

# Spring Newsletter



## INSIDE THIS ISSUE:

Team Hope Walk	2
Calendar of Events	3
Care for the Caregiver	3
HD Awareness Month	4
Amazon Smile	5
Advocacy	5
National Convention	6
New Social Worker	7
Schwan's Cares	7
New Regional Director	8
Resources	8

## Super-Sized Support Group Meeting

**SATURDAY, APRIL 9, 2016**

Registration - 10:30AM

Event - 11AM TO 2:30PM

Prairie West Library / 7630 W 26<sup>th</sup> Street / Sioux Falls, SD

## *Featured Speakers*

**Dr. Martha Nance**

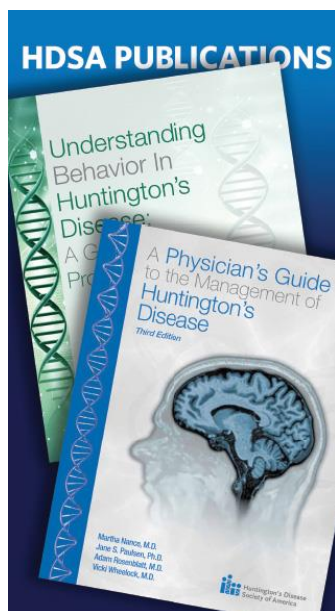
**Dr. Matos**

**Lior Borovik**

**Kari Plumbtree**

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

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



*Help for Today.  
Hope for Tomorrow.*





**HUNTINGTON'S DISEASE SOCIETY OF  
AMERICA'S  
TEAM HOPE WALK/5K & 10K  
SIOUX VALLEY HDSA**

**SERTOMA PARK**

(49<sup>TH</sup> Street & Oxbow – Sioux Falls, SD)

**SATURDAY, April 30<sup>th</sup>, 2016**

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

**Join the Sioux Valley Team Hope Walk/5K & 10K**

Register here: <http://hdsa.donordrive.com/event/siouxfalls/>

**For Information: Call Debbie Stadley Augustad**

Call: 612-816-0145

Email: [debstadley@gmail.com](mailto:debstadley@gmail.com)

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

**TEAM HOPE WALK/5K & 10K 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, Darwyn, Becky, Cindy and/or Debbie know!

**The sponsorship levels are:**

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



## Calendar of EVENTS

### April 9

Super-Sized Support  
Group Meeting, Prairie  
West Library; 11am to  
2:30pm

### April 30

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

### May 14

Support Group Meeting;  
11am-1pm; check website  
for location

### June 2-4

National Convention;  
Baltimore, MD

### June 11

Support Group Meeting;  
11am-1pm; check website  
for location

### July 9

Support Group Meeting;  
11am-1pm; check website  
for location

### August 13

Support Group Meeting;  
11am-1pm; check website  
for location

### September 10

Support Group Meeting;  
11am-1pm; check website  
for location

Website:

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

*Cont on Page 4.....*

## Care for the Caregiver

**Caring for a loved one strains even the most resilient people. If you're a caregiver, take steps to preserve your own health and well-being.**

*By Mayo Clinic Staff*

[www.mayoclinic.org](http://www.mayoclinic.org)

### Strategies for dealing with caregiver stress

The emotional and physical demands involved with caregiving can strain even the most resilient person. That's why it's so important to take advantage of the many resources and tools available to help you provide care for your loved one. Remember, if you don't take care of yourself, you won't be able to care for anyone else.

To help manage caregiver stress:

- **Accept help.** Be prepared with a list of ways that others can help you, and let the helper choose what he or she would like to do. For instance, one person might be willing to take the person you care for on a walk a couple of times a week. Someone else might offer to pick up groceries or cook for you.
- **Focus on what you are able to provide.** It's normal to feel guilty sometimes, but understand that no one is a "perfect" caregiver. Believe that you are doing the best you can and making the best decisions you can at any given time.
- **Set realistic goals.** Break large tasks into smaller steps that you can do one at a time. Prioritize, make lists and establish a daily routine. Begin to say no to requests that are draining, such as hosting holiday meals.
- **Get connected.** Find out about caregiving resources in your community. Many communities have classes specifically about the disease your loved one is facing. Caregiving services such as transportation and meal delivery may be available.
- **Join a support group.** A support group can provide validation and encouragement, as well as problem-solving strategies for difficult situations. People in support groups understand what you may be going through. A support group can also be a good place to create meaningful friendships.
- **Seek social support.** Make an effort to stay well-connected with family and friends who can offer nonjudgmental emotional support. Set aside time each week for connecting, even if it's just a walk with a friend.
- **Set personal health goals.** For example, set a goal to establish a good sleep routine or to find time to be physically active on most days of the week. It's also crucial to fuel your body with healthy foods and plenty of water.
- **See your doctor.** Get recommended immunizations and screenings. Make sure to tell your doctor that you're a caregiver. Don't hesitate to mention any concerns or symptoms you have.

Continued Page 4

## Care for the Caregiver continued.....

### Respite care

It may be hard to imagine leaving your loved one in someone else's care, but taking a break can be one of the best things you do for yourself — as well as the person you're caring for. Most communities have some type of respite care available, such as:

- **In-home respite.** Health care aides come to your home to provide companionship, nursing services or both.
- **Adult care centers and programs.** Some centers provide care for both older adults and young children, and the two groups may spend time together.
- **Short-term nursing homes.** Some assisted living homes, memory care homes and nursing homes accept people needing care for short stays while caregivers are away.

### The caregiver who works outside the home

Nearly 60 percent of caregivers work outside of the home. If you work outside the home and are feeling overwhelmed, consider taking a break from your job. Employees covered under The Family and Medical Leave Act (FMLA) may be able to take up to 12 weeks of unpaid leave a year to care for relatives. Ask your human resources office about options for unpaid leave.

### Calendar of EVENTS

*Cont.....*

#### **September 25**

Fall Education Event;  
Sanford Health  
Auditorium; Featured  
Speaker, Jimmy Pollard

#### **September 26**

Panel Discussion; USD  
Medical School;  
Vermillion, SD

#### **October 8**

Support Group Meeting;  
11am-1pm; check website  
for location

#### **November 12**

Support Group Meeting;  
11am-1pm; check website  
for location

#### **December 10**

Support Group Meeting;  
11am-1pm; check website  
for location

Website:

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

## 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. We encourage you to please post HD information to your social media pages to help educate friends about HD!





### AmazonSmile

Shop at 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](http://www.smile.amazon.com)

GET STARTED  
TODAY!

### HDSA MISSION

**The mission of HDSA is to improve 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, hope for tomorrow for people with Huntington's disease and their families.**

## 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!" 2015 was a record year for the Huntington's Disease Parity Act and it's all thanks to you!

Not only did we reintroduce the Parity Act in the House of Representatives and Senate, but we now have more cosponsors than we have ever had! Gaining 231 cosponsors in the House and 17 in the Senate is no easy feat, and could not have been done without the HD community across the country organizing, advocating, volunteering, and lobbying their members of Congress to cosponsor the Parity Act. Now, as 2015 ends and we head into 2016, we need to push the Parity Act over the final hurdle, passage into law!

This is what we need to do...tell your Representative and Senators to work to Pass the Parity Act! Go to: <http://hdsa.org/about-hdsa/advocacy/huntingtons-disease-parity-act-2/>

To send a letter to your representatives and senators our story!

## 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 events, please email:

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

## 31<sup>st</sup> Annual HDSA National Convention



June 2-4<sup>th</sup> at Hyatt Regency Baltimore Inner Harbor

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

### NATIONAL SCHOLARSHIPS

National Scholarships are available through HDSA.

Lundbeck is sponsoring a scholarship for first time attendees. **April 1<sup>st</sup>** is the deadline for this scholarship. Go to the above website for details.

National Youth Alliance is also sponsoring scholarships. **March 18<sup>th</sup>** is the due date! Go to the above website for details.

## Introducing our New Chapter Social Worker – Kari Plumbtree

I am so happy to be joining the HDSA family. It is truly an honor to be working with such a great community of people.

Before I joined HDSA I previously worked at the Veterans Hospital in Sioux Falls as a Primary Care social worker. I had the privilege of helping Veterans in our community receive the benefits and assistance they deserve. I have nonprofit experience working with neuromuscular diseases with the Muscular Dystrophy Association. I worked with young kids and adults with a variety of different muscular diseases and prognosis's. I also had the privilege of working as a summer camp director of the camp that MDA had each summer for all kids affected in the area. Best week of year for these kids and for people working with them. Before I graduated from USD with a Masters of Social Work, I worked at Avera McKennan running the Autonomic Lab under the director Dr. Todd Zimprich. I have over 12 years of medical experience.



In my down time I enjoy camping, anything outdoors and spending time with my family. I have 3 children, Madeline 7, Molly 3, and Caiden 1. Of course I have 2 fur babies also, Mina our rescued crazy lab and Lulu our tiny little pocket dog.

I am excited to continue to learn about Huntington's Disease and how it affects each individual person and how I can help. Please feel free to call or email with any questions or concerns, I look forward to meeting everyone.

### **SCHWAN'S CARES – Fundraising Event!**

**March 2 – April 16**

Schwan's will donate to our Sioux Valley HDSA Chapter.

#### **Here's how it works:**

- Invite friends and family to shop at Schwan's
- Earn 20% on Schwan's product sales
- Earn 40% on eGift Cards sales (limit 1 per customer, per campaign)

#### **Order Online:**

1. Go to: <https://www.schwans-cares.com/c/26419>
2. Enter Campaign ID: **26419**
3. Click "Buy Now" button to purchase an eGift Card or "Shop Now" to place a product order.



## Sioux Valley Chapter HDSA

PO Box 2675  
Sioux Falls, SD  
57101-2675



## 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

## Welcome Clarissa Trujillo!

Clarissa Trujillo is the new HDSA Regional Development Director for the Upper Midwest, working out of Minnesota. She supports HDSA Chapters and Affiliates in South Dakota, North Dakota, Minnesota, Iowa and Nebraska.

Clarissa is no stranger to HDSA and our patient community. Most recently, Clarissa was president of the Arizona Chapter for nearly two years until May 2014 when her family temporarily moved to Israel for her husband's unique job opportunity.

Clarissa's professional background includes more than 12 years in corporate communications and public relations. She first became a friend to HDSA in 2008 when she worked at Lundbeck, Inc. There she developed educational strategies around chorea associated with Huntington's disease and became a familiar face at events around the country.

She is the proud mother of twin three-year-old daughters Nina and Madison and has enjoyed many traveling adventures with her husband of nine years, George.

If you have any questions for Clarissa, she can be reached at:  
[ctrujillo@hdsa.org](mailto:ctrujillo@hdsa.org) or 612-499-4829



## Stay Connected

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

Watch your email for updates regarding:

**Team Hope Walk  
Support Group  
National Convention**

and much, much more!