Huntington's Disease
Society of America

Huntington's Disease Society of America, Inc.
Strategic Plan 2012 - 2016

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INTRODUCTION

The last strategic review of the Huntington's Disease Society of America was conducted thirteen years ago in 1998 and was largely focused on evaluating the organization's structure. Since then there have been significant developments in clinical care and scientific understanding of Huntington's disease. Additionally, HDSA has evolved. With a new regional structure, 45 Chapters and Affiliates and new volunteer and staff leadership, the organization is larger and becoming more strategic and professional than it was even five years ago.

As a result, in November 2009 the HDSA Board of Trustees agreed to launch a new strategic planning initiative for the Society. The purpose of this initiative was to undertake a systematic and thorough review of the Society's function, and develop a plan that would foster its growth and increased impact. A Task Force was convened in March 2010 following a Board Retreat to spearhead the development of the plan. Over the next 18 months, this Task Force met seven times in person and by phone to lead an inclusive process soliciting feedback from the community and volunteer leadership to identify the strengths, weaknesses, opportunities and threats facing HDSA.

An online survey (Appendix A) to which nearly 500 individuals from the HD community at large responded provided valuable insight and was critical to establishing the framework of the plan. Seven core strategic direction statements, which became Goals in the final version of the plan, were then presented to the Board of Trustees in June 2010 for consideration.

Following their approval, workgroups on the mission areas of the organization – advocacy, education, program services and research – were convened and met between August 2010 and April 2011 to delve into the Society's specific programs and initiatives. From there, the Task Force worked with HDSA Staff to develop the strategies, objectives and annual milestones that bring the Strategic Plan to life.

A complete draft of the Strategic Plan was presented to the Board of Trustees in December 2011 and after an open period of community comment; the final plan was published in early 2012.

CARE AND CURE

One fundamental question required attention immediately in the planning process: Should HDSA remain dedicated to both "Care" (services, education and advocacy) and "Cure" (research) or should it focus on just "Care"? After a thorough analysis of the HD scientific environment, the resounding and unanimous answer from the entire HDSA Board of Trustees was that the Society will continue its two-fold commitment.

A new HDSA research program will be launched that is complementary to the research funding provided by CHDI, the National Institutes of Health, and other funding agencies. This program will build on the successes of our previous programs.

Our major previous research program was the Coalition for the Cure, which was launched in 1997 by HDSA as a consortium to drive basic science for HD and answer key questions regarding the disease mechanisms. Many of the world's best HD investigators from labs spanning the globe participated in the Coalition and contributed volumes to our understanding of HD.

Based on the evaluation of the Research Workgroup, it was recommended that the Coalition evolve into a new program that fosters a new generation of HD scientists. The field of HD science is a relatively small one led by a handful of well-established labs. It is in the interest of the community and central to our efforts to find treatments and one day a cure for HD that the pipeline of new researchers be fueled. This will be our main research program. The white paper prepared by this workgroup is attached as Appendix B for more information.

Additionally, the Task Force reviewed the HDSA Centers of Excellence program in detail. Currently the Society has 21 Centers across the country. In some cases there are great distances between Centers making it necessary for families to travel many hours to see these multidisciplinary teams of HD specialists. As a result, data show that only approximately one-third of the HD community is receiving care at one of the Centers. Over the next five years, we will work to increase the number of Centers taking great care to increase resources for underserved communities.

Founded in 1998, the Center program is the backbone of HDSA's ability to ensure knowledgeable care to HD families. The Research Workgroup recognized that these Centers have access to a great wealth of data that can help improve the quality of life for people with HD, as well as accelerate scientific development of treatments. As a result, the Society will seek to enhance the Centers' role in clinical research by creating linkages with the new research program. Imagine if a basic scientist who was used to testing hypotheses in mice could finally test a theory on human blood samples made possible by a Center of Excellence? This is exactly the type of work that HDSA will seek to facilitate.

A COMMITMENT TO COMMUNITY SERVICE

HDSA is committed to offering programs that can have the broadest impact and affect the most lives. As a result, the Society is consciously making a shift from describing our work as "family" services and instead is focused on "community" services. Every program is now being evaluated by the overall impact it has on the HD community.

Personalized support, like financial aid or case management, for every family facing HD is not realistic for the Society given our budget. Based on conservative prevalence figures from the National Institutes of Health, approximately 30,000 Americans are living with HD and another 250,000 are living at risk. It is our Goal to have programs that can help support these large numbers so that every family, no matter where they are in the HD continuum, can find the information and support they are looking for from a core set of HDSA community services.

Programs like our network of social workers and support groups and resources like the Caregiver's Corner webinars and publications have vast reach so that many families can utilize them. Additionally, efforts to educate physicians about the specific care needs of HD families have a ripple effect throughout communities, and best practices for navigating long-term care, disability, and a variety of legal issues impact many.

THE NECESSITY OF GROWTH

The backbone of HDSA is the people who bring it to life. Currently, a vibrant network of forty-five Chapters and Affiliates organized into nine regions, the Society is comprised of thousands of volunteers who spread awareness, run programs and raise funds to support the overall work of the organization. Without these dedicated individuals and the lean team of staff who support them, HDSA has no voice and therefore no power to accomplish our mission.

In order for the Society to do more, we must bring new folks into our fight. This means branching out beyond the HD community to involve new supporters. Through media and educational initiatives to raise awareness of HD among the general population, we will welcome newcomers and expand our impact. Each year our plan of work will have specific Goals regarding new volunteer identification to broaden our base and therefore our reach.

The phrase "no money, no mission" is often used when describing non-profits, and in relation to the Society's ability to fund programs, this is certainly true. As the Strategic Plan articulates strategies for new research funding and expansion of the Center program, just to name two, it is dependent on the Society's ability to grow its annual revenue. By bringing more Chapters and Affiliates into existence, we increase the number of places and people who can help us education, care for and fund HDSA programming.

Across all of our income streams, we will work to achieve greater returns and therefore expand our organizational capacity. Conservatively, we are aiming for five percent growth each year organization-wide with a continued focus on keeping the overhead and event fundraising dollars to a minimum. Consistent with non-profit best practices, our Goal is to keep the percentage of overall revenue invested in mission programs at 75 percent or higher.

Many organizations for diseases as rare as HD are many times our size. It is imperative that we increase our capacity so that we can do more, fund more research and accelerate the accomplishment of our vision – a world free of HD.

WHO WE ARE: THE FUNDAMENTALS

Our Vision: A *world free of Huntington's disease.*

This vision statement represents our overarching commitment to the ultimate Goal of eradicating Huntington's disease.
When stated before the mission, it should be read in a manner that directly ties it to our mission as follows: *The vision of the Huntington's Disease Society of America is a world free of Huntington's disease. Until that time, our mission is to improve the lives of people with Huntington's disease and their families.*

Our Mission: *To improve the lives of people with Huntington's disease and their families.*

The mission of the Society is a concise, active statement of the Society's work. In comparison to the vision, it describes why the Society is operating today. The phrase "a national, voluntary health organization" was removed from the original statement as these terms define the Society's structure, not its mission.

It should be noted that the mission statement is separate from the organizational purposes as described in the organization's Bylaws. Those purposes provide background to the mission (historical reference) and serve as an adjunct descriptor. They are as follows:

- To promote and support research and medical efforts to eradicate HD.
- To assist people and families affected by HD to cope with the problems presented by the disease.
- To educate the public and health professionals about HD.

As a result, they will remain in the bylaws without edit, but from this point forward, we will no longer reference a three-part mission. The mission is one simple statement: *To improve the lives of people with Huntington's disease and their families.*

Our Core Values

These are the values that we share and are committed to building:

- *Dedicated* – We are dedicated to serving people with Huntington's disease and their families. We care intensely about those we represent and serve. We celebrate our wins and inspire dedication from those who work with us.

- *Community-based*– In direct correlation to the nature of Huntington's disease, we are a family-focused and community-based organization. Our structure, programs and decisions reflect a commitment to serving communities of families. We value the work of our volunteers who represent our communities and who function as a family. All members of our team – staff, volunteers, Chapter and Board leaders, donors, care providers, scientists, and sponsors – are important members of the HD community.

- *Compassionate* – We are a sympathetic and empathetic network of individuals. We know that excellence in care comes from sincere compassion and we strive to reflect this compassion in our community activities and relationships.

- *Strategically Mission-driven* – It is important to the Society that all work of the organization is driven by a consistent and strategic focus on accomplishing our mission. We are disciplined to our mission to ensure that our decision-making and leadership align with the mission and drive our growth.

- *Stewardship* – We are committed to demonstrating that we are a trustworthy organization by maximizing the effectiveness of the resources entrusted to us. As stewards, our volunteers and staff make decisions about how to invest time, people and money based on the highest and most impactful return on investment. We employ practices that maximize efficiency and effectiveness, and we evaluate initiatives in light of our strategic mission-driven objectives.

- *Accountability* – Stewardship is reinforced by our accountability. It motivates our volunteers and staff to manage our resources effectively and take actions in the best interest of the Society. We are transparent and honest. Accountability entails mutual responsibility at the national and local level.

- *Connective & Accessible* – We value the Society's role as a 'hub' or central 'portal' for the HD Community. No matter what the need, members of our community know that the organization will be able to either provide support or direct them to another who can. We are committed to maintaining and expanding our resources and support to broaden our reach and impact.

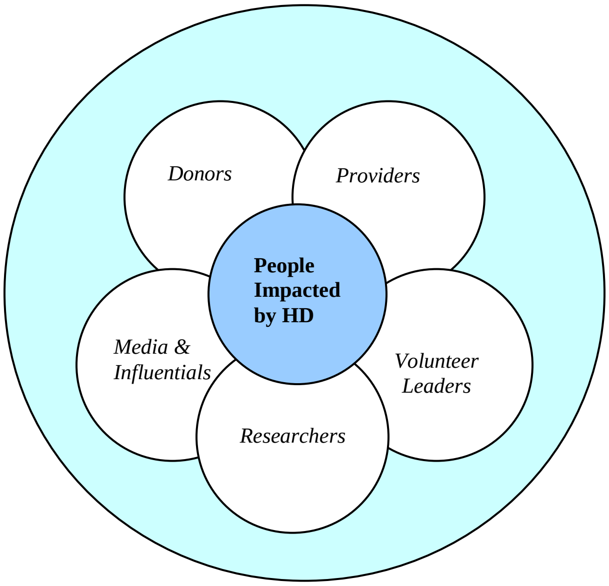
- *Bringing Hope* – Consistent with our mission, we believe that an important outcome of our work is the ability to inspire hope in everyone impacted by Huntington's disease. Our vision epitomizes this hope and we will conduct our work in all areas – advocacy, awareness, care, research and education – in a way that is always forward-looking.

Our Community

Our primary community is those impacted by Huntington's disease, which includes those symptomatic with the disease, those at-risk and the families and friends who are caring for those with HD.

All of the audiences and groups of individuals who contribute to the Society's ability to care for our primary audience constitute our secondary community. These include the care providers (clinicians, social workers, etc), researchers, HDSA volunteer leadership (national and field), HDSA donors and members of the media/influential thought-leaders.

The backdrop for these two categories of audiences is the general public, which represents our continuing community to raise general awareness of Huntington's disease and influence public understanding of the needs of our communities.



Whether motivated by organizational mission, cultural focus or concern for health, a commitment to improving the lives of everyone affected by Huntington's disease and their families is common to all groups we serve.

PLAN IN SUMMARY

In the upcoming pages, the Strategic Plan is presented as a grid that clearly states the overarching Goals and plans for attainment of these Goals throughout the next five years. The Plan is organized around the Seven Goals, formerly described as our "Strategic Directions," which are the key drivers of organizational growth. They are the fundamental business ambitions and represent the essential areas of our work.

For each Goal, strategies are then identified to reach the stated aim and specific objectives for each strategy articulate the plans for accomplishment. Next, the initiatives (and in some cases audiences) for each set of strategies and objectives are delineated. Finally, specific milestones for each of the five years of the plan are listed. These milestones are guideposts for progress. We expect that some projects will be completed early, while others may move later based on business conditions. There is a certain degree of flexibility built into the plan. Fundamentally, however, these milestones map the progress which we plan to achieve and the resulting impact that helps us reach our Goals.

It is important to note that the Goals and strategies are not listed in any particular order. All are of equal importance to the success of the organization. Following are narrative summaries of each of the Seven Goals to accompany review of the plan.

Goal I: Build an *HD Community-service* organization.

Fundamentally, our work is to serve the Huntington's disease community. They are our primary audience and all of our efforts must strengthen and align with this statement. Reflective of our core values, our work to build an organization focused on serving this community must put the families (a.k.a. community) first and our culture must reflect this service mentality. Staff and volunteers should exemplify a model of customer service where pride and results are defined by the positive impact of our service.

To accomplish this Goal, four core strategies have been identified: (1) expanding access to top clinical care, (2) enhancing social services and support resources, (3) improving access to long-term care facilities skilled in HD and (4) increasing access to counseling on key HD-related decisions (clinical and logistical.) Key objectives in this area are the expansions of the Center of Excellence program, the launch of an online continuing medical education program to teach new physicians about HD, the development of a regional network of social workers to augment the existing National and Field-based social workers, initiatives to bridge the support gap between the NYA and the Chapters and expand the age-appropriate support that is available to our youth, Best Practices for HD care in long-term care facilities and increased resources on genetic testing, the disability process, healthcare planning and the potential for discrimination.

Goal II: Support HD research & communicate its impact.

We know that hope rests on the ability to communicate that Huntington's disease care will be better for future generations than it is today. Research into the causes of the disease and scientific exploration of potential therapies are central to our work. In addition to directly supporting research through funding, we are committed to educating our community about its impact and their potential involvement. We see our researchers as partners and will work closely with them to communicate the impact of their work.

The four strategies in support of this aim are: (1) ensure a pipeline of new HD researchers, (2) strengthen and build partnerships with research partners, (3) establish a dynamic and reputable set of scientific advisors and (4) fuel clinical research by ensuring active engagement in clinical studies. To accomplish these strategies, the Society will launch a new research program in 2012 which builds on the strengths of the Coalition for the Cure as well as the organization's other cornerstone program – the Centers of Excellence. A new Director of Scientific Affairs and Scientific Affairs Committee will be identified to lead this new program and support the other research Goals of HDSA including our continued emphasis on educating the community about the importance of clinical research participation. Programs like the HDSA Diplomat and HDTrials.org will continue to support this area along with educational resources online and in person. We will also deepen our partnerships with other organizations – for profit and nonprofit – who are working to bring HD treatments and cures to our families.

Goal III: Remove barriers to quality care.

Central to improving the lives of people with Huntington's disease and their families is ensuring that barriers to care are diminished. By advocating for public policy change, improving our referral capabilities and expanding our network of support and care providers, including increasing physician education on Huntington's disease, we will have an important and positive impact on those we serve. Our work must be consistent across the entire family experience so that no matter where an individual is in the fight against Huntington's disease – at-risk, going through testing, newly diagnosed, applying for disability, entering long-term care – there is a corps of supporters and abundance of resources to help them navigate the best in care.

Four strategies to accomplish this Goal were identified. They are (1) pass legislation that directly improves the quality of life for HD families, (2) expand HD benefits in health insurance coverage, (3) reduce discrimination towards people with HD and (4) increase the number of HD specialized physicians and related care providers. Passage of the Huntington's Disease Parity Act in Congress is a primary objective of this Goal, but additionally, HDSA will work tirelessly to build an active and knowledgeable army of advocates that is engaged in the roll out of health insurance exchanges which are part of the Patient Protection and Affordable Care Act passed by Congress in 2010. Other initiatives will focus on educating law enforcement personnel on HD, providing resources for those applying for disability, training the HD community about the Genetic Information Non-Discrimination Act (GINA) and physician education also referenced in Goal I.

Goal IV: Become the premier communicator of HD information.

As the largest non-profit organization dedicated to serving the Huntington's disease community, it is imperative for our continued growth and service to people with HD that we are positioned as the 'first source' for all news, information, resources and education related to Huntington's disease (HDSA and non-HDSA). Our excellence is directly tied to our ability to be up-to-date and to consistently 'deliver the goods' so that all those who come to us, find the resources they seek and those they need. Importantly, the Society must be a comprehensive hub for the entire community, with links to resources outside the Society to underscore a one-stop-shopping experience.

To do this we will (1) enhance knowledge of HD and HD science, (2) increase awareness of HD among the general population and (3) expand awareness of HDSA. The relaunch of HDSA.org and its related sites (i.e. NYA, Extranet and HDTrials.org) is critical to achieving these aims and is on target for 2012. In addition, new engagement tools like an enhanced social media strategy, video contests and a mobile browser version of the website will supplement monthly e-newsletters and continued refinement of the Society's publications. A comprehensive public relations and marketing campaign will also work to keep our brand and story in front of the media and therefore the broad American audience.

Goal V: Grow volunteer involvement.

People are our most important resource. Our volunteers represent our Society, deliver important services, and ensure our growth. We recognize that it is of primary importance that we invest in strengthening and diversifying our volunteer base. Doing so will strengthen our Chapters and Affiliates, enhance our programs and events and expand our ability to impact more families. We are committed to providing the appropriate training to our volunteers, supporting them with resources and consistently showing appreciation for their good work.

The fundamental strategies that will be implemented to increase our volunteer base are (1) strengthen the relationship between the National Office and Chapters and Affiliates, (2) establish a comprehensive local network of knowledgeable HDSA volunteers, (3) deploy an "army of HD'ers" to give voice and action to HD causes and needs and (4) enhance the cultivation culture with consistent mechanisms for deepening relationships and expanding the organizational base. As the glue between the National Office and Field leadership, the National Field Committee will play an important role in the accomplishment of this Goal and will develop personal one-on-one relationships with Chapter and Affiliate leadership. From expanded resources on the Extranet to increased trainings through regional retreats and at the Annual Convention, the organization will invest in the volunteers who bring the Society to life. Also, there will be a concerted effort to bring new volunteers to HDSA with annual Goals, new relationship cultivation mechanisms and volunteer appreciation events. Furthermore, HDSA plans to have at least one Chapter or Affiliate in every state in the country.

Goal VI: Operate in a fiscally responsible manner.

To ensure the long-term health and growth of our Society, we must operate in a manner that provides for today and plans for tomorrow. We are committed to making timely payments to our grantees and vendors, and we know that fiscal responsibility earns trust. Additionally, we recognize the importance of having the appropriate operational reserves, so that we are a more stable, autonomous organization.

We will do this by (1) paying all grant funding obligations on time, (2) establishing a reserve of at least six months operating funds, (3) enhancing the transparency of the corporate culture with active engagement of the community and (4) maintaining or exceeding a 75 percent threshold in our mission/administrative funding ratio. Managing our cash flow and ensuring timely financial management in the Field will be vital to achieving this Goal. Additionally, an organization-wide effort to reduce the cost to raise a dollar (CTRAD) and therefore maximize the dollars invested into our mission programs will be launched. Finally, new online resources to encourage feedback about the organization's performance will be launched and funds will be regularly banked to establish financial reserves that protect the Society against risk and enable new program development.

Goal VII: Increase revenue to grow organizational capacity.

The last Goal could just as easily be the first -- without increased funding we can not increase the impact of our mission. The strengthening of our programs, expansion of our services and ability to fund ground-breaking research are directly tied to our ability to increase our revenue. To do this, we will continue to broaden our donor base, from inside and outside the Huntington's disease community, and redouble our commitment to our values of stewardship and accountability so that we continue to communicate clearly how our funds are changing lives.

To do this we will (1) increase our overall revenue by at least five percent annually. This will be achieved through expansion of our signature events, corporate and grant programs in the Field and by new individual giving programs at the National Office. Donor cultivation resources will be made available across the organization and collaboration throughout will be critical to taking advantage of funding opportunities. Next, we will (2) utilize new technology to radically change the way people give to the Society. From email campaigns to mobile giving, the Society will invest in and take advantage of new media to grow donor participation. These efforts will complement our work growing our volunteer base and as a result will have targeted mission messages that resonate with the appropriate donors. Lastly, (3) investing in a planned giving program to establish long-term stability financially will maximize the potential of our current – and yet to be identified – donor base, and it will allow the organization to do more for our HD families.

CLOSING THOUGHTS

Until Huntington's disease is eradicated, HDSA is of vital importance to our community, ensuring access to and developing more specialized HD care, fueling research, providing families with education, resources and support and advocating for regulatory and legislative change.

This Strategic Plan is a tool to help ensure that the Society remains effective and efficient in its ability to serve the HD community in its mission. As such, it will be an active, living document from which the annual Program of Work will be derived and which will be reviewed regularly to revisit timelines, push progress and help the Society evaluate opportunities.

It is notable that the period of the Plan is only five years – 2012 – 2016. Given how quickly the pace of HD science moves, it was the perspective of the Board that the document should not be too far reaching in its aims nor too short sighted. The HSDA Board of Trustees will monitor Strategic Plan accomplishment and modify the plan as we move forward. Additionally, at the beginning of 2015 a new Strategic Planning team will be convened to envision the next five years of the Society 2017 – 2021 to keep the work of HDSA current, responsive and realistic, but always expecting more from ourselves as we work to improve the lives of people with Huntington's disease and their families.

# # #

I. Our Goal: Build an *HD Community-service* organization.

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
1. Expand access to top clinical care.	– To increase the number of HDSA Centers of Excellence (COE) across the United States. – To accumulate the knowledge of the COE program to establish best practices. – To establish and promote a comprehensive list of HD care and service providers.	• HDSA Centers of Excellence • Physician and Care Referral Network • Web-based Continuing Medical Education (CME) program for physicians	➢ Publish “Decade of Centers” report on the COE program. ➢ Conduct COE needs assessment based on geography, community engagement and funding capacity. ➢ Work with COE directors to establish data pooling project. ➢ Launch web-based CME program. ➢ Update Referral Network tool online.	➢ Refine COE model. ➢ Develop training modules for new COE sites. ➢ Identify innovative programs for rural service delivery. ➢ Develop ancillary grant program for quality of life (QoL) initiatives. ➢ Re-accredit web-based CME program.	➢ Add and train two new COE’s. ➢ Expand Referral Network list to include ancillary healthcare professionals.	➢ Add and train two new COE’s. Ongoing Referral Network management.	➢ Add and train two new COE’s. Ongoing Referral Network management.
2. Enhance social services and support resources.	- To grow a network of regional social workers to augment chapter social worker network. - To expand delivery of services by educating and training non-HDSA social workers. - To strengthen support groups with training and resources. - To ensure that age	• Social Workers (SW) • Support Groups (SG) • National Youth Alliance (NYA) • Field Education Events • HDSA Annual Convention	➢ Develop collaborative opportunities between COE SW’s and Chapter SW’s. ➢ Launch regional SW program. ➢ Invite non-HDSA SW’s to Professional training.	➢ Pilot online Continuing Education Unit (CEU) modules for non-HDSA SWs. ➢ Recruit 2 regional SW’s (east/west). ➢ Develop strategies to integrate new resources into	➢ Recruit and integrate 3 regional SW. ➢ Build and present pyramid of social services. ➢ Integrate piloted non-HDSA SW in HDSA training activities. ➢ Ongoing communication	➢ Recruit 3 regional SW. ➢ Develop new social services delivery system using pyramid structure. ➢ Finish technical support for Electronic Medical Records – training in	➢ Recruit final 2 regional SW. ➢ Hold HDSA-only SW training at Convention 2016. ➢ Roll out new social services delivery system/ referral program. ➢ Have one educational event at 90% of

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
	appropriate support networks are available for HD youth. - To enhance programming at field-based educational events. - To host and broaden the impact and reach of a national community-wide, family-focused HD educational Convention.		➢ Hold standardized SG training at Convention using updated training materials. ➢ Pilot SG mentoring program. ➢ Continue to provide funding for field educational events. ➢ Hold Convention 2012 in Las Vegas and stream three live workshops. ➢ Draft Young Adult Recruiting Program for chapters to bridge NYA/Chapter gap.	HDSA SG network. ➢ Hold annual regional SG teleconferences with guest speakers. ➢ Continue to provide funding for educational events and introduce new workshop content. ➢ Develop standard ½ and full day programs. ➢ Hold Convention and stream more sessions live. ➢ Implement virtual NYA support groups where no live groups for this target group.	and annual regional teleconferences with guest speakers. ➢ Introduce one new workshop for educational events and introduce webcasting for larger events. ➢ Cluster NYA "sponsors" – older members to tutor/counsel younger members—online with other group members. ➢ Complete remote interactivity for Convention.	usage for families. ➢ Hold Convention. ➢ Hold regular Skype/data/video meetings of NYA Governing Committee and sub-committees.	chapters and 60 guest speakers at SGs annually. ➢ Add one new educational workshop annually. ➢ Hold regional NYA Meetings. ➢ National Convention – Streamed live online and available to other countries.
3. Improve access to long-term care facilities skilled in HD.	– To improve quality of life (QoL) for persons with HD, whether at home or in long-term care (LTC) facility. – To improve access to home-based and facility-based care. – To legislate to improve QoL for persons with HD.	• Best Practices Document • In-services	➢ Complete Report to Field on LTC. ➢ Begin development of standard in-service for HDSA social workers.	➢ Roll out in-service. ➢ Assess and prioritize recommendations from Field. ➢ Allocate funding for new initiatives based on stakeholder needs.	➢ Ongoing	➢ Ongoing	➢ Ongoing

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
4. Increase access to counseling on key HD-related decisions (clinical and logistical).	– To review international Genetic Testing (GT) guidelines. – To review and re-authorize GT centers. – To communicate roll-out of Genetic Information Non-Discrimination Act (GINA). – To provide long-term care (LTC) information. – To provide Disability information. – To develop online healthcare planning and implementation initiative. – To provide professional education to service delivery personnel.	• Genetic Counselors • Legal & Financial Resources (i.e. healthcare costs, eldercare planning, workplace discrimination)	➢ Review and approve revised GT guidelines. ➢ Develop reauthorization plan for current GT Centers. ➢ Update information on GINA and Disability. ➢ Develop healthcare planning initiative.	➢ Reauthorize current GT Centers and communicate to community. ➢ Expand network of GT Centers for HD. ➢ Roll- out healthcare planning initiative. ➢ Pilot continuing education for service delivery personnel on eldercare law, planning, etc. ➢ Launch series of Outside Speakers/ Consultants presenting on key issues – video plus PowerPoint – live with Q&A and archived.	➢ Ongoing ➢ Develop continuing training program for GC. ➢ Role-playing video library covering key issues (SSA, workplace discrimination, etc.)	➢ Ongoing	➢ Ongoing

II. Our Goal: Support HD research & communicate its impact.

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
1. Ensure pipeline of new HD researchers. *Also see Goal 1, strategy 1*	– To establish a new research program targeting young investigators (basic or clinical) to build a pipeline of new researchers. – To enable collaboration between basic and clinical scientists by involving the Centers of Excellence. – To support fellowships to young investigators.	• New research program (name to be determined) • Fellowships, i.e. Don King Fellowship (DKF) • Centers of Excellence	➢ Launch request for proposal (RFP) for new research program. ➢	➢ Announce and fund year one of 2013/14 round of research grants. ➢ Launch RFP for 2014/15 awards. ➢ Award DKF.	➢ Fund year two of 2013/14 and year one of 2014/15 grants. ➢ Launch RFP for 2015/16 awards. ➢ Award DKF.	➢ Fund year two of 2014/15 and year one of 2015/16 grants. ➢ Launch RFP for 2016/17 awards. ➢ Award DKF.	➢ Fund year two of 2015/16 and year one of 2016/17. ➢ Launch RFP for 2017/18 awards. ➢ Award DKF.
2. Strengthen and build partnerships with research partners.	- To build community understanding of HD research to motivate clinical research participation. - To position HDSA as a central source for HD community engagement in clinical research.	• HDBuzz • HD organizations (such as CHDI, Huntington Study Group (HSG), European HD Network (EHDN) and International Huntington Association (IHA) • Corporate relations	➢ Ongoing EHDN Working Group Cooperation, i.e. JHD, Young Adults. ➢ Continue to collaborate with HDBuzz to bring research information to the community. ➢ Ongoing consultation with pharmaceutical companies and biotechnology companies. ➢ Ongoing collaboration with	➢ Introduce "Meet the Scientists" webinars live and on video.	➢ Introduce Young HD Researchers presentations – live and on video – covering why they got into HD and their work.	➢ Host "Pipeline Conference" – Evaluate where HD community stands at this point and what areas need more promotion/ support.	➢ Publish monograph – "HDSA and HD 50 Years of Progress" – prepare for HDSA 50th anniversary.

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
			CHDI, IHA, EHDN, HSG, and other organizations. Continue support of Induced Pluripotent Stem Cell initiative with National Institute of Health.				
3. Establish a dynamic and reputable set of advisors to proactively position Society's lead role in discovery.	- To oversee and coordinate HDSA's research program and scientific initiatives.	• Director of Scientific Affairs (DSA) • Medical and Scientific Affairs Committee (MSAC)	➢ Hire DSA. ➢ Convene MSAC.	➢ Ongoing	➢ Ongoing	➢ Ongoing	➢ Ongoing
4. Fuel clinical research by ensuring active enrollment in clinical studies.	- To promote clinical and observational research opportunities. - To increase community knowledge of the importance and power of clinical research.	• HDTrials.org • HDSA Diplomats • Leverage HDSA community (i.e. Chapters, Affiliates, Social Workers, Support Groups)	➢ Utilize Diplomats at field educational events and support groups. ➢ Continue in-person and web-based training of Diplomats to build network. ➢ Develop new quality of life grants to COEs for non-interventional research studies to promote study participation. ➢ Promote	➢ Bring all Diplomats to pre-Convention meeting for one-day training and science session. ➢ Offer annual training on new research studies to non-COE social workers and all support group leaders. ➢ Launch quality of life grants. ➢ Expand communications strategy to raise awareness of	➢ Post regular Trial/Study updates by study principal investigators on website.	➢ Compile international round-up of clinical trials in HD and compare to other genetic & neurodegenerative diseases. ➢ Host conference of scientists and families to evaluate where clinical research progress stands.	➢ Ongoing

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
			HDTrials registration at all HDSA events. ➢ Add logic-tree to HDTrials.org and HDSA.org to improve patient navigation.	clinical trials.			

III. Our Goal: Remove barriers to quality care.

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
1. Pass legislation that directly improves the quality of life of HD families.	- To secure the passage and implementation of the HD Parity Act. - To obtain Compassionate Allowance designation that fast-tracks disability claims for people with HD. - To increase grassroots engagement and identify/train grasstops	• E-Advocacy • Congressional events • Policy statements	➢ Ongoing. Utilize new initiatives to gain sponsors. ➢ Develop strategies to obtain designation for HD. ➢ Hold regional trainings for grasstop development.	➢ Reconsider strategy at Q3 of 2013 to coincide with Congress adjourning. ➢ Train grasstops to respond on local level to issues.	➢ Develop advocacy pyramid utilizing grasstops as local leaders.		
2. Expand HD benefits in health insurance coverage.	- To ensure major symptoms of HD covered by health exchanges. - To collaborate with other agencies with conditions facing similar symptoms (i.e. mental health, depression, etc).	• E-Advocacy • Congressional events • Policy Statements	➢ Engage grassroots in dialog at state level (letters, calls, etc). ➢ Utilize opportunities to place grasstops on advisory boards. ➢ Collaborate with like-minded agencies to affect wholesale change in coverage (i.e. National Health Council, NORD).		➢ Health insurance exchange program roll out of essential benefits with HD coverage. ➢ Review official HDSA policy statements to make sure current on issues.		

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
3. Reduce discrimination towards people with HD. *Also see Goal 1, strategy 4*	- To develop tools for stakeholders that de-stigmatize HD in the community. - To educate stakeholders on legislation and programs that ensure a positive result the first time.	• Law enforcement • Disability • GINA	➢ Complete law enforcement project for community. ➢ Launch disability information resources online. ➢ Follow GINA roll out (timeline TBA). ➢ Hold online trainings for families on the topics of disability and GINA.	➢ Roll out part two of the law enforcement program. ➢ Ongoing support for disability process. ➢ Launch new online trainings for healthcare professionals on legal issues. ➢ Develop "professional" section on national web site.	➢ Launch new online trainings on legal issues for HD community. ➢ Develop compendium of online materials. ➢ Roll out "professional" section with password protected access for additional resources. ➢ Add healthcare professionals to resource list.	➢ Ongoing	➢ Ongoing
4. Increase the number of HD specialized physicians and related care providers. **Also see Goal 1, strategy 1.*	- To offer web-based trainings to primary care providers (PCP), general practitioners and healthcare professionals not familiar with HD. - To offer limited face-to-face learning opportunities (if funding permits.) - To tap into medical residents program at Centers of Excellence (COE) and movement disorder centers. - To design a medical residents mini "HD101" offered through Centers of Excellence.	• CME Physician Training Program • The Physician's Guide & other publications	➢ Launch web-based Continuing Medical Education (CME) program. ➢ Continue to offer Physicians' Guide program with resulting resource gathering.	➢ Develop mini-HD101 residency course for medical residents at COE sites. Pilot at 4 COEs. ➢ Obtain funding and offer one face-to-face training for PCPs on resource list who had not taken web-based CME. ➢ Renew accreditation of web-based CME.	➢ Expand the mini-residency program across COE program. ➢ Pilot same course at handful of movement disorder centers. ➢ Recruit additional MDC sites for 2015.	➢ Launch mini residency program at MDC centers. ➢ Offer one face-to-face training for PCPs on resource list who had not taken web-CME. ➢ Renew accreditation on web CME.	➢ Bring all "graduates" from CME course and mini-residency course to new one day continuing education course.

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
	- To capture names for future referrals. - To develop continuing education opportunities for primary care providers (PCP) and graduates of web-CME and mini-residency program.						

IV. Our Goal: Become the premier communicator of HD information.

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
1. Enhance knowledge of HD and HD science. *See Goal II, strategy 2.*	- To educate stakeholders on research, programs, services and advocacy initiatives of society. - To continuously engage stakeholders by providing information of interest to them. - To communicate news to community in timely manner.	• HDSA.org • HDTrials.org • Social media • Publications (i.e. *The Marker, Toward A Cure, We Are HDSA*)	➢ Ongoing engagement through HDSA publications and Caregiver's Corner/Lunch & Learns. ➢ Relaunch of HDSA.org with "Ask the Scientist" column. ➢ Social media presence expanded.	➢ Reports (text and video) from scientists, clinicians and family members regularly updated online. ➢ Launch mobile site (for easy access by smartphones) version of website.	➢ Feature Young Researchers at HDSA events (Field & National) to discuss their HDSA grants.	➢ Ongoing feature of Young Researchers at HDSA events (Field & National) to discuss their HDSA grants. ➢ In preparation for 50th Anniversary, prepare "Pipeline Conference" to evaluate where HD treatments stand and what areas need more support.	➢ Ongoing
2. Increase awareness of HD among the general population.	- To increase accurate media coverage and representation of HD. - To 'normalize' HD with a more informed populace. - To educate stakeholders on issues of importance to HD community.	• HD Awareness Month • Media – all forms	➢ Promote "Faces of HD" campaign in every market/Chapter/ Affiliate. ➢ Conduct outreach to local media. ➢ Host video contest. ➢ Launch "Relevance of HD" campaign.	➢ Ongoing new initiatives. ➢ Expand "Faces of HD" to showcase HD Heroes where people talk about (on video and in print) their HD experiences as participant in trial, volunteer creating an event, etc.	➢ Ongoing new initiatives. ➢ Create digital HDSA archives for use by Society and available to media and external audiences.	➢ Ongoing new initiatives.	➢ Ongoing new initiatives.

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
3. Expand awareness of HDSA.	- To build reputation of HDSA as the first source of HD information. - To enhance organizational capacity in advocacy efforts.	• Brand campaigns • Media, including Social media	➢ Launch new HDSA.org. ➢ Promote new strategic plan and conduct HDSA marketing campaign among community and stakeholders. ➢ Utilize Facebook presence to engage community in advocacy efforts. ➢ Expand Social Media presence. ➢ Actively utilize Public Relations to highlight HDSA achievements. ➢ Launch regular HDSA newsletter.	➢ Ongoing	➢ Ongoing	➢ Ongoing	➢ Ongoing

V. Our Goal: Grow volunteer involvement.

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
1. Strengthen relationship between the National Office and Chapters.	- To build a strong, ongoing dialogue between the NFC and Chapters that fosters a “we” and not “us vs. them.” - To create a Leadership Training Day at Convention that engages chapter leadership with new and powerful ideas to help build or strengthen their impact in their communities. - To have clear expectations and policies regarding the Field and National relationship.	• National Field Committee (NFC) • Leadership Day at Convention	➢ Monthly outreach from all NFC members to Chapter Leadership. ➢ Host Leadership Day at Convention with representation from every chapter and affiliate.	➢ Communicate teamwork approach to organizational success – “We are HDSA”. ➢ Enlist 2 new members of NFC. ➢ Update and implement Annual Chapter and Affiliate Charters. ➢ Host Convention Leadership Day at representation from every chapter and affiliate.	➢ Conduct annual review of Chapter/Affiliate performance. ➢ Ongoing evaluation of NFC relationships with field organizations. ➢ Enlist 2 new members of NFC. ➢ Host Leadership Day at Convention with representation from every chapter and affiliate.	➢ Ongoing	➢ Ongoing
2. Establish comprehensive local network of knowledgeable HDSA volunteers.	- To have at least one Chapter or Affiliate in every state. - To ensure that Affiliates apply for Chapter status (should not be affiliates for more than 4 years). - To have all 9 regions host a regional leadership retreat. To create a regional volunteer recognition program.	• NFC • Chapter or Affiliate in each state • Board development resources and trainings • Regional Retreats • Appreciation program	➢ Add 2 Affiliates and 1 Chapter. ➢ 3 Regions host regional leadership Retreats. ➢ Launch volunteer recognition program in those 3 regions to thank those who give repeatedly.	➢ Add 2 Affiliates and 1 Chapter. ➢ 5 Regions to host regional leadership Retreats. ➢ Launch volunteer recognition program in those 5 regions to thank those who give repeatedly.	➢ Add 2 Affiliates and 1 Chapter. ➢ 7 Regions to host regional leadership Retreats. ➢ Hold volunteer recognition program in those 7 regions to thank those who give repeatedly.	➢ Add 2 Affiliates and 1 Chapter. ➢ 9 Regions to host regional leadership Retreats. ➢ Hold volunteer recognition program in those 9 regions to thank those who give repeatedly.	➢ At least 55 Chapters and Affiliates nationwide. ➢ All Regions to host a regional leadership retreat and volunteer recognition program.

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
3. Deploy "HD Army" to give voice and action to HD causes and needs.	- To interconnect HD field volunteers, program participants, advocates, stakeholders, donors and supporters for coordinated outreach.	• Donors • E-advocates • NYA • Clinical research participants • Physicians, Social Workers & Support Groups • General online community	➢ Implement centralized database system with web interface for community-wide engagement.				
4. Enhance cultivation culture with consistent mechanisms for deepening relationships and expanding organizational base.	- To increase the number of volunteers who support the HDSA mission. - To create a "welcome to HDSA committee" in regions, chapters and affiliates to help train new volunteers and be the HDSA key contacts for their community. - To openly communicate appreciation and value for HDSA volunteers. supporters.	• Annual "new volunteer" Goal • Customer Relations Management system (aka centralized database) • "Thank You Thursdays"	➢ Add 212 new volunteers across the country ➢ Recognize Chapters, Affiliates and Regions at Convention for adding new volunteers. ➢ 5 Chapters and Affiliates create welcome committees and recruit volunteer leaders. ➢ Thursday night leadership reception at convention becomes the "Thank You Thursday" for Chapter and Affiliate Volunteers.	➢ Add 213 new volunteers across the country ➢ 12 Chapters and Affiliates create welcome committees and recruit volunteer leaders. ➢ Host "Thank You Thursday" events in 3 regions.	➢ Add 214 new volunteers across the country ➢ 22 Chapters and Affiliates create welcome committees and recruit volunteer leaders. ➢ Host "Thank You Thursday" events in 5 regions.	➢ Add 215 new volunteers across the country ➢ 34 Chapters and Affiliates create welcome committees and recruit volunteer leaders. ➢ Host "Thank You Thursday" events in 7 regions.	➢ Add 216 new volunteers across the country ➢ All Chapters and Affiliates create welcome committees and recruit volunteer leaders. ➢ Host "Thank You Thursdays" events in all regions.

VI. Our Goal: Operate in a fiscally responsible manner.

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
1. Pay all grant funding obligations on time.	– To provide adequate funding to support the Society's grant funding obligations. – To have all Chapters cut checks to national when their bank accounts exceed allowable dollars.	• Cash flow • Field cash management	➢ Discuss at Annual Leadership Day ➢ Develop procedure for field payments and communicate clearly what the allowable bank totals should be. ➢ Pay balance on grants awarded in FY11 and all current year grants.	➢ Ensure cash flow from the Chapters to the National Office is on schedule. ➢ Pay all current year grants.	➢ Maintain timely cash flow from the Chapters to the National Office. ➢ Pay all current year grants.	➢ Maintain timely cash flow from the Chapters to the National Office. ➢ Pay all current year grants. ➢ Consolidate to one nationwide bank for all Chapters and National Office.	➢ Maintain timely cash flow from the Chapters to the National Office. ➢ Pay all current year grants.
2. Establish reserve of at least 6 months operating funds.	- To implement a Board Reserve Policy and establish a Board Reserve account that will be available for operating shortfalls (if needed) with funding of at least 6 months of operating expenses.	• Board reserve policy • Quarterly payments to 'savings' account	➢ Create a clearly defined Board Reserve Policy. ➢ Fund reserve account on a quarterly basis.	➢ Fund reserve account on a quarterly basis for a fully funded account by the end of the fiscal year.	➢ Maintain a fully funded account that is reviewed on a quarterly basis for compliance with the Board Reserve Policy.	➢ Ongoing	➢ Ongoing

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
3. Enhance transparency of corporate culture with active engagement of community.	- To continue to update Extranet and ensure volunteers are regularly visiting this for updates in communication. - To add transparency and corporate culture content to Leadership Training and regional leadership calls. - To enforce the Whistle Blower Policy with online monitoring through a third party vendor for use by the entire HD community. - To ensure communications plans and activities reflect open dialogue from top leadership.	• Ethicspoint • Extranet • Policy distribution & adherence (consistent among field)	- Update Extranet - Update ethics policy paperwork regularly. - Add topic to agendas for regular updates to reinforce transparency. - Hold bi-yearly training for all Chapter Officers. - Provide training to staff and volunteers on the online monitoring system (Ethicspoint). - Roll out the online system to the HD community.	➢ Monitor monthly reporting from the online system and address all concerns.	➢ Ongoing	➢ Ongoing	➢ Ongoing
4. Maintain or exceed 75% threshold in mission/admin funding ratio.	– To monitor the operating results of all event activities and locations to ensure a ratio to meet or exceed the threshold of 75% in mission/admin expenses. – To educate staff and volunteers on Cost to Raise a Dollar management (CTRAD). – To ensure that monthly reporting and budgets are submitted and adhered to.	• Cost to Raise a Dollar Management (CTRAD) • Operational efficiency	➢ Review budgets to confirm spending ratios are in compliance before being presented for approval. ➢ Review quarterly y-t-d reports by staff with volunteers to track progress. ➢ Achieve ratio in year-end audit results. ➢ CTRAD added to	➢ Ongoing budget management and reporting. ➢ Adopt new technologies as developed.	➢ Ongoing	➢ Ongoing	➢ Ongoing

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
			agenda items for regional calls/ meetings and discussed at Leadership Day ➢ Staff and NFC to send reminders or make calls to ensure reports are submitted monthly and budget Goals are being met.				

VII. Our Goal: Increase revenue to further support the mission work of the Society.

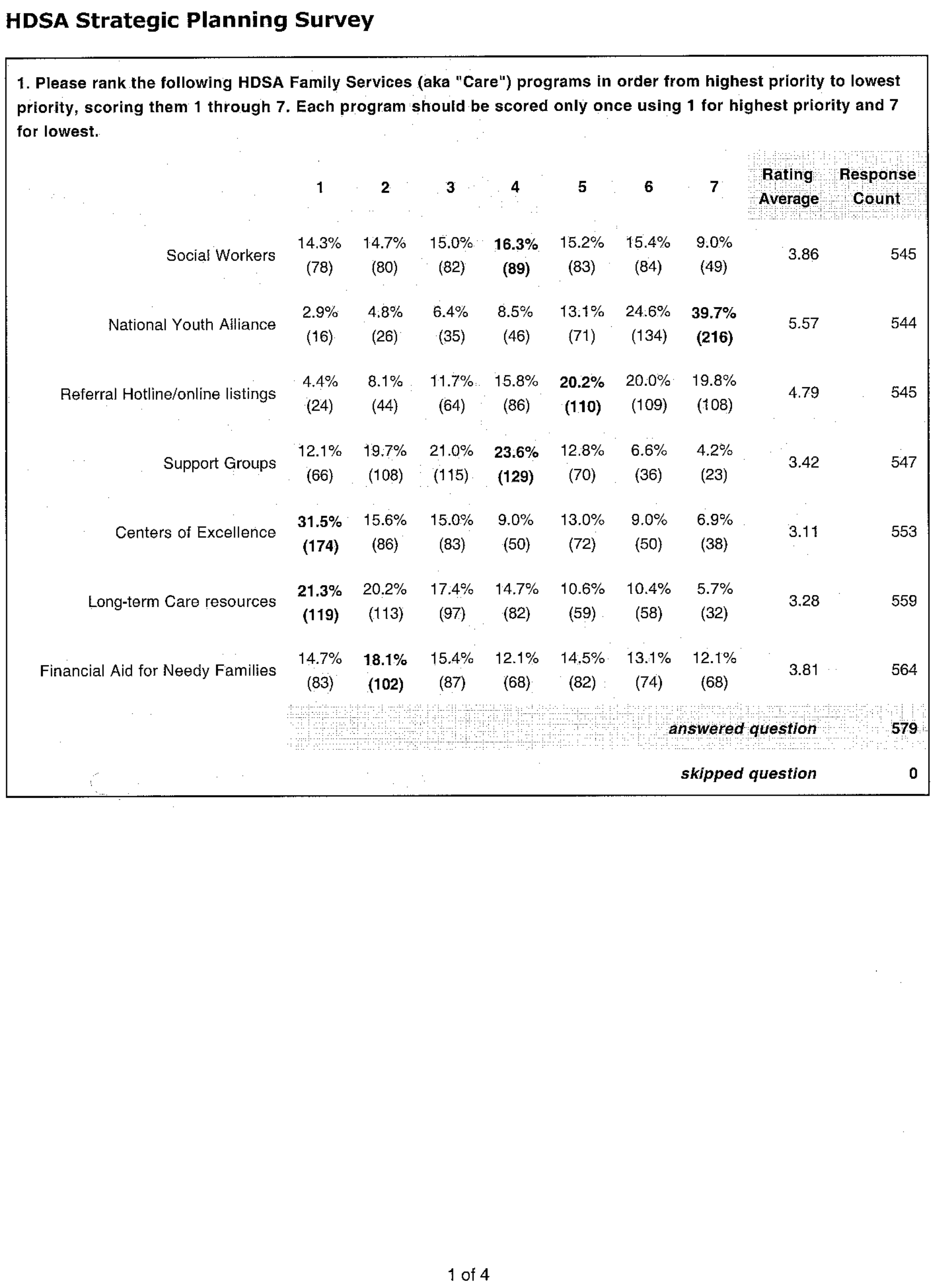
Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
1. Increase overall revenue by at least 5% annually.		– Individuals – Corporations – Foundations – Government – Signature events	➢ *Raise $8.4 million overall*	➢ *Raise $8.82 million overall*	➢ *Raise $9.2 million overall*	➢ *Raise $9.72 million overall*	➢ *Raise $10.2 million overall*
	FIELD – To add new Team Hope Walks in markets across the country. – To hold Celebration of Hope (COH) events for each Centers of Excellence (COE). – To encourage more people to give online. – To increase grant and corporate support. – To have Staff, Chapters and Affiliates exceed their budgets.		➢ Host 10 new TH Walks. ➢ Hold 15 COHs. ➢ Create incentives for online giving. ➢ Secure $125K in national event sponsorships. ➢ Raise $10K in grants per region.	➢ Host 10 new TH Walks. ➢ Hold 17 COHs. ➢ Secure $150K in national event sponsorships. ➢ Raise $15K in grants per region.	➢ Host 10 new TH Walks. ➢ Hold 19 COHs. ➢ Secure $200K in national event sponsorships. ➢ Raise $20K in grants per region.	➢ Host 5 new TH Walks. ➢ Hold 21 COHs. ➢ Secure $225K in national event sponsorships. ➢ Raise $25K in grants per region.	➢ Host 5 new TH Walks. ➢ All COE's recognized at a local COH. ➢ Secure $250K in national event sponsorships. ➢ Raise $30K in grants per region.

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
	NATIONAL – To increase the number of individual donors through all National fund raising campaigns. – To create a major gift program based on new research funding program. – To create a program to regularly communicate with individual donors as form of stewardship & cultivation. – To institute a collaborative program with the Field staff to identify individuals who have the capacity to make a major gift. – To actively engage the Development Committee in the stewardship & cultivation of individual major donors. – To expand corporate support base and increase corporate support with new partnerships to support National initiatives. – To collaborate with Education & Program Services Dept. to identify programs and services that require underwriting.		➢ Utilize e-campaigns to increase number of donors. ➢ Launch major donor program for research with related marketing materials. ➢ Use e-newsletters to cultivate donors & develop special research update for donors $10K and above as ongoing stewardship. ➢ Establish field-based donor identification program. ➢ Hold solicitation training for National Board of Trustees and Development Committee.	➢ Marketing materials updated for research funding campaign.	➢ Ongoing cultivation, training and updating of materials.	➢ Ongoing cultivation, training and updating of materials.	➢ Launch major donor campaign for 50th Anniversary of HDSA. ➢ Ongoing cultivation, training and updating of materials.

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
2. Utilize new technology to radically change ways people give to the Society.	– To work collaboratively with Communications/ Marketing Dept. to develop new methods & messages to communicate & solicit donors & cultivate potential donors. – To have all Nat'l broad based ground mail appeals be sent electronically as well. – To transition donors that respond to e-campaigns from receiving ground mail appeals. – To utilize social media to distribute fund raising messages. – To communicate with donors online in ways other than soliciting. – To create a Cell Phone Giving program.	• E-campaigns • Text, podcasts, etc • Cell phone based fundraising	➢ Send all Nat'l broad based ground mail appeals via email. ➢ Transition donors that respond to e-campaigns from receiving ground mail appeals. ➢ Use social media to distribute fund raising messages. ➢ Utilize e-newsletter and other tools to communicate with donors for non-solicitation resources. ➢ Research and prepare for cell phone giving program. ➢ Conducted e-mail direct mail campaigns.	➢ Develop targeted micro-campaigns for select DM donors. ➢ Continue use of social media to underscore revenue messages. ➢ Roll out program for cell based giving.	➢ Conduct video direct email campaigns featuring scientists and family members.	➢ Ongoing evaluation of new technology and giving trends to refine appeals.	➢ Collaborate with Communications & Marketing Dept on developing e-campaign to celebrate 50th anniversary.
3. Invest in planned giving program to establish long-term stability financially.	- To develop special campaign to create an endowment. - To identify individuals that are current donors who may be prospects for planned gift and conduct targeted appeal to them.	• Wealth research tools • Legal advisors	➢ Create endowment campaign theme and plan. ➢ Identify and conduct targeted campaign for individuals identified that are	➢ Collaborate with Field staff on identifying prospects for planned gifts. ➢ Ongoing	➢ Ongoing	➢ Ongoing	➢ Endowment materials & promotion updated to tie into 50th anniversary in 2017

Strategies	Objectives	Initiatives	2012	2013	2014	2015	2016
	- To establish collaborative program with Field staff on identifying prospects for planned gifts. - To establish team of advisors to help craft planned gifts and work with prospects on the different vehicles as desired.		current donors who maybe a prospect for planned gift. ➢ Establish team of advisors to help craft planned gifts and to work with prospects.				

APPENDIX A:



HDSA Strategic Planning Survey

1. Please rank the following HDSA Family Services (aka "Care") programs in order from highest priority to lowest priority, scoring them 1 through 7. Each program should be scored only once using 1 for highest priority and 7 for lowest.

	1	2	3	4	5	6	7	Rating Average	Response Count
Social Workers	14.3% (78)	14.7% (80)	15.0% (82)	**16.3%** **(89)**	15.2% (83)	15.4% (84)	9.0% (49)	3.86	545
National Youth Alliance	2.9% (16)	4.8% (26)	6.4% (35)	8.5% (46)	13.1% (71)	24.6% (134)	**39.7%** **(216)**	5.57	544
Referral Hotline/online listings	4.4% (24)	8.1% (44)	11.7% (64)	15.8% (86)	**20.2%** **(110)**	20.0% (109)	19.8% (108)	4.79	545
Support Groups	12.1% (66)	19.7% (108)	21.0% (115)	**23.6%** **(129)**	12.8% (70)	6.6% (36)	4.2% (23)	3.42	547
Centers of Excellence	**31.5%** **(174)**	15.6% (86)	15.0% (83)	9.0% (50)	13.0% (72)	9.0% (50)	6.9% (38)	3.11	553
Long-term Care resources	**21.3%** **(119)**	20.2% (113)	17.4% (97)	14.7% (82)	10.6% (59)	10.4% (58)	5.7% (32)	3.28	559
Financial Aid for Needy Families	14.7% (83)	**18.1%** **(102)**	15.4% (87)	12.1% (68)	14.5% (82)	13.1% (74)	12.1% (68)	3.81	564
								answered question	**579**
								skipped question	**0**

1 of 4

2. Please rank the following HDSA Research (aka "Cure") programs in order from highest priority to lowest priority, scoring them 1 through 3. Each program should be scored only once using 1 for highest priority and 3 for lowest.

	1	**2**	**3**	**Rating Average**	**Response Count**
Fellowships (For young investigators to encourage them to pursue HD research)	26.4% (149)	29.7% (168)	**43.9% (248)**	2.18	565
Coalition for the Cure (For basic research to find new therapeutic targets)	**47.9% (268)**	31.6% (177)	20.5% (115)	1.73	560
Grants (To established investigators for specific projects)	27.5% (155)	**38.7% (218)**	33.7% (190)	2.06	563
			answered question		**579**
			skipped question		**0**

3. Please rank the following HDSA Advocacy programs in order from highest priority to lowest priority, scoring them 1 through 3. Each program should be scored only once using 1 for highest priority and 3 for lowest.

	1	**2**	**3**	**Rating Average**	**Response Count**
E-Advocacy (letter-writing through the internet)	30.7% (173)	30.7% (173)	**38.5% (217)**	2.08	563
Advocacy Day on Capitol Hill	**36.4% (204)**	32.6% (183)	31.0% (174)	1.95	561
Support for Local/Grassroots Advocacy Initiatives, i.e. in-district meetings	34.4% (196)	**36.2% (206)**	29.3% (167)	1.95	569
			answered question		**579**
			skipped question		**0**

4. Please rank the following HDSA Education programs in order from highest priority to lowest priority, scoring then through 8. Each program should be scored only once using 1 for highest priority and 8 for lowest.

	1	2	3	4	5	6	7	8	Rating Average	Res C
Caregiver's Corner Webinars	8.7% (48)	8.7% (48)	9.6% (53)	14.3% (79)	15.7% (87)	13.2% (73)	13.7% (76)	**16.1% (89)**	4.95	
Educational Publications	4.0% (22)	10.2% (56)	12.5% (69)	16.9% (93)	17.1% (94)	**17.6% (97)**	13.2% (73)	8.5% (47)	4.81	
HDSA.org Website	**24.3% (135)**	14.9% (83)	13.7% (76)	12.1% (67)	11.3% (63)	9.7% (54)	9.4% (52)	4.7% (26)	3.61	
Education about Clinical Trials	11.8% (66)	17.1% (96)	15.9% (89)	**18.0% (101)**	12.7% (71)	11.3% (63)	7.9% (44)	5.4% (30)	3.95	
HD Continuing Medical Education Training for Physicians	**27.1% (152)**	19.8% (111)	15.2% (85)	9.1% (51)	11.4% (64)	7.1% (40)	6.3% (35)	3.9% (22)	3.24	
Educational Videos	2.4% (13)	4.1% (22)	7.2% (39)	8.9% (48)	14.1% (76)	19.0% (102)	20.1% (108)	**24.2% (130)**	5.86	
General Public Awareness/Education	**16.4% (91)**	15.7% (87)	13.7% (76)	9.7% (54)	8.5% (47)	12.3% (68)	13.9% (77)	9.7% (54)	4.19	
National HDSA Convention	7.6% (42)	10.1% (56)	13.0% (72)	11.0% (61)	8.7% (48)	9.4% (52)	14.3% (79)	**26.0% (144)**	5.18	
									answered question	
									skipped question	

5. Please rank the four mission areas of the HDSA in order from highest priority to lowest priority, scoring them 1 through 4. Each number area should be scored only once using 1 for highest and 4 for lowest priority.

	1	2	3	4	Rating Average	Response Count
Advocacy	10.1% (56)	18.0% (100)	30.9% (172)	**41.1% (229)**	3.03	557
Education	5.6% (31)	18.0% (100)	**42.2% (234)**	34.2% (190)	3.05	555
Family Services	35.0% (198)	**36.8% (208)**	17.5% (99)	10.6% (60)	2.04	565
Research	**50.2% (286)**	26.8% (153)	9.3% (53)	13.7% (78)	1.86	570
					answered question	**579**
					skipped question	**0**

APPENDIX B:
HDSA Research Planning Meeting
White Paper

Meeting Description:

As part of the HDSA's ongoing Strategic Planning Initiative, a meeting was held in Boston on 28 April 2011 to discuss the best way to focus a research direction for HDSA.

- Attendees (alphabetical):
    - Jang-Ho Cha, MD PhD, Chair, CPEAC, former *Coalition for the Cure* Investigator, and Strategic Planning Committee member
    - Kenneth Fischbeck, MD, Chief, Neurogenetics Branch, National Institute of Neurological Disorders and Stroke, and former Chair of the *Coalition for the Cure* Steering Committee
    - Marcy MacDonald, PhD, Massachusetts General Hospital, Chair, MSAC and current *Coalition for the Cure* Investigator
    - Karen Marder, MD, Chair, Parkinson Study Group, and Director, Columbia University *Center of Excellence*
    - Rick Morimoto, PhD, Northwestern University. Current *Coalition for the Cure* Investigator
    - Harry Orr, PhD, University of Minnesota, Chair, *Coalition for the Cure* Steering Committee
    - Ira Shoulson, MD, Chair, Huntington Study Group; Director, Program in Regulatory Science & Medicine, Georgetown University
    - Louise Vetter, CEO, HDSA

Executive Summary -- High-Level Team Recommendations:

1. HDSA should recruit and hire a Medical-Scientific Director to oversee and coordinate research programs going forward.
2. HDSA should develop a new research program, targeting young investigators (basic or clinical) and focusing on collaborations between basic and clinical science.
    a. This program would be targeted at young investigators who, in the pilot year, would be mentored by experienced HDSA investigators.
    b. Projects would involve collaboration with an HDSA *Center of Excellence* (COE).
    c. This program would be initiated with its first candidates who would be mentored by current or past *Coalition for the Cure* (C4C) investigators, in collaboration with current HDSA COEs. After the pilot period, this application would be opened up to applicants with non-C4C mentors.
    d. Recommendation is for 10 Research Projects a year @ ~$75,000 per year, and would ideally expand as funding becomes available.
    e. Research fellows and their mentors would meet annually in conjunction with the annual HDSA Convention.
3. Sufficient funding must be confirmed in advance to guarantee that research commitments are covered.

DETAILS

HDSA Commitment to Research

At present, HDSA is completing its funding commitments to *Coalition for the Cure* investigators and *Centers of Excellence.*, The HDSA Board has unanimously decreed that research remains fundamental to HDSA's mission. Commitments to research must be underpinned by sound financial practices, so that future payments are not delinquent. The Board also recognizes that "research" is a broad term, and that many different types of research serve to benefit HD patients and families. In this context, the ideal research program will: benefit HD patients and families, capitalize on the strategic advantages that HDSA has as an organization, and not be duplicative of existing research efforts. HDSA should therefore support research in a manner that optimizes the resources of the organization.

Strategic Advantages

In order to inform the optimal research strategy, participants discussed HDSA's strategic advantages, including, but not limited to:

- Strong relationship with HD patients and families
- Dedicated families for research
- Dedicated collaborative research community
- Dedicated clinicians
- Respected "brand" of HD within the research community: priority disorder involving research, public policy, genetic issues
- HD is a vanguard disease and model for other neurodegenerative disorders
- Courageous community, including youth movement
- Unanimous commitment to research from the HDSA Board of Trustees

In addition, several successes of existing and past programs were discussed, especially as pertains to research.

- The *Coalition for the Cure* is a novel paradigm of collaborative cutting-edge research
- Grants and Fellowships have been effective at recruiting talented researchers into the HD field, as well as providing seed monies that leverage NIH funding
- Recognition that substantial research activities are occurring and the HDSA has strong visibility at the academic medical centers of the 21 existing *Centers of Excellence*

Things to Avoid

Several pitfalls to be avoided were identified, including:

- No R01-style grant akin to those funded by NIH
- Arbitrary division between "Care" and "Cure" boxes
- Funding research without funding securely in place

Priorities for a new HDSA Research Program

Several important factors were considered as part of HDSA's research program. One critical aspect was the ability to attract and retain talented young investigators, in order to ensure a vibrant corps of future researchers. Another critical aspect was to make the best use of the existing world-class expertise represented in the current *Coalition for the Cure* investigators. To this point, the arbitrary division between "Care" and "Cure" has not adequately acknowledged the important research occurring at existing *Centers of Excellence.* Integrating the COE's into the research program would not only raise the awareness of such activities, but would also provide a clinical context for basic science researchers who may not otherwise focus on clinical questions. Indeed, integrating the *Centers of Excellence* into HDSA's research program leverages important strategic advantages, and unifies both the "Cure" and "Care" missions of the organization.

The recruitment and hiring of a HDSA Medical-Scientific Director were judged to be a very high priority in ensuring that any research programs undertaken would be of the highest quality and efficiently administered. In addition, such a dedicated Medical-Scientific Director (preferably MD and/or PhD degree with a background in neurodegenerative diseases, genetics and non-profit organizations) could provide timely and consistent guidance to HDSA about medical and scientific issues.

Proposed Program

A new *Coalition* model was proposed, one that integrates the best aspects of the current *Coalition for the Cure,* the Grants and Fellowships program, and the *Centers of Excellence.* An evolutionary process is envisioned, with subsequent expansion as made feasible by financial constraints.

All projects will have a clinical component, rooted in one of the existing *Centers of Excellence.* For the first pilot year, projects will be awarded to junior investigators who are mentored by current or past *Coalition for the Cure* Investigators. After the first year, the program would be opened to applicants with non-*Coalition for the Cure* mentors, to engage the broader research community. The proposal is that 10 junior scientists would be funded. This model is explicitly collaborative: involving collaboration with a *Center of Excellence.* Some examples include:

- Using blood samples or induced Pluripotent Stem (iPS) cells from COE patients to explore a biomarker hypothesis
- Clinical research projects targeting disease phenotype, measuring treatment intervention, or caregiver burden

The proposed model is explicitly collaborative, hopefully fostering cross-disciplinary interactions. While some current *Coalition* Investigators are at institutions with a COE*,* not all are. HDSA will therefore serve as a clearing house in order to match those COE's that are willing to collaborate with investigators. It is critical that HDSA hire a Director of Medical and Research Affairs in order to coordinate such a program. Such a research program has the potential to raise the research visibility of existing COE's. The first year cost of the program would be $75,000 per project, as well as the cost of a yearly meeting and the HDSA staffing = ~ $1 million a year. The intent would be to pilot the program initially restricting to those candidates who would be mentored by senior *Coalition* Investigators, and to current COE's. In subsequent years, the expectation is that this application process would be opened up to non-Coalition applicants, collaborating with HDSA COE's. Note that such a research program does not require any change in existing COE's; those COE's with an interest in participating may declare their interest.

Coalition Fellows, along with their mentors, would present their findings in a yearly scientific meeting, ideally to be held at the same time as the HDSA Convention. This yearly meeting would be a critical part of the program, as an important role of the Society is to communicate its research program to its constituency.

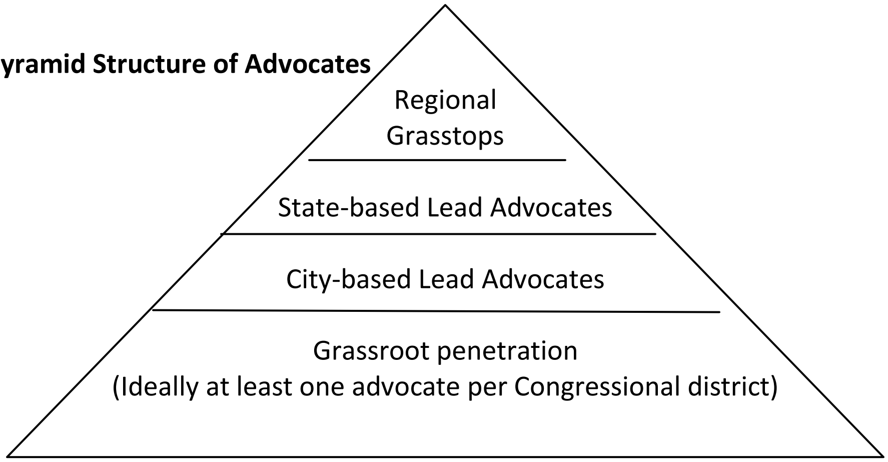
The group recommended forming a working group, comprised of current COE directors and current *Coalition* Investigators, to flesh out the actual program and create the request for application (RFA).

Strategic Planning: Advocacy Workgroup
Conference Call held September 21, 2010
Participants: Steve Ireland, Deb Lovecky, Steve Seekins & Louise Vetter

Newest Mission area – only 2.5 years old

- Very effective – huge community mobilization response and very little staff time (part Jane and part Deb)
- Still acclimating to the process – Committee getting on schedule of meetings, public policy statements under review
- Program is more reactive than proactive: HR678 is our first Proactive legislative initiative
- Concern regarding pushing too hard

Goal to build Pyramid Structure of Advocates



- Need to have multiple regional advocates so that we are prepared to take on multitude of issues
- Timeframe to do this?   Right now only 2 states don't have some support for HR678
    - Consider mapping current advocacy base
- HR678 is the perfect community-wide advocacy initiative: engages everyone
    - Many bills will not resonate as broadly
    - With stronger program will need to be prepared to educate advocates about niche issues, which may be equally as important but have direct impact on fewer families at the time
- With more engaged community, will be more prepared to take on local/state legislation
- Must educate grasstops about the legal rules of non-profit advocacy
    - Specific rules for 501c3 organizations, i.e. not candidate endorsement
    - Hold grasstops meeting at convention
    - Continuous training opportunities through lead advocate network (webinars?)
- Capitol Hill event
    - Try and do at least once every two years; call-in days on alternate years and/or when issues require community-wide mobilization
- Goal towards full-time staff team

    - With additional staff (in HQ) be able to proactively participate in more issues, actively collaborate with non-profit colleagues, network and build coalitions
    - Continue to utilize DC based lobbying firm
- Big Issues on which to advocate:
    - Social Security
    - Medicare/Medicaid
    - Healthcare Reform
    - Reimbursement rates, especially as related to long-term care, home health care, etc.
    - Orphan Drug Development
    - New & Emerging Research Approaches, like stem cell
    - Clinical Research/trial issues
    - Genetic information protection, i.e. GINA expansion, OTC genetic testing kits
    - Patient Safety, i.e. law enforcement training/issues
    - Guardianship rules
- Differentiate between federal, state and municipal policy issues
- Consider role of regional staff with mature program – will there be regional staff capable of supporting mission areas?

###

Strategic Planning: Education Workgroup
Conference Call held September 21, 2010
Participants: Don Barr, Jang-Ho Cha, MD, Deb Lovecky, Martha Nance, MD, and Louise Vetter

Review of Educational programs

- Convention
    - "Platypus" – all things to all people
    - Education, family services, advocacy, field, etc
    - Social worker training very important, build skills for in-services
    - Uniquely provides programming for young individuals – not a lot for the young and/or at-risk
- Physician Education
    - CME event, Physician's Guide,
    - Medical Student programs by COE's – need to collect this data more
        - How many young MD's rotate through clinics? Grand rounds conducted? Case conferences?
    - Have COE directors groom other local docs – extend impact of COE network beyond their center
    - Focus on those MD's who express interest in HD (those who opt in) rather than chasing broad MD pool
    - Make sure Physician Guide online; offer CME online
- Family Guide Series of publications
    - On track to have all 7 titles update by early 2011
    - Ongoing challenge to have print versions and online versions
        - Print editions are expensive
        - Families & chapters want them (for events)
        - Hard to keep print versions up to date
    - Focus on keeping online versions no more than 2 years old; print versions can be older
    - Add dates to online versions, i.e. last reviewed 8/9/10, to communicate timely review of materials
- Other Publications: Toward A Cure & The Marker
    - TAC has fundraising component; research focused ties
    - The Marker – general educational component
        - The one most general marketing and educational tool; close to being a sacred cow
        - Expensive to print
    - Need to make sure that as much content as possible from these publications are on our website
- Field Educational Events
    - Program in growth mode – made possible by Mini-grant program

        - Lundbeck funding to national to run mini-grant program for chapter/regional educational events; funding encourages more (no cost to chapter) and higher attendance (free to attendees)
    - Some have identity crisis – trying to appeal to too many audiences
        - Attendance ranges from 60 to 200 participants
        - Need to focus the goal of these events to educate families
    - New in FY10: ‘workshops in a box’ for Advocacy and Clinical Research
    - Focus on expanding these – one per chapter/affiliate
- Long-term Care Providers
    - Consider expansion of resources, i.e. brochures, CD’s/CME trainings
    - Best practice standards to help build experience/comfort caring for the HD population
- Other Ancillary Care providers – PT/OT, Genetic Counselors, Speech Pathologists
    - Best practice standards?
    - See EHDN workgroups for more information – manuals/tool kits
- Use of the Website
    - Need to put as much information as possible online
    - Much more cost-efficient than in-person trainings
    - Use HDSA.org for trainings as well as publication of resources and webinars
    - Monthly broadcasts? Consider caregiver’s corners but for other audiences
        - Make sure there’s new educational information highlighted monthly
    - New Educational Programming for those At-risk? Patients?

# # #

Strategic Planning: Family Services Workgroup
Conference Call held September 17, 2010
Participants: Jang-Ho Cha, MD, Deb Lovecky, Steve Seekins & Louise Vetter

Need to define family services:

Family | services| care| education | resources

- The term "care" is ambiguous and we don't supply direct care.
- Care, like cure, is more meaningful as a marketing word.
- "Family" implies very individualized care
    - Confusion at the field level -- sense that we should be providing hands-on, individualized family care, like grocery shopping, personalized attention to fill out form for disability, etc.
- Replace "family" with "community" = **we provide "Community Services"**
    - Shows not just about your family, all families
    - Gets people thinking outside themselves
    - Bridges our existing programs together
    - Aligns nicely with strategic direction statement #1
- Education means helping people better understand… not a service.
    - Still a separate area of the Society; not folded under community service

National Convention:

- Community engagement event – all things to all people
- Serves as both a service, educational event, research update, field training and advocacy activity

Centers of Excellence

- Need to look for ways to get more out of the center relationships that we currently are
- We have steady flow of patients and are well-equipped to capture more data
- Data gathering or common data compilation is key, but requires analysis and output
    - Input of energy and dollars to make this happen (long term planning)
- Short term opportunities:
    - Can we fund QOL research that's already going on at the COE's?
    - Move COE's to a "network" model with greater collaboration
        - Channel 'pent-up enthusiasm'
        - Use workgroup model to develop care standards
- Patient Based Observational work is really important – not a lot of funding
- Growth of this program requires significant staff time/in-house leadership

Social Workers

- Currently 17 across HDSA + COE social workers (some overlap)
- Access to a social worker is very inconsistent – different hours allocated, different expectations by chapters
- Consider growth to regional SW's from HDSA who coordinate with local SW's

Support Groups

- Currently 140+ nationwide; provide valuable emotional support and shared resources
- Need to survey SG's and assess SG leaders
- Track participation – understand ebb and flow of participation
- Ensure a core set of tools and resources after training, including refresher trainings, newsletters, etc.
- Make sure every SG leader has a Mentor – a social worker in the region they are working closely with

Caregiver's Corners

- Easy to put on with high level of return/benefit to families and Society
- Attendance consistently climbing (25 to 75)
- Further develop online "Caregiver's Corner" with more articles in addition to webinars, like contents from the Marker

HD Connect

- A lot of excitement for the program, but not seeing the anticipated need; FY2011 is make or break year
- When testing rates climb above current rates of 8-10% then we may see greater demand for this

Continuing Medical Education Events for Physician – improve community services, but are more directly an educational activity

- Agreement to move to a webinar model -- available to primary care MD's, residents & interns in addition to neurologists
- COE directors as faculty

National Youth Alliance – not a community service; even though they are loosely defined as providing support to their members, they do not have the components of a support group

- Valuable social outlet; look for opportunities where they fit into HDSA programs and activities
- NYA as "farm team" for chapters
    - Consider Young Leaders subgroup or training at Convention to move those appropriate from NYA into Chapters and promote field integration
    - Age range is a consideration
- Map expectations of greater HDSA integration and then work with new leadership Committee to implement

# # #

APPENDIX C:

Strategic Plan 2012-2016: Glossary of Terms

The following glossary of terms has been compiled to accompany the HDSA Strategic Plan 2012-2016 and serve as a handy reference as you navigate abbreviations and acronyms throughout that lengthy document.

1. **Caregivers Corners** – An HDSA online webinar program for caregivers that covers topics specifically related to caring for an HD family.
2. **CFC** – HDSA's *Coalition for the Cure* research consortium; also referred to as "the Coalition."
3. **CHDI** – A private, not-for-profit research organization working with an international network of scientists to discover drugs that slow the progression of Huntington's disease. www.chdifoundation.org
4. **CME** – *Continuing Medical Education:* A specific form of continuing education for medical practitioners maintain competence and learn new skills.
5. **COE** – HDSA's *Centers of Excellence* program, also referred to as "the Centers."
6. **COH** – *Celebrations of Hope*: HDSA fundraising events which showcase the Centers of Excellence program.
7. **CTRAD** – *Cost to raise a dollar:* A business calculation used to assess the net impact of funds raised from an event in which the cost to run an event is divided by the gross revenue of that event. For example, if an event raised $20,000 but cost $5,000 to run, the cost to raise a dollar is 0.25 cents per dollar or an expense ratio of 25 percent.
8. **DKF** – *Don King Fellowship*: An HDSA research fellowship program for graduate students awarded annually each summer. The program was named for HDSA's past Chairman Don King.
9. **DSA** – *Director of Scientific Affairs*: A new staff position for HDSA.
10. **E-advocacy** – A method of advocating for public policy that is done completely using online tools, such as online letter-writing or email campaigns.
11. **EHDN** – *European HD Network:* A platform for professionals and people affected by HD and their relatives to facilitate working together throughout Europe. www.euro-hd.net
12. **Ethicspoint** – A software consulting firm which provides online systems to support whistleblower policies and allow individuals to share concerns regarding an organization's business practices.
13. **Extranet** – A password-protected website for HDSA leadership, i.e. the Board of Trustees, National Field Committee and Chapter and Affiliate leadership, to share organizational resources.
14. **GINA** – *Genetic Information Non-discrimination Act*: A federal law passed in 2008 to protect Americans against discrimination based on their genetic information when it comes to health insurance and employment.
15. **GT** – Shorthand for *genetic testing*.
16. **HD** – *Huntington's disease*.
17. **HDBuzz** – A global internet portal for the rapid dissemination of high-quality Huntington's disease research news, written in plain language, by HD clinicians and scientists. HDBuzz receives 25 percent of its support from HDSA. www.hdbuzz.net
18. **HDSA** – *Huntington's Disease Society of America*, Inc; also referred to as "the Society." www.hdsa.org
19. **HDSA Diplomats** – An HDSA program to develop community-based advocates who speak about their experiences participating in HD clinical research.
20. **HDTrials.org** – A web collaboration of the leading HD organizations and volunteer groups dedicated to enabling clinical research participation. Interested individuals sign up for a confidential email list which provides quick notification to HD families about clinical trials and studies. www.hdtrials.org

21. **HSC** – *Huntington Society of Canada:* HDSA's counterpart in Canada. www.huntingtonsociety.ca
22. **HSG** – *Huntington Study Group*: A non-profit group of physicians and other health care providers from medical centers in the United States, Canada, Europe, Australia, New Zealand and South America, experienced in the care of Huntington patients and dedicated to clinical research of Huntington disease. www.huntington-study-group.org
23. **IHA** – *International Huntington Association*: A federation of national voluntary health agencies that share common concern for individuals with Huntington's disease (HD) and their families. www.huntington-assoc.com
24. **iPS cells** or **iPSCs** – *induced pluripotent stem cells*: Adult cells that have been genetically reprogrammed to an embryonic stem cell-like state by being forced to express genes and factors important for maintaining the defining properties of embryonic stem cells. Although additional research is needed, iPSCs are already useful tools for drug development and modeling of diseases.
25. **JHD** – *Juvenile Huntington's disease*.
26. **LTC** – *Long-Term Care,* as in "LTC facilities."
27. **MDC** – *Movement disorder centers.*
28. **MSAC** – *Medical and Scientific Affairs Committee*: A volunteer committee of HDSA comprised of physicians and scientists who advise the Society on issues related to HD medicine and research.
29. **NFC** – *National Field Committee:* A volunteer committee of HDSA focused on supporting the Chapters and Affiliates of the Society.
30. **NHC** – *National Health Council*: A Coalition of more than 100 disease-specific health non-profits providing a unified voice for Americans living with chronic disease and their caregivers. HDSA is a member of the NHC. www.nationalhealthcouncil.org
31. **NIH** – *National Institutes of Health*: A part of the U.S. Department of Health and Human Services, it is the nation's medical research agency. www.nih.gov
32. **NINDS** – *National Institute of Neurological Disorders and Stroke*: A division of the National Institutes of Health focused on research into neurological disorders including Huntington's disease. www.**ninds**.nih.gov
33. **NORD** – *National Organization of Rare Diseases*: A federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. www.rarediseases.org
34. **NYA** – HDSA *National Youth Alliance*: HDSA's youth education and support program for all youth up to age 29 who are in HD families. www.hdsa.org/nya
35. **PCP** – *Primary care physician*. Also known as a GP or general practitioner.
36. **Q1, Q2, Q3** or **Q4** – Quarter 1, 2 3, or 4 of the Society's fiscal year which runs from January 1 to December 31st each year.
37. **QoL** – An abbreviation for "*Quality of Life*."
38. **RFP** – *Request for proposal*: Primarily used by the Society to solicit applications for research funding.
39. **SG** – Organizational shorthand for "*Support Group*."
40. **SSA** – *Social Security Administration*: A division of the U.S. government dedicated to delivering social services, including disability, to the American public. www.ssa.gov
41. **SW** – Organizational shorthand for *"Social Worker."*
42. **TBA** – An abbreviation of the phrase "*to be announced*."
43. **Team Hope** – HDSA's signature event Walk program to raise funds for the HDSA mission. www.hdsa.org/teamhope
44. **Thank you Thursdays** – Volunteer appreciation events to recognize supporters of HDSA.
45. **Y-T-D** or **YTD** – **Year to date**: typically used in the context of financial planning.

# # #