Strategic Plan for The Hemispherectomy Foundation

This document sets out a strategic plan for The Hemispherectomy Foundation. It reviews strengths, weaknesses, threats and opportunities; presents a series of statements relating to The Hemispherectomy Foundation's vision, mission, values and objectives; and sets out its proposed strategies.

Strengths, Weaknesses, Threats & Opportunities

This strategic plan addresses the following key strengths, weaknesses, threats and opportunities for The Hemispherectomy Foundation:

Strengths:

- Grass Roots organization
- Dedicated volunteers with wide ranging skill set
- Regional and Specialty Directors in place
- Medical Advisory Board in place
- Support from leading pediatric neurologists and surgeons
- Low overhead

Weaknesses:

- Need dedicated office
- Little non-profit management experience
- Overdependence on few key staff
- Absence of strong fundraising expertise

Threats:

- Economic slowdown could reduce fundraising
- Competing organizations

Opportunities:

- Regional fundraising
- Increase grant revenue
- Creation of endowment fund
- Partnership with other organizations

Vision

The Vision of The Hemispherectomy Foundation in 3-4 year's time is:

The Hemispherectomy Foundation is headquartered in Aledo, Texas in a Foundationowned lot/building. The building is divided into 3-4 office/business areas. The Foundation is officed in half of the building and the remaining space is leased to local businesses to generate revenue that is used to provide full-time office management/administrative assistance. The board of directors will consist of at least five family representatives affected by hemispherectomy and two members of varying expertise in finance and fundraising. The Foundation manages a \$5 million endowment fund and has an annual operating budget of \$100,000. The Foundation will have a strong presence in the United States with regional directors and a volunteer support staff supporting at least 5 defined regional areas. Specialty directors will oversee support groups for families considering or having had hemispherectomy for Hemimegalencephaly, Cortical Dysplasia, Sturge-Weber syndrome, Rasmussen's Encephalitis, Pediatric Stroke, and Tuberous Sclerosis. Each regional area will host a 1-day gathering of families to provide networking opportunities. A 3-4 day national conference will be held annually on a rotating basis in Baltimore, MD, Indianapolis, IN, and Los Angeles, CA. At least one day of the conference will be dedicated to break out meetings for each disease type. International directors will be in place in at 3 different countries. Every 4 years an international conference may be held in each representative country. 1, full-ride scholarship and 3, \$1000 scholarships will be awarded to college or trade school students annually. At minimum, 10, fully paid camp grants will be paid to applicants annually. At minimum, 20, \$1000 grants for life aids or travel assistance will be awarded to applicants. Research grants will be awarded annually and the previous year's awardees research presented on one day of the annual national conference.

Mission Statement

The central purpose and role of The Hemispherectomy Foundation is to:

To Encourage and Support impacted families considering surgery by connecting them with other families who have had a hemispherectomy or similar surgery.

To Work together with medical professionals to fund and support research into the cause and treatment of the diseases that lead to intractable epilepsy, hemispherectomy, and the surgery itself.

To Raise Money for camp fees, scholarships for trade schools and higher education as well as provide financial relief for struggling families.

Corporate Values

Values governing The Hemispherectomy Foundation will include the following:

Accountability – responsible stewardship of funds to ensure support of families and research continue into the future.

Passion – be passionate about providing emotional, financial, and educational support to individuals and their families who have undergone, or will undergo, a hemispherectomy or similar brain surgery.

Excellence – be the best in quality and in everything we do.

Respect – be measured by how we treat each other, by the contributions that flow from our diversity, by the productivity of our relationships, and by a job well done.

Unity – We are one Foundation, one team. Balancing interdependence and empowerment makes us strong. Together as a foundation, our impact on the world is greater than any individual accomplishment.

Diligence – the Foundation will work hard, with steadfast determination to lead the search to find a treatment other than surgery for intractable seizures.

Strategic Priorities:

Strategic priorities of The Hemispherectomy Foundation are:

- Increase credibility with the Hemispherectomy Families we support, potential donors and the medical community
- Establish an endowment fund to provide long-term family support, research, and college, trade school and camp tuition
- Establish the Foundation's role as a leader in scientific discovery

Key Strategies

Community

Strategic Priority:

Establish credibility with the Hemispherectomy Families we support, potential donors and the medical community

Strategic Objectives:

To maintain a respectable web presence that is professional, easy to navigate and provides meaningful information to both families and medical professionals

To produce and distribute a quarterly e-newsletter

To host an annual national conference and regional events

To acquire a standalone office to house the Foundation headquarters

Finance

Strategic Priority:

Become financially stable by increasing income revenue

Strategic Objectives:

To establish an endowment fund to provide long-term family support, research, and college, trade school and camp tuition

To establish freelance grant writing and fundraising positions based on percent commission

To organize annual regional fundraising events

Research

Strategic Priority:

Establish the Foundation's role as a leader in scientific discovery

Strategic Objectives:

To establish research awards in each disease category (Cortical malformations, Rasmussen's Encephalitis, Pediatric Stroke, Sturge-Weber Syndrome, and Tuberous Sclerosis).

To establish a reference video library of PT/OT/ST activities/strategies for therapists and families