



Huntington's Disease Society of America, Inc. Strategic Plan 2017-2021

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.

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 Those purposes provide background to the mission (historical reference) and serve as an adjunct descriptor.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.

They remain in the bylaws without edit, but we 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

We are committed to these shared values:

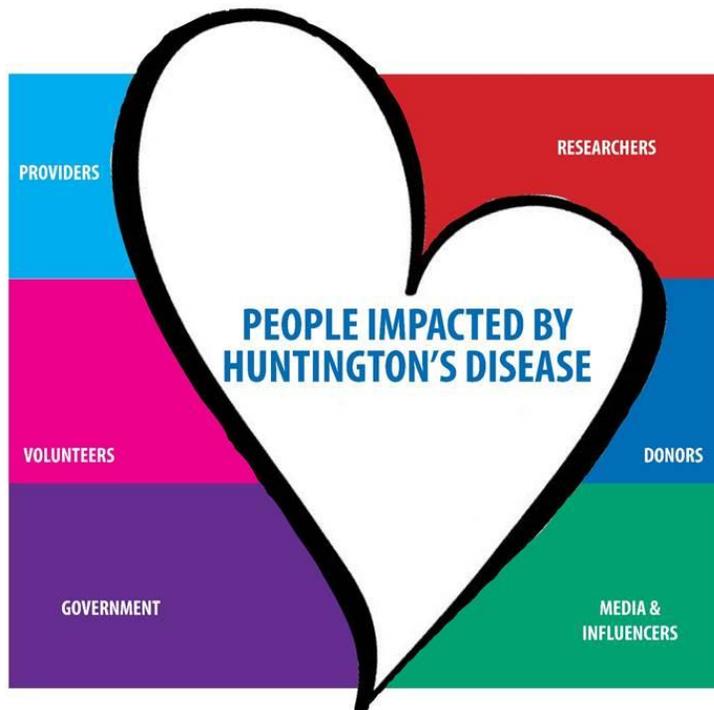
- *Hopeful* – We conduct our work in all areas in a manner that inspires hope. Our vision epitomizes this hope, and we conduct our work in all areas in a way that is always forward-looking.
- *Dedicated* – We are dedicated to serving people with Huntington’s disease and their families and supporting research to drive a cure. We care intensely about those we represent and serve. We celebrate our wins and inspire dedication from those who work with us.
- *Family-Focused* – In direct correlation to the nature of Huntington’s disease, we are a family-based and family-focused organization. Our structure, programs and decisions reflect a commitment to a family-centric model. We value the work of our volunteers who represent our families and who function as a family. All members of our team – staff, volunteers, Chapter and Board leaders, donors, clinicians, care providers, scientists, and sponsors – are important members of the HDSA family.
- *Compassionate* – We are a sympathetic and empathetic network of individuals and families. We know that excellence in care comes from sincere compassion, and we strive to reflect this compassion in our community activities and relationships.
- *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. Our policies, positions and programs are rooted in credible and well-validated science, and we ensure that our decision-making and leadership align with the mission statement. Our drive to grow is so that we can expand our resources, support and impact for more families.
- *Collaborative & Accessible* – We are a ‘hub’ or central ‘portal’ for the HD Community, its families and all stakeholders. We partner and collaborate with others who serve the HD community, and we listen and act to provide support to our community, or direct them to another who can.
- *Stewardship* – As stewards, our volunteers and staff are accountable to our donors. Decisions about how to invest time, people and money to accomplish our mission are based on the highest impact of return on investment to our mission. We employ practices that maximize efficiency and effectiveness, and we evaluate initiatives in light of our mission-driven objectives. We are transparent, with mutual responsibility at all levels of the organization.

Our Community

In the truest sense, the heart of our community is those impacted by Huntington’s disease, which includes individuals symptomatic with the disease, those at-risk, and the families and friends who are caring for people with HD. From the youngest affected by juvenile-onset HD to the grandparents who have lost spouses, children and care for grandchildren who carry its burden, we are driven to serve everyone who is affected by HD.

Many audiences contribute to the Society’s ability to care for and support a cure for HD families, and they constitute our secondary community. These include care providers (clinicians, social workers, etc.), members of the media and thought leaders in public health (also known as “influencers”), researchers, members of government (both elected officials and regulators), HDSA volunteers, and our donors.

The backdrop for these two categories of audiences is the general public with whom we seek to raise general awareness of Huntington’s disease and therefore influence public understanding of the needs of our HD families.



PLAN OVERVIEW

The Strategic Plan is organized around Seven Goals which are the key drivers of organizational growth. They are the essential areas of our work which, in equal measure, are imperative to HDSA's ability to accomplish its mission.

For each Goal, strategies are identified to reach the stated aim. Specific objectives for each strategy articulate the plans for accomplishment. **FOLLOWING COMMUNITY FEEDBACK, THE SPECIFIC ACTIVITIES AND MILESTONES FOR EACH OBJECTIVE WILL BE DEVELOPED. WE DELIBERATELY REQUEST COMMUNITY INPUT BEFORE THE PLAN IS FURTHER DEVELOPED SO THAT WE CAN BE MOST RESPONSIVE.**

~~Next, the initiatives 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.~~

Goal I: Enhance and Deliver Best Practices in HD Family Care.

HDSA is committed to ensuring that all HD affected families have access to the highest quality care. This care must be HD experienced, comprehensive and compassionate. Additionally, best practices in HD family care must span the entire progression of the disease and its impact throughout generations. From the youngest members of the community, those ill, at-risk and often caregiving, to those in its final stages, our commitment to enhancing care will exemplify a model of customer service where results are defined by the quality of life of HD families nationwide.

To accomplish this Goal, five core strategies have been identified:

1. Expand access to HD-experienced clinical care.
2. Enhance social services and support resources.
3. Improve access to long-term care facilities skilled in HD.
4. Increase access to counseling on key HD-related decisions, including genetic counseling and preimplantation genetic diagnosis in vitro fertilization (PGD IVF).
5. Grow network of and resources for HD specialized ancillary services, including occupational therapists, physical therapists, speech language pathologists, and nutritionists.

Key objectives in this area are the continued development of the HDSA Center of Excellence program, expanding the age-appropriate support that is available to our youth, new online curriculum and learning practices for ancillary care providers, 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: Advance HD Research.

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 to consistently advance all areas of HD science. Researchers and families working together will bring treatments forward, and HDSA will be vital connector to breakthroughs.

The four strategies in support of this aim are:

1. Ensure a pipeline of new HD researchers.
2. Strengthen and build partnerships with research collaborators.
3. Fuel clinical research by ensuring active engagement in clinical studies.
4. Educate the community about the importance and impact of HD research.

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 community team of supporters and abundance of resources to help them navigate the best in care.

Three 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.

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 educating law enforcement personnel on HD, providing resources for those applying for disability, and training the HD community about the Genetic Information Non-Discrimination Act (GINA).

Goal IV: Communicate comprehensive and credible HD information.

As the largest non-profit organization dedicated to serving the Huntington's disease community, it is imperative that HDSA is 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. Expand awareness of HDSA.
3. Increase awareness of HD among the general population.

A comprehensive public relations effort 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: Increase volunteer engagement.

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 organizational dialog and operations.
2. Develop and retain knowledgeable HDSA leaders and volunteers.
3. Expand HDSA’s organizational reach.
4. Identify and cultivate new volunteers.

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 HDSA Connect to increased trainings online and at the Annual Convention, the organization will invest in the volunteers who bring the Society to life. Furthermore, HDSA plans to have at least one Chapter or Affiliate in every state in the country.

Goal VI: Manage growth 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.

To do this we will:

1. Ensure funding of all financial obligations.
2. Grow Board Operating Reserve to six months National operating expenses.

3. Increase unrestricted net assets.
4. Increase mission/administrative funding ratio to meet or exceed 80/20 ratio.

Managing our cash flow and ensuring timely financial management in the Field will be vital to achieving this Goal. Additionally, funds will be regularly banked to establish financial reserves that protect the Society against risk and enable new program development.

Goal VII: Increase revenue by at least 5% annually 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:

1. Expand our signature event, individual, corporate, and foundation giving programs throughout the organization.
2. Embrace technology to improve the way people give to and engage with the Society.
3. Invest in a Planned Giving Program to establish long-term stability.

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.

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***Please Note:* The following pages list the planned objectives and tactics to accomplish each strategy. In subsequent drafts, following community input on the content developed to date, specific activities and milestones will be developed for each tactic to map achievement over the five years of this Plan.**

Goal #1: Enhance and Deliver Best Practices in HD Family Care

Strategy #1: *Expand access to HD-experienced clinical care.*

Objectives/Tactics:

1. Increase the number of HDSA Centers of Excellence (COE) across the United States.
2. Increase the percentage of HD patients and families that receive their care at a COE.
3. Identify the best clinical practices for management of HD symptoms.
4. Increase psychiatric expert care for HD
5. Launch an HDSA-sponsored telemedicine pilot program to ensure those unable to travel can still receive expert HD care.
6. Better incorporate local physicians into HDSA Educational Days to improve their knowledge and awareness of HD resources, such as the Physician's Guide.

Strategy #2: *Enhance social services and support resources.*

Objectives/Tactics:

1. Identify gaps in essential HD services across the country and create new HD resources for caregivers and care providers.
2. Enhance delivery of HD services by educating and training both HDSA and non-HDSA social workers.
3. Expand youth-specific support for HD community through growth of the National Youth Alliance (NYA) and by developing a nationwide network of youth-trained HD social workers.
4. Enhance programming at field-based educational events.
5. Host and broaden the impact and reach of a national community-wide, family-focused HD educational Convention.
6. Provide ongoing training to professional and lay Support Group Leaders.

Strategy #3: *Improve access to long-term care facilities skilled in HD.*

Objectives/Tactics:

1. Develop training programs to improve expertise at and quality of life (QoL) for persons with advanced HD, whether at home or in long-term care (LTC) facility.
2. Legislate to improve QoL for persons with advanced HD.
3. Increase outreach and educational efforts to LTC facilities about HD.
4. Expand the number of LTC facilities and units specializing in HD across the country.

Strategy #4: *Increase access to counseling on key HD-related decisions, including genetic counseling and PGD-IVF.*

Objectives/Tactics:

1. Update the HD Genetic Testing Protocol.
2. Ensure HDSA genetic testing protocol gets in hands of local physicians treating HD families.
3. Persuade insurance companies to provide coverage to HD families that desire to have children via PGD-IVF.
4. Educate community about preimplantation genetic diagnosis with In-vitro fertilization (PGD-IVF) as a family planning option.

Strategy #5: *Grow network of and resources for HD specialized ancillary services, including occupational therapists, physical therapists, speech language pathologists and nutritionists.*

Objectives/Tactics:

1. Develop Continuing Education Courses for ancillary service healthcare professionals.
 2. Get newly-trained ancillary service professionals exposed to HD community.
 3. Advertise HD educational opportunities with professional organizations/societies
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Goal #2: Advance HD Research

Strategy #1: *Ensure a pipeline of new HD researchers.*

Objectives/Tactics:

1. Expand support for existing research programs targeting young investigators (basic or clinical) to build a pipeline of new researchers
2. Foster collaboration between basic and clinical scientists by involving the Centers of Excellence in research programs.
3. Work with Scientific Advisory Board to identify critical voids in global HD research pipeline that could be positively impacted by new HDSA research investments.
4. Provide unique opportunities for HDSA-supported scientists to get out of laboratory and interact with HD patients and families.
5. Maintain our organizational research focus on understanding HD biology as it occurs in humans.

Strategy #2: *Strengthen and build relationships with research collaborators.*

Objectives/Tactics:

1. Identify new ways to work together with other HD or neuroscience organizations to accelerate drug development
2. Position HDSA as the central source for nationwide HD community engagement in clinical research with pharmaceutical and biotechnology partners.
3. Educate the HD community on the latest HD research breakthroughs
4. Establish more regular communications with all research organizations focused on HD.

Strategy #3: *Fuel clinical research by ensuring active management in clinical studies.*

Objectives/Tactics:

1. Increase US family participation rates in interventional and observational trials.
2. Build community understanding of HD research to motivate clinical research participation.
3. Develop patient-friendly resources about HD research and clinical trials.
5. Increase US awareness and participation in the global HD Clinical Trial Research platform, Enroll-HD.
6. Provide support to Clinical Trial Navigator Call Center component of HDTrialfinder.

Strategy #4: *Educate the community about the importance and impact of HD research.*

Objectives/Tactics:

1. Promote clinical and observational research opportunities.
 2. Develop patient friendly educational materials/resources on HD research.
 3. Increase community involvement and perspectives in HD clinical trial protocol development.
 4. Continue to host regular Research Webinars and other HD research symposia for community.
 5. Establish an HD-specific brain bank to enable human HD research.
 6. Continue organizational support for HD Buzz to bring research information to the community.
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Goal #3: Remove barriers to quality care

Strategy #1: *Pass legislation that directly improves the quality of life for HD families.*

Objectives/Tactics:

1. Secure the passage and implementation of the HD Parity Act.
2. Convince health insurance companies to cover costs of PGD-IVF for HD gene positive individuals.
3. Make advocacy efforts an essential component of all HDSA Chapter/Affiliate activities.
4. Work to expand GINA to cover LTC and Life Insurance protections.
5. Create ethically and legally sound standards for patients with HD to access Death with Dignity measures.

Strategy #2: *Expand HD benefits in health insurance coverage.*

Objectives/Tactics:

1. Collaborate with other organizations representing health conditions with similar symptoms (e.g., depression).
2. Educate HD community regarding changes in Social Security program that directly affect them.
3. Convince health insurance companies to cover costs of PGD-IVF for HD gene positive individuals.

Strategy #3: *Reduce discrimination towards people with HD.*

Objectives/Tactics:

1. Educate emergency room professionals about HD.
 2. Educate correctional facilities about HD (long term).
 3. Develop model for HD assisted living facilities.
 4. Update and implement Law Enforcement Educational and Awareness program.
 5. Educate acute psychiatric facilities about HD.
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Goal #4: **Communicate comprehensive and credible HD information.**

Strategy #1: *Enhance knowledge of HD and HD science.*

Objectives/Tactics:

1. Communicate HD and HD science news in a timely manner utilizing all internal and external media relations tools, including traditional print, TV and radio outreach as well as HDSA online and social media platforms.
2. Educate stakeholders on HD and relevant issues through promotion of HDSA's programs and campaigns.
3. Utilize visual tools (infographics, videos) to communicate HD impact.
4. Continue partnership with HDBuzz.

Strategy #2: *Expand awareness of HDSA.*

Objectives/Tactics:

1. Promote HDSA fundraising and educational events using all forms of local and national media (traditional and social).
2. Cultivate relationships with celebrities and other public figures to generate awareness.
3. Instill action through motivational messaging "Volunteer. Education. Advocate. Donate."
4. Launch 50th Anniversary Campaign to tell organization's history and impact.

Strategy #3: *Increase awareness of HD among the general population.*

Objectives/Tactics:

1. Build on the *Family is Everything* theme to personalize HD to people who are not familiar with it.
 2. Increase accurate media coverage and representation of HD.
 3. Promote relationship between HD and other neurodegenerative diseases.
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Goal #5: Increase Volunteer Engagement

Strategy #1: *Strengthen the organizational dialog and operations.*

Objectives/Tactics:

1. Build relationship between NFC and Chapter & Affiliate leaders.
2. Support Chapter & Affiliate Agreement implementation.
3. Invest in and increase use of HDSA Connect, webinars and other internal community content resources.

Strategy #2: *Develop and retain knowledgeable HDSA leaders and volunteers.*

Objectives/Tactics:

1. Build and implement volunteer training curriculum for new Chapter & Affiliate leaders and volunteers.
2. Utilize technology to provide ongoing communication and engagement tools.
3. Develop regular leadership forums (CEO webinars, Leadership Day) to provide direct communication between volunteer and staff leadership.
4. Define and promote pathway of growth for volunteers that reaches from local event involvement to National Board membership.

Strategy #3: *Expand HDSA's Organizational Reach.*

Objectives/Tactics:

1. Establish at least one Chapter or Affiliate in each state.
2. Ensure Affiliates grow to Chapter status.
3. Cultivate and spur relationships between Chapters, Affiliates, their local Centers of Excellence and support groups to strengthen community-based organizing.

Strategy #4: *Identify and cultivate new volunteers.*

Objectives/Tactics:

1. Celebrate and communicate appreciation for HDSA volunteers.
2. Train event organizers on volunteer recruitment strategies with an emphasis on corporate team cultivation.
3. Break down silos between inter-organizational volunteer groups (advocacy, NYA, event donors) to increase engagement of existing volunteers and motivate cultivation of relationships.

Goal #6: Manage Growth in a Fiscally Responsible Manner

Strategy #1: *Ensure funding of all financial obligations.*

Objectives/Tactics:

1. Budget grant awards based on planned activities.
2. Plan payment timeline with the cash flow schedule and grant milestones.

3. Maintain funds in operating account for ongoing financial obligations and money market account for larger payments.
4. Schedule consistent cash distributions from Chapters and Regions.

Strategy #2: *Grow Board Operating Reserve to six months of National operating expenses.*

Objectives/Tactics:

1. Budget annually for a surplus for funding of the Board Operating Reserve Fund.
2. Increase investment income on the Board Operating Reserve Fund accounts.
3. Revise investment policy to govern the investment of funds in the Board Operating Fund.

Strategy #3: *Increase unrestricted net assets.*

Objectives/Tactics:

1. Revise fundraising communications strategies for increased unrestricted donations.
2. Monitor activities annually for maximum release of temporarily restricted revenue.
3. Match temporarily restricted donations with expenses.

Strategy #4: *Increase mission/administrative funding ratio to meet or exceed 80/20 percent.*

Objectives/Tactics:

1. Monitor results of all fundraising activities to maximize mission return.
2. Continue to educate staff and volunteers on the importance of cost to raise a dollar.
3. Review monthly financial reports with staff and volunteers to improve communications and budget management.

Goal #7: Increase Revenue by at Least 5% Annually to Grow Organizational Capacity

Strategy #1: *Expand our signature event, individual, corporate, and foundation giving programs throughout the organization.*

Objectives/Tactics:

1. Explore new revenue streams for adding additional Signature Events to engage and increase community involvement with an eye to new audience development.
2. Increase the number of individual donors through all National fundraising initiatives.
3. Develop a case statement and marketing campaign that encourages unrestricted giving.
4. Launch Major Giving initiative tied to 50th Anniversary of HDSA.
5. Expand Corporate support base and increase Corporate support with new partnerships to support national and regional initiatives.
6. Collaborate with Mission team to identify programs and services attractive to Foundation support.
7. Regularly communicate the value in growing the organizational capacity.
8. Maintain and expand donor stewardship and cultivation programs.

Strategy #2: *Embrace technology to improve the way people give to and engage with the Society.*

Objectives/Tactics:

1. Encourage more people to give online.
2. Work collaboratively with Communications Department to integrate fundraising strategy into all web, app and social media based outreach.
3. Increase response to e-fundraising appeals.

Strategy #3: *Invest in a planned giving program to establish long-term stability.*

Objectives/Tactics:

1. Continue to conduct targeted appeals to individuals that are current donors who may be prospects for planned gifts.
2. Incorporate 50th Anniversary messages into planned giving campaigns to encourage planning for long-term stability of the Society.
3. Collaborate with Field Staff to raise awareness of Planned Giving impact and giving opportunities.

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