Spastic Paraplegia Foundation, Inc.


This report represents Spastic Paraplegia Foundation, Inc.’s responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.

Spastic Paraplegia Foundation, Inc.
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Mission:
The Spastic Paraplegia Foundation is committed to promoting research to find cures for Hereditary Spastic Paraplegia and Primary Lateral Sclerosis, to educating people and their families affected by these conditions to help them live full and productive lives and to creating opportunities for mutual support and sharing.

The content of this Charting Impact Report is the sole product and responsibility of Spastic Paraplegia Foundation, Inc. This report does not in any way represent an endorsement from Independent Sector, BBB Wise Giving Alliance, or GuideStar, nor does it represent fulfillment of the BBB Wise Giving Alliance’s Standards for Charity Accountability. For more information on Charting Impact, visit www.guidestar.org/chartingimpact
1. What are we aiming to accomplish?
1. To support research to find a cure or treatment for two closely related rare upper motor neurological disorders, Hereditary Spastic Paraplegia and Primary Lateral Sclerosis. 2. Increase funds raised to support HSP and PLS research by 5%. 3. There are 7 states where we do not have someone with the position of “ambassador” whose responsibilities are to maintain communication, both written and fellowship meetings with people in their state. Our goal is to fill those positions in early 2015. 4. To begin the work of creating an international, multilingual Patient Registry for HSP and PLS. 5. To improve our Donor Management Software system. 6. Improve our quarterly newsletter, Synapse, to better coordinate with seasonal themes and better research progress reports. 7. Improve our web site by creating a board position who regularly reviews our website for suggestions on what stories should be eliminated or added and what links should be corrected or eliminated.

2. What are our strategies for making this happen?
1. A systemized donor communication program where separate demographics are communicated with at set times of the year. 2. Test several new fund raising programs such as galas in 3 different areas of the country, developing a system where we are able to use email blasts to communicate with donors based on their recency, frequency and monetary giving history. 3. Working better with volunteers to find people with language skills and expertise that they could use to write articles for our newsletter. 4. Establishing a Director for Ambassadors who will better coordinate and communicate goals, expectations and communication with all state ambassadors. 5. Develop a strategy to better know the financial capabilities of each person on our data base. (Zillow) or hire a service to do that.

3. What are our organization's capabilities for doing this?
Our board of directors is comprised of many highly skilled individuals who donate countless hours to our Foundation on a volunteer basis. These include an experienced attorney, a CPA, a PhD in genetics, a retired president of a Direct Marketing Co., a prize winning high school teacher, a judge, an engineer, an investment analyst and several more. We work closely with NORD, AFP, NEALS and several international organizations with a similar mission statement to help help and support research to cure HSP in Australia, Spain, England, and Germany. We have a Scientific Advisory Board of world renowned international neurological experts who volunteer their expertise to rate all research proposals we receive so we are able to support the very best research possible.

4. How will we know if we're making progress?
The indicators that progress is taking place with HSP and PLS research is that in 2014, a research paper was published on HSP and PLS every 3 days. In 2015 we will be supporting research that is actually testing 2 drugs in a phase 2 trial with people with HSP. Another one of our supported research will be testing a drug on people with PLS. Our fund raising has increased over 20% in the last year. Our website has been revamped. Our newsletter has been improved with 50% more pages. We are developing a communication plan with major donors that is showing great progress.

5. What have and haven't we accomplished so far?
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