. Contributions
over this five-year period add to your final

Membership Level.

☐ *Sprinter* \$2,000

☐ *Silver* \$10,000

☐ *Platinum* \$50.000

#### **Membership Form**

Please return this form with your check, money order or credit card information to: Spastic Paraplegia Foundation, Treasurer's Office, P.O. Box 1208, Fortson, GA 31808.

☐ *Marathoner* \$5.000

☐ *Pioneer* \$100.000+

☐ *Gold* \$25,000

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