Enclosed You Will Find More Information About Participating in a Team Hope Walk!

Huntington’s Disease Society of America
SIoux Valley HDSA
SERTOMA PARK – SIOUX FALLS, SD
SATURDAY, May 6th, 2017
REGISTRATION – 8:00 AM
Adults - $35 / Children under 12 - $15
WALK/5K & 10K KICK OFF – 9:00 AM
LIVE AUCTION – 10:15 AM

www.hdsa.org/thwsouthdakota
Dear Team Hope Participant,

Welcome to the Team Hope family and thank you for walking with us! Team Hope is HDSA’s signature grassroots fundraising campaign designed to provide hope and support for those touched by this devastating disease. Team Hope Walks are a way to showcase individuals who want to raise awareness in their local communities. Proceeds from Team Hope support the mission of HDSA, the largest voluntary health agency dedicated to finding a cure and providing assistance to those individuals living daily with HD. More than a fundraiser, it is a time for the entire community to join together in a day of camaraderie, inspiration, and above all, hope.

As you embark on your Team Hope journey with us, please use this Team Hope Walk Participant Packet to guide you through your entire Team Hope experience. This packet will walk you through every step of your Team Hope Walk experience by providing you with information about HDSA, Team Hope, resources, and fundraising ideas.

As you walk for HDSA, remember that you walk to support the mission of HDSA by raising awareness in your local community and by raising funds to support HDSA’s programs nationally and in your local community. With the funds you raise by walking, you make HDSA’s care, education, advocacy and research programs possible. Recruit your family members, your friends, your coworkers, and everyone else in your community to walk with you and raise as much money as you can for the mission of HDSA!

If you have any questions along the way, please don’t hesitate to reach out to me!

Good Luck!

Debbie Stadley Augustad
Board of Directors President
debstadley@gmail.com

South Dakota HDSA
PO Box 2675
Sioux Falls, SD 57101-2675
About Huntington’s Disease

- Huntington’s disease (HD) is an inherited brain disorder that results in the progressive loss of both mental faculties and physical control. Symptoms usually appear between the ages of 30 to 50, and worsen over a 10 to 25 year period. Ultimately, the weakened individual succumbs to pneumonia, heart failure, or other complications.
- Everyone has the HD gene but it is those individuals that inherit the mutated version of the gene who will develop HD and may pass it onto each of their children.
- Presently, there is no cure. Although medications can relieve symptoms, research has yet to find a means of slowing the deadly progression of HD.
- Approximately 30,000 Americans have HD, but the devastating effects of the disease touch many more.
- Current estimates are that 1 in every 10,000 Americans has HD and more than 250,000 others are at-risk of having inherited it from a parent.
- Every child of a parent with HD has a 50/50 chance of inheriting the gene that causes the disease.
- Once thought a rare disease, HD is now considered one of the more common hereditary diseases.

HDSA’s Programs & Services

- The Huntington Disease Society of America (HDSA) has a nationwide care network that provides support and referrals for individuals with HD and their families.
- HDSA is currently working towards the passage of the Huntington’s Disease Parity Act, which when passed will improve the lives of people facing HD.
- In 1993, researchers identified the gene that causes HD. HDSA supports the goals of clinical, translational and basic research aimed at developing treatments and, ultimately, a cure at leading research facilities globally.
- HDSA has established and supports 39 HDSA Centers of Excellence, which are facilities around the United States that provide expert comprehensive team medical care in one central, convenient location for those with HD.
- HDSA currently has 57 Social Workers around the country working to provide help and hope to the HD community. HDSA social workers assist families with navigating HD by providing information, referrals, and by helping to start and maintain support groups.
- HDSA currently has over 170 support groups in local communities throughout the United States.
# What A Dollar Buys

As you begin raising awareness and fundraising for your Team Hope Walk, use the below information as you explain to potential donors what a donation from them can do to positively and directly impact the lives of those living with HD.

<table>
<thead>
<tr>
<th>Donation Amount</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>$1</td>
<td>Sends a Fast Facts Information Packet to a newly diagnosed HD patient.</td>
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<tr>
<td>$5</td>
<td>Provides a Law Enforcement Tool Kit to educate Law Enforcement Officials or First Responders about how to recognize HD and how to resolve potentially dangerous situations.</td>
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<tr>
<td>$50</td>
<td>Funds one monthly volunteer-led HD Caregiver support group.</td>
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<tr>
<td>$100</td>
<td>Supports a Social Worker-led HD Patient support group for one month.</td>
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<tr>
<td>$250</td>
<td>Allows an HD family of four to attend a local Education Conference.</td>
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<tr>
<td>$500</td>
<td>Pays a licensed Social Worker to cover a local HD Phone Helpline for one month.</td>
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<tr>
<td>$1,000</td>
<td>Funds an HD Advocate’s trip to Washington, DC to meet with Senators and Representatives to voice support for the HD Parity Act as part of Advocacy Day.</td>
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<tr>
<td>$2,500</td>
<td>Pays for an HD patient and caregiver to attend the Annual HDSA National Convention: a three-day conference bringing together people with HD and their family members with physicians, researchers, social workers and other healthcare professionals to hear about the latest research breakthroughs, new clinical trials, best care practices, advocacy efforts, and educational programs while simultaneously renewing friendships and receiving comfort and support from being among others who truly understand the daily challenges of HD.</td>
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<tr>
<td>$5,000</td>
<td>Funds a Don King Summer Research Fellowship for a young investigator researching basic HD biology in conjunction with an established HD researcher.</td>
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<tr>
<td>$10,000</td>
<td>Sponsors the National Youth Alliance (NYA) Day at the HDSA National Convention. The NYA is made up of youth and young adults from across the country whose mission is to make their generation the last to ever have to live with Huntington's disease. NYA Day is a day filled with support, education, and fun activities for the youths who are coping with HD and Juvenile HD.</td>
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<tr>
<td>$25,000</td>
<td>Brings people together across the country as a Team Hope National Partner. Over 100 walks happen each year in cities nationwide, bringing thousands of HD families together and building awareness of HD in local communities.</td>
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<tr>
<td>$50,000</td>
<td>Underwrites an HDSA Center of Excellence for one year. HDSA’s 21 Centers of Excellence around the nation are unique expert multi-disciplinary clinical care centers for HD patients and their families, providing a full range of health care services including: ongoing clinical care; innovative laboratory research; clinical trials; professional social worker services; genetic counseling and testing; speech, occupational and physical therapies; support groups; and professional and family education.</td>
</tr>
<tr>
<td>$75,000</td>
<td>Supports Research by funding an HD Human Biology Project researcher for one year. This program, in conjunction with the HDSA Centers of Excellence, invests in new scientists to fund groundbreaking research by challenging basic researchers to work with clinical care centers to better understand HD biology as it occurs in humans as well as support quality of life research.</td>
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Team Hope – Helpful Information

- Everyone is welcome to participate in a Team Hope Walk!
- Most walks will take place, rain or shine.
- As a team captain, team member, or individual participant for a Team Hope Walk, don’t forget to:
  - Register and set up a personal and team fundraising page because we all know how easy it is to ask for and receive donations online through emails and social media!
  - Set a fundraising goal and create a plan to achieve it. You can do it!
  - Recruit family members, friends, co-workers & everyone else you know to join your team.
  - Initiate a letter writing campaign and send out e-blasts through your DonorDrive account to your email contacts (you can upload your email address book to your account on DonorDrive).
  - Post your personal fundraising page to your social media accounts, like Facebook and Twitter!
  - Host wrap around events before and after the walk to raise extra money.
  - Add the link to your personal fundraising page to your email signature.
  - Build momentum, team enthusiasm and spirit throughout the event.
  - Celebrate your group’s success at your local walk!
- All checks should be made out to ‘HDSA’.
- This packet contains two forms you may use to mail in donations. You may use the Team Hope Offline Registration & Donation Form to register offline and submit multiple offline donations (any donation not made online, such as checks, cash, money orders, matching gifts and wrap around events.).
  - Or, if you are just sending in one donation, you can use the Team Hope Offline Donation Form. Please send all offline donations and registrations, with either form attached, to the local walk coordinator.
- Be creative and create your own team t-shirts, team banners and team signs!
Team Hope – Fundraising 101

This section will help you learn all there is to know about fundraising so that you can reach and even exceed your goals for your local Team Hope Walk.

**Fundraising Tips**

- Set a fundraising goal for yourself – and keep in mind, your local walk might offer prize incentives! If the local walk doesn’t, there are always the national Team Hope Walk fundraising prizes!
- You won’t get a donation unless you ask for a donation – so don’t be afraid to ask!
- Start asking for donations early, even if the walk is months away. The more time you give yourself to raise money, the easier it will be to reach your fundraising goal.
- You may hear “No” many times before you hear “Yes”, so don’t get discouraged from a few “No’s”! Keep asking and eventually you will get a “Yes”!
- Don’t know who to ask? How about a few suggestions...

  | Mom | Uncle | Your Employer | Clinics | Vet |
  | Dad | Cousin | Doctors | Dentist | Contractor |
  | Brother | Grandparent | Bank | Rehab Center | Dry Cleaner |
  | Sister | Teacher | Coach | Hospital | Florist |
  | Aunt | Co-Worker | Vendors | Church | Small Businesses |

- Send an email or write a compelling letter campaign to everyone above and anyone else you know, telling them about HD, HDSA, and Team Hope and ask them for a donation.
- Post your personal fundraising page to your social media accounts, like Facebook and Twitter!
  - Here’s an example post:
    “$50 funds one monthly volunteer-led HD Caregiver support group – support me as I walk to end HD by donating here:  [www.hdsa.org/thwsouthdakota](http://www.hdsa.org/thwsouthdakota)

**Raise $200 By Asking Ten People!**

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<thead>
<tr>
<th>Ask Your</th>
<th>Amount</th>
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<tbody>
<tr>
<td>Parents</td>
<td>$20</td>
</tr>
<tr>
<td>Brother/Sister</td>
<td>$20</td>
</tr>
<tr>
<td>Aunt/Uncle</td>
<td>$20</td>
</tr>
<tr>
<td>Grandparents</td>
<td>$20</td>
</tr>
<tr>
<td>One Friend</td>
<td>$20</td>
</tr>
<tr>
<td>One Coworker</td>
<td>$20</td>
</tr>
<tr>
<td>Your Employer/Supervisor</td>
<td>$20</td>
</tr>
<tr>
<td>Your Neighbor</td>
<td>$20</td>
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<tr>
<td>Your Doctor</td>
<td>$20</td>
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<tr>
<td></td>
<td>$20</td>
</tr>
<tr>
<td><strong>Total Raised</strong></td>
<td><strong>$200!!</strong></td>
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</tbody>
</table>
Matching Gifts
- Matching gifts are an excellent way to maximize your fundraising efforts as well as push you to that final fundraising goal that you’ve set for yourself. Most large companies have a matching gift program for their employees.
- To make your gift to HDSA grow, just ask for a matching gift form from your company or the donor’s Community Relations Department, and enclose the form with the gift to HDSA. We need the Team Hope Walk site, date, and participant name on the form to make sure you get credit!
- Any questions? Contact your Regional Field Staff or Robert Coffey at the HDSA National Office (coffeyr@hdsa.org, 212-242-1968 Ext. 210).

Team Fundraising Tips
- Why walk alone when you can walk with your family, friends, or coworkers?
- If you are the team captain, make sure each team member:
  - Creates their own personal fundraising page to tell their story.
  - Establishes a personal fundraising goal.
  - Fundraises (the money they raise individually will count toward the team total!) 
  - Host wrap around events/fundraisers before and after the walk to raise additional money for your participation. Some ideas include Hearts for Huntington’s at your workplace; In Your Genes at your school; or a car wash, bake sale, or restaurant night in your neighborhood.
  - Host regular meetings, calls or send email blasts to your team members leading up to the walk to discuss recruiting more team members, fundraising tips and goals, team prizes (if you have any), making signs and banners for the day of the walk to represent your team, and where to meet on the day of the walk.
  - Provide support and guidance to your team members, especially new members.
  - Remind team members to follow up with potential donors and send thank you notes to everyone who has already donated.
  - After the walk is over, be sure to personally thank all team members and invite them to walk again next year.
  - Send the HDSA field team and/or walk coordinators your team updates.

Ways to Ask
- In Person – The Face-to-Face Ask
  - This can be the most effective way to ask for a donation, since you are asking another person face to face.
  - Be sure to share your story, and why you are participating in the Team Hope Walk – they won’t be able to say no!

- Phone Calls
  - If you don’t know someone well enough, or if people you know live too far away for a face-to-face ask, pick up the phone!
  - Phone calls can be just as effective as a face-to-face ask.
Social Media
- The majority of fundraising is done online in today's hyper-connected and wired world.
- Post your personal fundraising page to your social media accounts, like Facebook and Twitter. Here's an example post:
  “$50 funds one monthly volunteer-led HD Caregiver support group – support me as I walk to end HD by donating here:  [www.hdsa.org/thwsouthdakota](http://www.hdsa.org/thwsouthdakota)
- Create a widget and attach to your websites and emails.

Letter Writing Campaigns
- Writing to everyone you know is still one of the best ways to ASK a donation – regardless if you send the letter via snail mail or e-mail.
- In the letter share your personal story (if you feel comfortable sharing it), include a picture of you and your family, inform people about HD and HDSA, and ask for a donation to support you or your team.
- Once you have written a heartfelt letter, make copies of it, personalize it to each recipient, and e-blast it out to everyone you have an address or email for.
  - Helpful tip – you can do this through your DonorDrive account! All you have to do is upload your email address book to DonorDrive and then e-blast out the letter! Check out the screenshots below for instruction.

- Need some help writing your letter? Check out the two sample letters on the next two pages!
Sample Letter One:

Dear Friends,

As many of you know, three years ago my family lost a loving mother, wife, sister, aunt and friend to Huntington’s disease.

I watched as my mother went through all of the stages of HD, from the chorea to the dementia, and it is my dream that no one ever has to go through what she and my family had to endure. To work towards that dream, I will be walking for her in the Sioux Falls, SD Team Hope Walk on Saturday, May 6th, 2017!

This walk aims to raise awareness about HD, as well as money to support the mission of HDSA. The money I raise through this walk will support over 39 HDSA Centers of Excellence, 57 social workers and over 170 local support groups.

Please join me as I walk to support the mission of HDSA. Please donate to my personal fundraising page and join my team. If you cannot join my team, please consider making a donation online or by mailing a donation to me (payable to HDSA).

Thank you so much for all of your support!

Best,

Sam

[Insert Link To Your Personal Fundraising Page]
Dear Friends,

HD is a devastating, hereditary, degenerative brain disorder that results in a loss of cognitive, behavioral and physical control, and for which, presently, there is no cure. Over 30,000 people in the United States currently have Huntington’s disease (HD), and 250,000 are at risk.

I am one of those numbers – I am a face of HD. I recently tested for HD and found out that I am HD positive, which means that one day I will become symptomatic. And while I may know a tough road lies ahead for me, I will not walk down it quietly.

On May 6th, 2017, I will walk in the Sioux Falls Team Hope Walk to raise awareness about this disease and raise as much money as I can to support the programs and services of the Huntington’s Disease Society of America (HDSA).

I ask all of you to walk with me. Please visit my personal fundraising page at (insert your personal fundraising page link) and register as a member of my team. If you cannot walk with me, please consider a donation to my fundraising page. Every donation helps make a difference!

$1 Sends a Fast Facts Information Packet to a newly diagnosed HD patient.
$5 Provides a Law Enforcement Tool Kit to educate Law Enforcement Officials or First Responders about how to recognize HD and how to resolve potentially dangerous situations.
$50 Funds one monthly volunteer-led HD Caregiver support group.
$100 Supports a Social Worker-led HD Patient support group for one month.
$250 Allows an HD family of four to attend a local Education Conference.
$500 Pays a licensed Social Worker to cover a local HD Phone Helpline for one month.

Thank you so much for all of your support!

All the best,

Alex
Below are two sample Team Captain e-blasts to send out to your team members. Be sure to customize anything highlighted in yellow!

Dear Colleagues,

As many of you know, I will be walking in the Sioux Falls Team Hope Walk on Saturday, May 6th, 2017 to raise awareness about Huntington’s disease (HD). HD is a devastating, hereditary, degenerative brain disorder that results in a loss of cognitive, behavioral and physical control, and for which, presently, there is no cure. Over 30,000 people in the United States currently have Huntington’s disease (HD), and 250,000 are at risk.

I am reaching out to all of you to join my corporate team for the walk. By joining my team and walking with me, you can help raise awareness about HD as well as raise vital funds to support the mission of the Huntington’s Disease Society of America (HDSA). HDSA works in local communities across the country by offering:

- 170 Support Groups in local communities around the county.
- 57 Social Workers across the country to provide help and hope to the HD community.
- 39 Centers of Excellence which provide people with HD and their families comprehensive medical, psychological and social services, in addition to physical and occupational therapy and genetic testing and counseling.
- Educational resources for HD families, medical professionals and the general public.

Please, join me and my team as we walk for help today and hope for tomorrow. To join my team, click on the link below and click the large green ‘Register’ button on the top right side of the page:

Insert Your Team Personal Fundraising Page Link

Best,

Daniel
Team Name

Dear Team Members,

Thanks to your support and dedication Team Name has raised over $500 for the Sioux Falls Team Hope Walk, and I have no doubt we are going to reach our team fundraising goal of $1,500.

As the walk approaches, please don’t forget to:

- Register online here: www.hdsa.org/thwsouthdakota
- Establish a personal fundraising goal.
- Fundraise (the money they raise individually will count toward the team total!)
- Send personal, hand written thank you notes to your donors.
- Follow up with potential donors.
- Remind your donors to submit for matching gifts.
- Consider hosting a wrap around event.
- Send me updates about your fundraising success!

Our next team conference call will be on Monday, August 9th, at noon. Please dial in to the call if you can make it by using the dial in information below:

Dial In: 000-000-000
Password: 0000

Best,

Daniel

Insert Link To Your Personal Fundraising Page
Team Hope Walk Offline Donation Form

Please use this form to mail in a donation for a participant or a team.

I am supporting: ____________________________________________________________
(Participant or Team Name)

Who is walking in the: ______________________________________________________
(City & State)

Donation Information

Donation Amount: ________________ (Please make all checks payable to “HDSA”)

Donor Name: ____________________________________________________________

Donor Address: ___________________________________________________________

Donor City: _________________ Donor State: ______ Donor Zip: ________

Donor Email: ____________________________________________________________

Donor Phone Number: ____________________________________________________

Payment Information

Payment Type: Check _____ Cash _____ Credit Card: _____

Check Number: _______ Credit Card Type: Visa/MasterCard/American Express/Discover

Card Holder Name: ________________________________________________________

Credit Card Number: _____________________________________________________

Expiration Date: ________________ Security Code: ________ Billing Zip: ________

Card Holder Signature: ____________________________________________________

Thank You For Your Donation!

Please mail all donations with this form filled out for each donation to:

South Dakota HDSA Chapter
Team Hope Walk/5K & 10K
PO Box 2675
Sioux Falls, SD 57101-2675
Please make all checks payable to: "HDSA"

Please convert all cash to a check if possible.

<table>
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<tr>
<th>Name of Organization:</th>
<th>Address:</th>
<th>Phone:</th>
<th>ZIP:</th>
<th>City:</th>
<th>State:</th>
<th>Walk Location:</th>
<th>Team Name:</th>
<th>Participants Name:</th>
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</thead>
<tbody>
<tr>
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<td>None</td>
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<td>None</td>
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</table>

Date: 

Signature: 

Property of the HDUSA:

Immediately after this event without compensation to me, understand and agree that all photographs and videotapes will be the sole and complete

right to use, reproduce and publish any and all photographs and videotapes which may be taken of me, or my child, immediately before, during, or after the event, and hereby assume liability for any loss, damage, or other liability from such events. I hereby give permission to the HDUSA and their respective districts
casual use or any failure to act by HDUSA. It is theober to the extent of their abilities, to record, photograph, and to use any film, tape or other device, which may be

Team Hope Offline Registration & Donation Form