

# Fall Newsletter



## INSIDE THIS ISSUE:

Team Hope Walk	2
Calendar of Events	2
Caregiver's Corner	2
Tips for Caregivers	3
Board Member Update	3
Keep a Family Physician	4
NYA	4
Tee Off Fore HD	5
Hitting the Hill for HD	6
Advocacy	6
Thank You, Tom	7
What is HD	7
Chapter of Year	8
Resources	8

## Fall Education Event & National Youth Alliance Event

**SUNDAY, SEPTEMBER 25, 2016**

**Time:** 11:30am, Registration  
Noon to 4:00pm, Education Event

**Location:** Schroeder Auditorium, Sanford Medical Center  
(Grange & 18<sup>th</sup>) / Sioux Falls, SD

### *Featured Speakers*

**Jimmy Pollard, CHDI Foundation**

**Havanna Lowes, NYA Member**

Come join us for an afternoon of great information and camaraderie!

Information about clinical trials, where to find resources, and advocacy!

**PANEL DISCUSSION WITH USD MEDICAL STUDENTS**

Featured Speaker – Jimmy Pollard / Panel from HDSA –  
Sioux Valley Chapter  
Monday, September 26<sup>th</sup>

UNIVERSITY OF SOUTH DAKOTA – VERMILLION, SD



*Help for Today,  
Hope for Tomorrow.*

**Calendar of EVENTS**

**September 10**

Support Group Meeting;  
10am to Noon;  
Ronning Library

**September 25**

Fall Education Event;  
Sanford Medical Center  
Jimmy Pollard, Speaker  
Havana Lowes, NYA

**September 26**

Panel Discussion;  
USD Medical School,  
Vermillion, SD

**October 8**

Support Group Meeting;  
10am to Noon;  
Ronning Library

**November 12**

Support Group Meeting;  
10am to Noon;  
Ronning Library

**December 10**

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

**Website:**

[siouxvalley.hdsa.org/](http://siouxvalley.hdsa.org/)



# Team Hope Walk/Run 2016



Team Hope Walk/Run 2016 was a great success despite the rainy weather! Thank you to our families, friends, sponsors and participants for their continued support! This was our best walk ever – revenue was a little over \$33,000! Congratulations!



## Caregiver's Corner

The 31<sup>st</sup> HDSA Annual Convention was packed with amazing speakers and presentations. You can view recordings of select workshops at: [www.hdsa.org/convention](http://www.hdsa.org/convention). One of the speakers was Peter Rosenberger. He is a radio host and 30 year caregiver!

Rosenberger wrote *“Hope for the Caregiver – Encouraging Words to Strengthen Your Spirit”*. Here are some great quotes and segments from Rosenberger’s book:

### Chapter Three – A DIFFERENT PERSPECTIVE

“Sometimes, it helps to get a different perspective on a situation. Let’s start with a few qualifying questions.”

- “Did you create the condition your loved one endures?”
- “Can you cure them?”
- “Can you control what is happening to them?”

Obviously, with HD – the answers are NO. So, what does this mean for the caregiver --- this is your role accordingly to Rosenberger “I’m learning my role is to love my spouse, do the best I can, and grow as a healthy individual to the best of my abilities.”

So, how do caregivers do this? .....continued on page 3

## Tips for Caregivers

H-E-L-P M-E Plan; 1 – 2 - 30

### Hhealth

- 1 annual flu (or shingles) vaccination
- 2 well visits
- 30 minutes of daily exercises

### Emotions

- 1 counseling session per month
- 2 support groups
- 30 days in church per year

### Lifestyle

- 1 thing per week that YOU enjoy
- 2 weeks' vacation from caregiving per year (may not be possible in a "block")
- 30 minutes of laughter (daily --- may not be possible in a "block")

### Profession

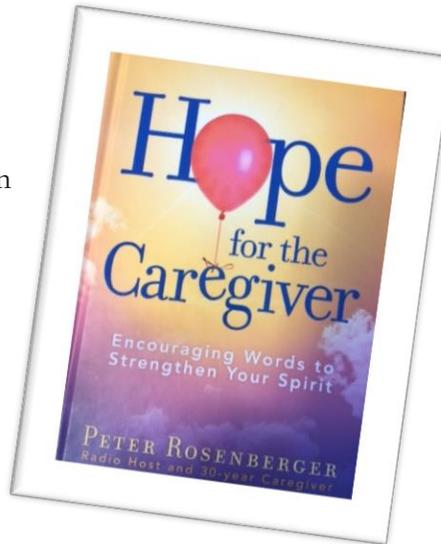
- 1 training class per year to learn a new skill
- 2 performance meetings with supervisor each year
- 30 minutes daily away from desk/phone

### Money

- 1 charity you can financially support
- 2 meetings per year with a financial advisor
- \$30 per paycheck into savings/investment

### Endurance

- 1 daily contact with positive/loving friends or family members
- 2 hours per week of "Me time"
- 30 minutes daily devotional/quiet time



## BOARD MEMBER UPDATE

We are thrilled to announce that we have four new board members joining our mission as of July 2016!

Please help in welcoming them to our HD Family.

**Gail Nash** lives in Crooks, SD. Gail is a Global Entrepreneur Leader with Jeunesse Global.

**Michael Hight** lives in Sioux Falls, SD. Michael works for Billion Toyota in the Digital Marketing and Customer Relations department.

**Doreen Heickes** lives in Sioux Falls, SD. Doreen is the Financial Secretary at the Living Word Free Lutheran Church.

**Kraig Kronaizl** lives in Sioux Falls, SD. Kraig is an attorney at Lynn, Jackson, Shultz & LeBrun, P.C.

As you already know, our existing board members are: Debbie Augustad, Becky Mutziger, Cindy Trager, Noel Lais, Margaret Geertsema, Brad Lingen, Darwyn Sprik, Kevin Sandbulte and Peter Anderson.



## Let the FDA know:

Families Need HD Treatments Now!  
There is an HD drug awaiting review, let the FDA know that we need action on deutetribenazine now!

Sign the petition here:

<http://cqrcengage.com/hdsa/app/sign-petition?7&engagementId=233473>

## Why it's important to keep a family physician! Kari Plumbtree, Social Worker

One of the presentations at this year's convention was the importance of keeping a family physician. It may not seem important to keep a family doctor when you have a disease that requires a specialist so here's a few reasons why this is important.

1. Having an extra set of eyes in between appointments with your Neurologist. Coordination of care.
2. If you have a UTI a neurologist is not the right Dr. to treat you. Your family physician will refer you to the proper person to treat you or will treat you with correct medications.
3. If you would be hospitalized, you would want a family doctor or Internal Med physician to follow you while hospitalized along with your specialist.
4. They may observe swelling in an area of your body that you hadn't noticed, something that might look normal to a physician that wasn't familiar you, because it was too soon to be noticed as a threat.

The most important reason is your family physician gets to know you over a period of time. Even when we all feel rushed during appointments. They get to know you as a person get a sense of who you are, your values, family situations, job pressures, and maybe even your life goals. These may seem like unimportant aspects in relation to your healthcare, but all of these have a profound effect on your health. Knowledge of these things may provide valuable information as they assess what is troubling you. They know your complete history. Keeping a family physician along your journey is an important part of coordinating your care.

### #HDTips

#### Why Join an HDSA Support Group?

- ⇒ Connect with others who understand your journey
- ⇒ Build relationships with people that can help
- ⇒ Hear the experiences of others even if you are not feeling quite ready to share your own
- ⇒ Add to the support you may already receive
- ⇒ Seeking support is not a weakness



### #HDTips

#### How Can An HDSA Social Worker Help?

- ▲ Knowledge Of Huntington's Disease
- ▲ Assist With Resources
- ▲ Answer Questions About Genetic Testing
- ▲ Help With Information On Disability
- ▲ Answer Questions About Long Term Care Placement



### 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."

## 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 Tee Off Fore HD Golf Fundraiser, please email:

**Debbie at**  
**debstadley@gmail.com**

## Tee Off Fore HD, 2<sup>nd</sup> Annual Golf Event Held on August 27th, Northern Links Golf Course



Our 2<sup>nd</sup> Annual Tee Off Fore HD event was a huge success! We had 20 teams play this 9-hole event and we generated just over \$11,000 in revenue. Hats off to the generous sponsors (listed to the left), golfers, volunteers and our local board. It fills the heart knowing so many are willing to help beat this terrible disease and support our HD families.



## 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.

## Hitting the Hill for HD

“I love being able to talk about it and bring that awareness. But this is going to be a whole other thing to go up to someone who can make a difference for EVERYONE, to be able to get the awareness on a bigger scale. Congress can affect the whole country and every Huntington’s disease family”. Jay Waagmeester

Jay Waagmeester wrote a biography about his father for an eighth grade social studies and technology education project at Central Lyon. Jay’s father has Huntington’s disease. Shortly after his presentation it caught the eye of the Huntington’s Disease Society of America (HDSA) via social media.

HDSA contacted Jay to see if he would bring his presentation to Washington D.C. and present it before Congress on June 1st, which happened to be his father’s birthday. Jay eagerly accepted!



Jay went to Washington DC to encourage Congress to back the Huntington’s Disease Parity Act by changing the rules of Medicare and make benefits for HD patients easier to obtain.

“People with HD apply for disability benefits, and in most cases - it’s hard for them to get accepted because only the involuntary movement part of the disease is recognized. The Social Security Administration doesn’t recognize how the brain deteriorates with the disease.” explained Waagmeester.

Jay met with seven different representatives while on the hill! After his visit, Nevada Rep Joe Heck, D.O. signed up to support the Parity Act. It was a successful day!

Part of the Parity Act was achieved. Social Security is updating the guidelines for Huntington’s disease. The elimination of the two-year wait period is something we will have to keep pursuing.

Our mission is not complete yet. Please check our Advocacy updates!!

## Our Advocacy Journey Continues

**Medicare Benefit’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 ...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!”

This is what we need to do...send a letter to your Representative and Senators to work to Pass the Parity Act! See the web address highlighted in yellow.



Go to:

<http://hdsa.org/about-hdsa/advocacy/huntingtons-disease-parity-act-2/>

## A very special THANK YOU to a very special NFL fan: TOM GENGLER

The Sioux Valley Chapter has been blessed with three amazing gifts from Tom Gengler! Tom Gengler from Sioux City, Iowa has a “man cave” or “man palace” like no other! He has donated three NFL signed and framed jersey’s from the great Clay Matthews, Julio Jones and Jared Allen to our Chapter for fundraising opportunities.

We raffled the Clay Matthews jersey at the 2015 Tee Off Fore HD golf event. In August 2016, we raffled the Julio Jones jersey. The Matthews and Jones jersey each raised over \$2,000.00! Watch for the Jared Allen jersey to be a live auction item at our 2017 Team Hope Walk!

***Thank You Tom Gengler for your generous gifts!***

### 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



## Sioux Valley Chapter HDSA

PO Box 2675  
Sioux Falls, SD  
57101-2675  
Phone # contacts below.



## Resources

**Social Worker**  
**Sioux Valley Chapter**  
Kari Plumbtree  
612-910-6651  
[kplumbtree@hdsa.org](mailto:kplumbtree@hdsa.org)

**Board President**  
**Sioux Valley Chapter**  
Debbie Augustad  
612-816-0145  
[debstadley@gmail.com](mailto: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

## Awarded Chapter of the Year!

The **Sioux Valley Chapter** was awarded the 2015 Chapter of the Year at the 31st HDSA Annual Convention in Baltimore MA. This is the most prestigious award that a chapter/affiliate can receive. There are 54 chapters and affiliates in the United States. The Chapter/Affiliate that works for the mission of HDSA through family service, education programs, advocacy, fundraising, communication and board development. One chapter and one affiliate is given this award at the Annual Convention. The 32nd HDSA Annual Convention is in Schaumburg, Illinois – June 22-24th, 2017 --- **Save the date!**



Accepting the award at Convention left to right: Brad Lingen, Julie Lingen, Tom Geertsema, Debbie Augustad, and Margaret Geertsema

➔  
Your local Sioux  
Valley Chapter  
Board ... at the  
golf event!



## Stay Connected

Website: [siouxvalley.hdsa.org/](http://siouxvalley.hdsa.org/)

Watch your email for updates  
regarding:

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

and much, much more!



Future Board  
Member!

## HDSA MISSION

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