

Fall Newsletter



INSIDE THIS ISSUE:

Team Hope Walk	2
Calendar of Events	3
Health Care Maze	2
National Convention	4
Advocacy Journey	5
What is HD	6
NYA	6
Stages of HD	6
HDSA	7
Golf Event	7
Wrap Around Event	7
Board of Directors	8
Resources	8

Super-Sized Support Group Meeting

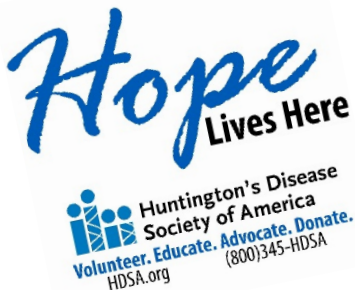
SATURDAY, APRIL 8, 2017

Time: 10:00am – 2:00pm

Location: Ronning Library, 49th Street & Southeastern Ave
Sioux Falls, SD

Join us for an event of great information and camaraderie!

**Committed to Building Awareness, Providing Support,
and Raising Funds for a cure!**



*Help for Today,
Hope for Tomorrow.*



**Huntington's Disease Society of
America's
TEAM HOPE WALK/5K & 10K
South Dakota HDSA**

SERTOMA PARK

(49TH Street & Oxbow – Sioux Falls, SD)

SATURDAY, MAY 6, 2017

**REGISTRATION – 8 AM
WALK/5K & 10K KICKOFF – 9 AM
LIVE AUCTION – 10:15 AM**

To join the South Dakota Team Hope Walk/5K & 10K

Register here: www.hdsa.org/thwsouthdakota



For Information:

Brad Lingen: 701-640-8446

Debbie Stadley Augustad: 612-816-0145

brad.lingen@gmail.com

debstadley@gmail.com

Website: siouxvalley.hdsa.org/



SPONSORS NEEDED!

Don't forget to tell your local business owners about our TEAM HOPE WALK! We are looking for sponsors for our event! We need financial sponsors, items for the Live Auction and water and snacks for the day of the event!

If have contacts – let Brad Lingen, Michael Hight, Cindy Trager or Debbie Augustad know.

The sponsorship levels are:

- Gold - \$1500.00
- Silver - \$1000.00
- Bronze - \$500.00
- Event - \$300.00

How to Navigate the Health Care Maze

by: Kari Plumbtree, MSW / HDSA – South Dakota Chapter Social Worker

Family members and patients are often shocked to find that insurance will not pay for many services and items that are needed at home that are often paid for in the hospital. Most patients and family caregivers do not have a good idea of what medical insurance will pay for until the need arises. Here are a few tips to help you navigate this confusing part of healthcare.

Know what your insurance or managed care company is responsible for covering.

- If you or a loved one has been hospitalized insist on being consulted by the discharge planner about the care plan before any decisions are made. Be sure to explore all the options, not just the one the discharge planner recommends.
- Find out what your insurance company will approve.
- Make sure you or your loved one fully understands his or her condition so that correct home care services and equipment are provided.
- Don't let your insurance company deny coverage for something that has been covered in the past or that you believe should be covered.

Identify and use all available resources

- Get to know your local pharmacist, they are an excellent and readily available resource.
- Familiarize yourself with internet resources, credible sources hold great information.
- Discuss your options with people outside of your network who have experienced your situation. Monthly support groups are a great place to meet and speak with others in similar situations.
- Learn to delegate daily tasks and ask others for help. This will help with stress so you can focus on caring for your loved one.

Be assertive about your rights

- You have the right to say no if hospital discharge planners want to send you or your loved one home and you feel you are not prepared to provide or receive the necessary care at home.
- Make sure the proper transportation is set up to and from outpatient visits.
- Ask for a re-evaluation of the situation at a specified time, several weeks or a month later.

Continued bottom of page 4.....

Calendar of EVENTS

March 11

Support Group Meeting;
10am to Noon;
Callie Library

April 8

Super-Sized Support
Group Meeting
10am-2:00pm
Ronning Library

May 6

Team Hope Walk
8am Registration
9am Walk/Run
10:15 Live Auction
Sertoma Park

May 13

Support Group Meeting;
10am to Noon; Check
website for location

June 10

Support Group Meeting;
10am to Noon; Check
website for location

June 22-24

Nation Convention in
Schaumburg, IL

July 8

Support Group Meeting;
10am to Noon; Check
website for location

August 12

Support Group Meeting;
10am to Noon; Check
website for location

August 26

Tee off Fore HD
Spring Creek Golf Course

Website:

siouxvalley.hdsa.org/

32nd Annual HDSA National Convention



June 22-24th * Schaumburg, IL

Registration, convention details and hotel information available at <http://hdsa.org/about-hdsa/annual-convention/>

Huntington's Disease Society of America is pleased to announce four unique Convention Scholarship opportunities for 2017:

- **National Convention Scholarship** – This scholarship is open to first time Convention attendees who are not Illinois or Wisconsin residents. (Application Deadline: April 19, 2017)
- **National Youth Alliance (NYA) Scholarship** – The NYA is offering full and partial scholarships for children and young adults from HD families to attend the Convention and participate in NYA Day, a special day-long program for young members of HD families. (Application Deadline: April 12, 2017)
- **National Convention Scholarship: Illinois Residents** – **This scholarship is for** residents of Illinois. (Application Deadline: April 19, 2017)
- **National Convention Scholarship: Wisconsin Residents** – **This scholarship is for** residents of Wisconsin. (Application Deadline: April 19, 2017)

SCHWAN'S FUNDRAISING EVENT

--- April 1st through May 16th!

Once again, we have our Schwan's Cares Campaign this year! Just by buying your groceries from Schwan's – The South Dakota Chapter benefits!

We will:

Earn 20% on Schwan's product sales

Earn 40% on eGift Cards sales (limit 1 per customer, per campaign)

www.schwans-cares.com/c/31620

Continued from page 3

How to Navigate.....

Recognize how the system can work against you

- Instead of providing greater coverage by having two insurance policies they could actually mean you have less coverage. They each play against the other delaying or actually limiting benefits. Make sure you have a clear agreement and knowledge of who is the “primary” insurance.
- More often than not you will have out-of-pocket expenses for things that are not considered “medically necessary.” Make sure to familiarize yourself with what is covered for things that may be needed on a daily basis such as daily dressing changes and certain medications.

A spouse is legally responsible for their partner's bills and his or her income is included in determining Medicaid eligibility. An unmarried couple is considered as a single individual making it easier to get Medicaid benefits, which may include home care. The sooner this is looked into the better and will make financial planning easier for the caregiver.

#HDTips

Managing Caregiver Stress...You might try:

- ◆ Prioritizing & making lists.
- ◆ Establishing a daily/weekly routine.
- ◆ Identifying specific things that trigger outbursts in your loved one & work to reduce them.
- ◆ Asking for help from friends, family & community.
 - ◆ Learning about caregiving resources.
 - ◆ Being kinder to yourself.

Volunteers Needed

We are always looking for volunteers to help carry out our educational and fundraising events.

Volunteers can be anyone in our lives that want to give back to their community. They don't need to have HD in their families --- but, they are interested in helping us execute our HDSA mission.

Volunteering provides an opportunity to meet new people and to pursue interests in your daily life. Volunteering can also provide career experience - it can offer you the chance to try out a new career without making a long-term commitment. It is also a great way to gain experience in a new field.

If you are interested in volunteering at our Team Hope Walk, Educational Events, or our other fall fundraising events, please email:

Debbie at
debstadley@gmail.com

Our Advocacy Journey Continues!

Social Security Disability

- People with HD applying for Social Security Disability Insurance (SSDI) are routinely denied or experience long delays due to the Social Security Administration's (SSAs) use of outdated, medically inaccurate guidelines.
- As a result, the outdated guidelines cause individuals with HD to experience long delays and multiple denials of critical SSD benefits.

Medicare Benefits

- Medicare's two year waiting period is particularly devastating for people with HD. Once a person with HD is finally deemed eligible for SSD benefits, they are forced to wait two years to receive Medicare benefits. During the two year wait, HD's destructive impact cognitively and physically robs the person of their ability to live independently.

The Huntington's Disease Parity Act (H.R. 842/S. 968) will improve access to Social Security Disability benefits and Medicare coverage for individuals with Huntington's Disease (HD). The legislation will ...

- Direct the Commissioner of SSA to revise its outdated medical and evaluation criteria for determining disability, thus enabling individuals with HD to receive the essential disability benefits that they are often denied.
- Waive the Medicare two year waiting period, thereby ensuring individuals receive critical health benefits and care in the early stages of the disease.

We can make a difference and "tell our story!" 2016 was a record year for the Huntington's Disease Parity Act and it's all thanks to you!

This is what we need to do...tell your Representative and Senators to work to Pass the Parity Act! www.cqrcengage.com - Use this link to send a letter to your representatives and senators our story!

#HDTips

COPING STRATEGY FOR APATHY

Do not interpret a lack of initiation or activity as "laziness." Educate family members and friends about the inability to "begin" or "initiate" behaviors and ask others to encourage participation in activities.
Gently guide behaviors but respect "no."

 Huntington's Disease Society of America
Volunteer. Educate. Advocate. Donate.
HDSA.org (800)345-HDSA

May is HD Awareness Month

May is HD Awareness Month and a great time to educate people outside the HD community about Huntington's disease and how they can join us in our efforts to provide "Help for Today and Hope for Tomorrow" to everyone affected by HD.

What Is Huntington's Disease?
 Huntington's disease is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain.


HD deteriorates a person's physical and mental abilities usually during their prime working years and has no cure.

Every child of a parent with HD has a 50/50 chance of carrying the faulty gene that causes Huntington's disease.

Today, there are 30,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease.

In approximately 10% of cases, Juvenile Huntington's disease (JHD) affects children or adolescents. JHD typically progresses more rapidly than adult onset HD.

The symptoms of HD are described as having ALS, Parkinson's & Alzheimer's diseases - simultaneously.



Huntington's Disease Society of America
 Volunteer. Educate. Advocate. Donate.
 HDSA.org (800)345-HDSA

HDSA's NATIONAL YOUTH ALLIANCE (NYA)

The NYA motivates youth to get involved in their local HDSA Chapters, Affiliates, and Support Groups in efforts through education, fundraising, advocacy and awareness for Huntington's disease.

The NYA is a collection of children, teens and young adults from across the country.

We are made up of young women and men ages 9-29 that are impacted by Huntington's. The NYA is dedicated to our vision of being the last generation with Huntington's disease and as an essential part of the future of HDSA; we pride ourselves on our ability to persevere throughout the years. Since 2004, NYA has grown from a small group of kids to over 500 members!

It is our mission to not only support young people within the HD community, but also inspire the youth of HDSA to get involved in the battle against HD and be proactive in this fight.

The NYA is dedicated to making ours the last generation with Huntington's disease."

Stages of HD

Source: Caregiver Guide for Mid to Late Stage Huntington's Disease: For Long-Term Care Facilities and In-Home Care Agencies by Huntington's Disease Society of America

Traditionally, Huntington's disease has been categorized into 5 stages based on symptoms and degree of disability. But this degree of detail is mostly used in HD research. Seldom do a person's symptoms fit neatly and precisely into a category. For this purpose, three phases of HD are described below.

As with most neurological disorders, persons with HD will experience a unique progression of their disease. Some persons will have chorea early and cope well with it, showing few changes in their thinking, while others will have mood and memory problems early and uncontrollable movements later.

PHASES OF HUNTINGTON'S DISEASE			
	Stage 1- Early	Stage 2-Middle	Stage 3-Late
Symptoms	Subtle or mild symptoms, manageable with medications	Increasingly intrusive motor, cognitive, or behavioral symptoms	Poorly controlled movements
Location of Care	Home	Home with assistance or assisted living	Skilled nursing care
Activities of Daily Living	Independent	Not driving, managing finances, may need help with self-cares	Fully dependent on others for daily cares
Disability	No disability but may require work modifications	Unable to work	Unable to work
Emotional Cognitive	Depression, suicide risk	Mood changes, irritability, perseveration	Dementia, reduced ability to communicate

Calendar of EVENTS

Continued.....

Sept 9

Support Group Meeting;
10am to Noon; check
website for location

Sept 24

Fall Education Event
Sanford Health
Auditorium
Louise Vetter, CEO of
HDSA, Featured Speaker

October 14

Support Group Meeting;
10am to Noon; check
website for location

November 11

Support Group Meeting;
10am to Noon; check
website for location

December 9

Support Group Meeting;
10am to Noon; check
website for location

Website:

siouxvalley.hdsa.org/



The Society is a National, voluntary health organization dedicated to improving the lives of people with Huntington's disease and their families.

To promote and support research and medical efforts to eradicate Huntington's disease.

To assist people and families affected by Huntington's disease to cope with the problems presented by the disease.

To educate the public and health professionals about Huntington's disease.

START PLANNING YOUR SUMMER GOLF SCHEDULE

Our 3rd Annual TEE OFF FORE HD Event is planned for **Saturday, August 26th**.

Due to the increasing attendance over the last two years at Tee-Off Fore HD, we have decided the golf tournament will be moving to **Spring Creek Golf Course**. The tournament will now be an **18-hole tournament** to allow everyone to enjoy an extra nine holes of golf in the morning. HDSA South Dakota will still provide great food after the tournament. The tournament will start at 7:00 a.m. to allow the tournament to finish about the same time, so get your golf game ready bright and early!

- 4-person team is \$320.00
- Hole Sponsors is \$200.00
- Hole Sponsor and the 4-person team is \$475.00

HDSA South Dakota looks forward to making the Third Annual Tee-Off Fore HD Golf Tournament even more enjoyable than the last two years.

WHAT IS A WRAP AROUND EVENT?

A WRAP AROUND EVENT is fun way for your friends, family, neighbors, co-workers to create your own event to raise money for the South Dakota Chapter.

That is exactly what Cindy Trager did with 25 of her friends and co-workers. What a better thing to do than pretend you are an up and coming Picasso on a wintry January day. Especially if it means spending time with friends and raising money for Huntington's Disease. They painted a charming snowman, had LOTS of laughs, some snacks and raffled off some gift baskets.

The day was a lot of fun and maybe most of us realized we should stick to our day jobs but we did manage to raise \$850 on behalf of Huntington Disease.

They are already brainstorming for next year!



**South Dakota Chapter
HDSA**
PO Box 2675
Sioux Falls, SD
57101-2675
Phone # contacts below.



Resources

**Social Worker
South Dakota Chapter**
Kari Plumbtree
605-214-8486
kplumbtree@hdsa.org

**Board President
South Dakota Chapter**
Debbie Augustad
612-816-0145
debstadley@gmail.com

Sanford Huntington's Disease Clinic

- Dr. Matos
Neurologist
- Lior Borovik
Genetics Counselor
- Nathan Anderson
Social Worker
- Diane Johnson
Mitchell – Family
Therapist
Sanford Health -
Sioux Falls, SD
605-312-1000

South Dakota Chapter Board of Directors

President - Debbie Augustad / 612-816-0145 / debstadley@gmail.com
Vice President – Michael Hight / 605-212-8645 / hightrm@gmail.com
Treasurer – Doreen Heicks / 605-201-7898 / dmhoeck22@hotmail.com
Secretary – Brad Lingen / 701-640-8446 / brad.lingen@gmail.com
Cindy Trager / 605-941-3173 / cst6319@hotmail.com
Becky Mutziger / 605-228-1178 / becky@lloydcompanies.com
Darwyn Sprik / 605-413-5808 / darwyn@sprikfinancial.com
Kraig Kronaizl / 605-321-6215 / kkronaizl@lynnjackson.com
Gail Nash / 605-359-1545 / gail.nash63@gmail.com
Honorary Board Member – Kevin Sandbulte

The Huntington's Disease Society of America

HDSA is the premier nonprofit organization dedicated to improving the lives of everyone affected by Huntington's disease. From community services and education to advocacy and research, HDSA is the world's leader in providing help for today and hope for tomorrow for people with Huntington's disease and their families.

HDSA's network of chapters, affiliates, HDSA Centers of Excellence, social workers and support groups provides a seamless connection for help, education and outreach to HD families and health care professionals across the United States.

Stay Connected

Website: siouxvalley.hdsa.org/

Watch your email for updates
regarding:

**Team Hope Walk
Support Group
National Convention
Education Events**

and much, much more!

AmazonSmile

Shop AmazonSmile and Amazon will make a donation to the Huntington's Disease Society of America (HDSA). Up to 0.5% of your purchase will benefit HDSA.

www.smile.amazon.com

HDSA MISSION

**The mission of HDSA is to
improve the lives of everyone
affected by Huntington's disease.**