Hope for HIE Foundation

Year in Review

Developed on August 8, 2015

Fiscal Year:
September 1, 2014-August 31, 2015
Summary

Hope for HIE is a US-based 501(c)3 non-profit organization with a worldwide presence, dedicated to promoting awareness, education and support for Hypoxic Ischemic Encephalopathy (HIE).

Currently, Hope for HIE is run solely by volunteers. These volunteers are parents of children who have the HIE diagnosis. Structurally, the Board of Directors is responsible for the strategic direction and overall management of the foundation operations.

Over the past year, many elements have come together to position and grow Hope for HIE from solely a social media support network, to a recognized, non-profit organization. Amongst an exhaustive list, creating a non-profit has included designating a Board of Directors (currently five members from four different states), establishing accounting and financial systems, conducting regular, formal board meetings with comprehensive minutes and developing a compliant, legally accountable organization.

The Year in Review will focus on summarizing the completion of top priorities as written in the Hope for HIE Three Year Strategic Plan developed and approved on August 1, 2014, as well as other key accomplishments.
**Vision**
Empowering Communities to Find Hope in the HIE Journey

**Mission**
To foster hope in families affected by HIE (hypoxic ischemic encephalopathy) through support, education, and awareness.

**Values**

**Advocacy**
We will work to actively advocate for our children and fellow families. We will relentlessly pursue a world where HIE families can fully realize their potential.

**Empathy**
All families and children who experience HIE deserve empathy for the path they are on, no matter the outcome.

**Integrity**
We will be who we say we are, work together honestly and direct ourselves toward building the organization for the greater good.

**Unity**
We will be open and honest with each other. We realize we are stronger together, and group needs are stronger than individual agendas.

**Reflection**
We will carefully analyze all decisions that are made and adjust the scope or expectations accordingly in order to best benefit the HIE community at large.
**Awareness**

**Key Objectives, Strategies & Tactics Completed**
- Outreach outlined to develop groups in geographies beyond the U.S.
- Developed Facebook groups specific to each country or specific demographic group
- Set up a worldwide steering committee to help lay the foundation for future global growth.

**Key Accomplishments**
- Developed formal mission, vision and values statements along with a three-year strategic plan to drive the organization forward.
- Developed a 43-page powerpoint on our history to address a wide-range of questions and concerns in transitioning from solely a social media/Facebook group to a recognized, 501(c)(3) non-profit organization.
- Key mind-maps were created and shared to more effectively communicate the transition and also the importance of our international families involvement.
- Renamed the International Planning Committee to the Volunteer Committee to more formally address and encompass the organization’s structure and legal concerns via the approved by-laws and three-year strategic plan.
- Through regular communication and marketing, Hope for HIE went from a few hundred families to now over 1,500 families worldwide that are receiving awareness, education and support from the organization.
  - We have a growing presence in Malaysia, India and Pakistan
  - The Facebook foundation page is receiving on average, 20 new likes per week which now boasts over 2,700 likes, and reaches 20,000+ people per week with its content, almost doubling the amount of reach and followers from a year prior.
- Secured Google AdWords grant, increasing Hope for HIE’s online presence and targeting specific search criteria in Google to drive traffic to the website.
  - Hope for HIE comes up in search results significantly higher with over 120,000 impressions and over 500 click-throughs since October 2014.
- Promotional Book Giveaway was successfully implemented with Julie Keon which resulted in 10 new volunteers and 2 new donors after 71 entries.
- Created online storefront that features multiple opportunities to purchase awareness items such as apparel, accessories, drinkware, car accessories, and stationary. 100% of net proceeds of each purchase contributed to the overall fundraising efforts to support operational costs.
- Key Strategic partners have helped us gain a large amount of awareness via new avenues of online marketing and presence
  - BonfireFunds.com blog review
  - Featured in the Perinatal Newsletter of the American Association of Pediatrics
  - Key articles/posts on TheMighty.com via multiple HIE families and authors linking to the HopeforHIE.org website
  - Successful interview and article with the Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD), a branch of the National Institute of Health (NIH) - went to neonatologists, pediatricians, and other key medical leaders across the country and received international attention.
Forged partnerships with key organizations such as National Perinatal Association, National Association of Perinatal Social Workers and other neonatal/perinatal research organizations worldwide.

- Brought awareness to local communities through holiday events such as the Brookfield Zoo tree trimming where the local Chicago chapter sponsored a Hope for HIE decorated tree that was seen by thousands of visitors from around the world.
- Partnered with Becky Kerrins, coach of the Oak Forest, Ill., Barracuda swim team, and HIE mom, matching 60+ swimmers with HIE children to increase empathy and awareness of children with different abilities.
- Created a Branding & Style Guide to define the organization’s expectations and make sure every visual element (collateral, website, social media, promotional product creation, etc.) and overall brand are consistent.
  - Hired a professional design firm to create organizational collateral (business cards, letterhead and envelopes) and outreach materials (NICU/PICU flyers, parent-focused tri-fold brochures and medical professional educational materials).

**EDUCATION**

**Key Objectives, Strategies & Tactics Completed**

- Create a website to be the hub of all communication and resources for the constituents and families benefiting from the organization.
  
  **Strategies**
  - Search engine optimization
  - Drive traffic to the website with online a variety of communication channels.
  - Rich Content Development

  **Tactics**
  - Develop tracking reports that regularly report the number of new people who visit [www.HopeforHIE.org](http://www.HopeforHIE.org).
  - Connect to online referral sources
  - Utilize Google Grants and other tools available to 501(c)(3) organizations to increase visibility, measuring online interactions.
  - Outline and contact content contributors; develop a schedule for regular posts
  - Fill, manage & maintain an active and energetic website committee

**Key Accomplishments**

- Created a blog featuring multiple HIE family authors within a new structure of categories: Self Care, Therapy, Equipment, Prescriptions, Toys, Books and Blogs
  - A few key posts included: “Best Recommended iPad Apps for Special Needs Education and Parenting”; A review on how to select a wheelchair; “Stem Cells: One Family's Journey”; “How Daily Gratitude Changed My Life”; “Fundraising Ideas, Tips & Tricks”
- Regular, timely and informed articles, links and resources posted to the Hope for HIE Foundation Facebook page
- Developed and shared social media infographics, which in turn are shared worldwide to educate a broader community on HIE.
SUPPORT

Key Objectives, Strategies & Tactics Completed
✓ Establish a sound accounting system with proper checks and balances ensuring a workable structure is in place.
✓ Establish specialized opportunities to give such as honorarium or memorial gifting.
✓ Capitalize on applicable free and low-cost resources available to 501(c)(3) organizations to streamline operations and minimize costs.
✓ Complete necessary paperwork at the local, state and federal levels to ensure the organization is structurally compliant with applicable laws.

Strategies
✓ Apply and obtain the 501(c)(3) status
✓ Establish Bylaws
✓ Establish affiliation guidelines, policies, procedures and comprehensive brand standards.
✓ Create Risk Management Plan

Tactics
✓ Purchase liability insurance on behalf of the organization
✓ Purchase a P.O. Box for official organization physical address
✓ Read and understand applicable IRS tax laws; create compliance standards
✓ Use Robert’s Rules of Order for all Board Meetings

✓ Establish a US-based Board of Directors with people who are passionate, share the vision, and are committed to achieving Hope for HIE’s maximum potential.

Strategies
✓ Identify and ask a board member to serve in specific roles needed to drive the organization forward. Ideally, this will represent expertise each member can bring to the organization in various roles.

Tactics
✓ Outline expectations and time commitments for each role
✓ Schedule regular board meetings to pursue the execution of the strategic plan.

✓ Create documented job descriptions and suggested training for each board member responsibility.

Tactics
✓ Train the treasurer on non-profit accounting and financial management practices.

✓ Define time commitment and involvement for those wanting to be in leadership roles for each country.

Tactics
✓ Write expectations of global leaders and get commitment and agreement in writing.
Other Key Accomplishments

- Financially grew from $0 to $11,000 through fundraising efforts via NationBuilder (website platform) and individual fundraisers for specific support and operational budget targets:
  - By utilizing the NationBuilder platform, the organization was able to develop a secure and globally compliant online donation portal, streamlining financial management and fundraising efforts.
  - The organization's first major fundraising campaign, the 2014 Holiday Appeal, netted over $3,000 USD from worldwide contributions.
  - Memorial and honorarium fundraising netted over $5,000 USD contributing to funding operational, family loss and hospitalization support.
  - Created an opportunity for donors to set up recurring donations through the NationBuilder platform, allowing flexibility of giving options.
  - Partnered with Art Institute of Fort Lauderdale to be the beneficiary of a charity fitness program.
  - Through the online storefront and affiliated merchants, raised over $3,000 to support operating and outreach costs.
  - 15% of the active HIE community donated to the foundation.

- Grew the current annual Hope for HIE North American Meetup from 24 attendees to 43 attendees (nearly doubling) in Gatlinburg, TN - May 2015. Attendees from the United States and Canada traveled from near and far to attend.

- Organized a large group of international volunteers, outlining specific skills, contact information and completion of volunteer compliance forms.
  - Google Groups, Google Hangout access, Gmail accounts (name@hopeforhie.org) and Google Drive (folder structure) were created to support the immense interest in helping the organization to grow and thrive.
  - The Volunteer Community (our local and global representation) now boasts 78 volunteers from a wide variety of countries and communities.

- Facebook forums continued to grow allowing for our families to gain more detailed and adequate support for the different demographics and stages of HIE
  - New to HIE; Hope for HIE 10 years & up; Hope for HIE Communication Challenges; Hope for HIE Cognitive Challenges; Hope for HIE Single Parenting; and 15 geographic/local support groups formed to provide local events and support for all HIE families

- Through the resources of NationBuilder, Hope for HIE has a dedicated voicemail that multiple families utilized to access support, shifting from support solely provided on Facebook, to other communication channels.

- Improved and formalized local support which brought a new level of involvement for families to bridge virtual connections into in-person relationships.