



Sioux Valley Chapter HDSA / P.O. Box 2675 / Sioux Falls, SD 57101-2675

Fall Newsletter – 2014

FALL EDUCATION EVENT 2014

SUNDAY, SEPTEMBER 28TH, 2014 / NOON TO 4 PM
Schroeder Auditorium / Sanford USD Medical Center

Featured Speaker

Dr. Arik Johnson

Psychologist

HDSA Center of Excellence at UCLA

Come join us for an afternoon of great information and camaraderie! Dr. Michael Kruer and Lior Borovik from our Sanford HD Clinic will also be our fall seminar event.

In addition, there will be information about clinical trials, research ambassador, talking with Kids about HD, and advocacy! And, don't forget --- we will have a silent auction and refreshments!

See you on Sunday, September 28th – Noon to 4pm at Schroeder Auditorium / Sanford USD Medical Center – 1305 W. 18th Street, Sioux Falls, SD.

USD Education Event

Panel Discussion

Monday, September 29th 10 am to Noon

Sanford School of Medicine

The University of South Dakota

We are looking for HD families – caregivers, siblings, and people with HD to join a panel discussion at USD. Our panel will be for first year medical students at USD. It has always been a great informative event for the 1st year medical students. Please let Margaret or Debbie know if you would like to join.

A MESSAGE FROM THE SANFORD HD CLINIC

Hi everyone,

We are happy to say that our clinic is off to a strong start. We currently see HD patients on the fourth Thursday of every month.

The clinic is directed by Lior Borovik, certified genetic counselor and advocate for HD patients and Dr. Michael Kruer, neurogenetics and movement disorders physician. We are happy to announce that social worker Nathan Anderson has joined our clinic. Nate is a wonderful man, and has been hard at work learning how best to help patients and families dealing with HD. Nate can help families navigate challenging topics such as health insurance, social security, and government assistance. Although Nathan is new to the HD field, he is eager to learn and has been reading and attending special sessions focused on HD.

We would also like to mention that one of Sanford's psychologists, Dr. Sarah Konrady, is providing her expertise to individuals with HD and their family members. Dr. Konrady can provide both neuropsychological testing and psychotherapy depending on an individual or family's needs. Dr. Konrady has been eager to learn more about care needs specific to HD through both professional development and from patients and family members.

We are hoping to add other specialists to our team (such as dietitians, speech therapists, and physical and occupational therapists). Our team will continue to grow and evolve in response to the needs and input of families but we are currently "open for business." We are applying for designation as a level 3 HDSA Center of Excellence this month and are excited about the opportunities for continued growth this will bring.

As always our goal, first and foremost, is to provide outstanding care to patients and their families at every step. We are always happy to assist with any requests or needs of patients and their families. The start of the HD Clinic has not been without challenges, but we have had a tremendous response already, and for that we thank you.

The clinic welcomes referrals from primary care physicians, neurologists, psychiatrists, and patients and family members. Both adults and children are seen at the clinic. Appointments are being scheduled now, and patients are seen within a few weeks of contact. To make an appointment, please call 605-312-1000 or for more information contact Lior Borovik at 605-328-7744 or 605-328-4641.

Thank you

Lior Borovik, MS,LCGC

Genetic Counselor

Michael Kruer, MD

Neurogenetics & Movement Disorder Physician



PIE IN THE FACE CHALLENGE FOR HD!

Social Networking is working in our favor! What a great "organic" fundraising event that Pete Frates with the ALS ice bucket challenge started! It proves that "grass roots" events are the most effective way to "tell our stories" and gain awareness to a great cause.

So, with that in mind...we have the PIE IN THE FACE CHALLENGE FOR HD! If you have not yet been nominated, please start it yourself with your family, friends and neighbors. Post it to your FB page and tag your friends and family! It is a fun way to "tell the stories of our loved ones" and raise money for HDSA

What is support group?

Why is a support group important? The goal of a support group is to know what others before you may have already been through and figured out. Another is to learn ways to cope, survive and to get the most out of the life that HD has handed you.

When we meet at the support group meetings, we talk about what we may be struggling with, or what we have accomplished and/or ideas we have implemented to improve our life and the life of our loved ones. We have at times talked about how to put a plan in place when things start to get challenging in caring for our loved ones. We can help you brainstorm a plan, and an alternate plan for a situation and/or the future. You will get the support you need. There are so many situations and scenarios that we all experience every day caring for a loved one with HD. It is good to talk about your needs as a caregiver.

Our support group meetings are the 2nd Saturday of every month. Watch your emails, and check out the website and FB page for details.

SOCIAL WORKER TIDBITS – EILEEN KRUEGER

The board members asked if I would write an article that contains some tips for those caring for people with HD or those with HD. One of the hardest topics to understand and learn all of the dynamics of is the mood and behavior management with our HD loved ones. This seems to be one of the most difficult things to deal with for caregivers and the most confusing for those with HD.

Even before we see the physical symptoms of HD there are mood changes that we see. For example when the brain starts to change the thought process slows. So the person with HD may not be able to process as well and thus not follow the conversation or the subtleness of the conversation. You may ask a question and the person with HD is not responding how you think they should. You may get upset and the person with HD explodes.

Another things that you may notice would be not making good decisions --- like managing money, or making other poor decisions. One of the keys is to respond appropriately by slowing down and thinking before you respond. One strategy to use is to calmly ask the person with HD what they were thinking. This seems like a simple way to get to the root cause, but when in the moment we have a hard time thinking about these things.

When a person with HD does lose their temper and acts out aggressively we may not understand what triggered that reaction. Many people that come to the support group also talk about different strategies for dealing with behavior issues. This is just one of many things that can happen at different times during the disease process. Talking can really help when we have these issues.

FALL FUNDRAISING EVENT

1st ever Wine Tasting Event!

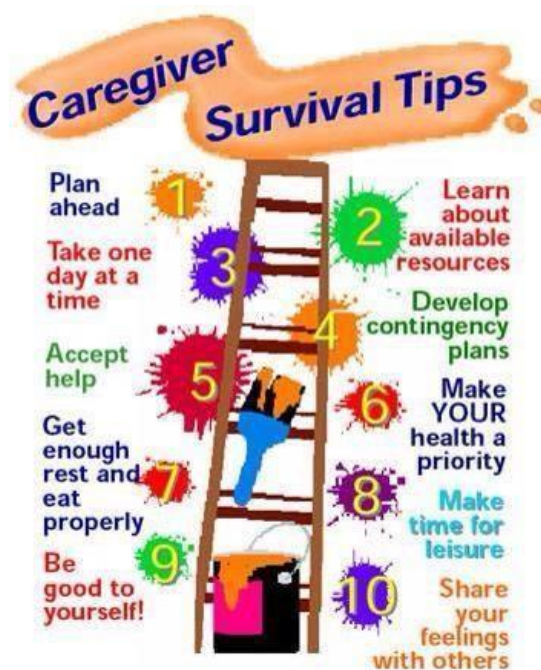
We are working with a local business owner to help us involve the community!

It will be in October or early November!

Stay tuned!

25 THINGS EVERY CAREGIVER SHOULD KNOW

1. A caregiver is someone who cares for an aging, ill, injured or chronically ill person.
2. Caregiving duties range from occasional errand-running and other supportive care to 24-hour, live-in support
3. You don't have to live with an HD person to be a caregiver.
4. About ¼ of adults are caregivers.
5. There is no one-way to care for an HD person. Each situation is different.
6. You can provide care yourself or bring in other family members. You can also hire a professional caregiver.
7. Each HD person being cared for has different needs.
8. Help and support can come from community organizations, religious organizations, family members, friends and neighbors.
9. Taking care of yourself is as important as caring for your loved one.
10. Be sure to eat well, get enough rest and exercise regularly.
11. Don't be afraid to say you need a break – no one can do it all by themselves.
12. When people offer to help – SAY YES!!!
13. Keep a list of things that you can use help with, such as bring dinner or giving you a break. When someone offers to help, have them choose from the list.
14. Find out about meal delivery, transportation services, adult day care and respite care.
15. As a caregiver, you will need to learn about medical, financial and legal issues.
16. Find out about Durable Power of Attorney for health care and finances. These give you the legal right to make decisions if your loved one cannot.
17. You may need to know about income, bank accounts, wills and insurance policies.
18. Talk with a lawyer about legal issues and financing care. Legal aid is available to people who cannot afford to pay for a lawyer.
19. Learn as much as you can about HD.
20. Get information about the condition by talking to a health care provider, social worker, reading books, attend support group meetings, attend conventions or searching the internet.
21. All caregivers feel overwhelmed at times. If you feel overwhelmed, you may need help.
22. Support groups can help you connect with others who are going through similar experiences.
23. A sense of humor can help you deal with the emotional ups and downs.
24. It is critical for caregivers to develop support systems.
25. One of the best resources for caregivers is other caregivers – keep asking questions and networking!



HUNTINGTON'S DISEASE SOCIETY OF AMERICA VEHICLE DONATION PROGRAM

Donate your car to HDSA: <http://hdsa-cardonations.org/HOME.html>



CALL 855-500-7433 or 855-500-RIDE



HDSA will tow your vehicle at no cost to you!



Get a tax deductible receipt and help our cause.

CHAPTER'S WEBSITE

The chapter's website and contents are every-changing. If you have items you'd like to see on the website, let us know and we will try to accommodate your request. If you find incorrect information, pass that along and we'll get it fixed. To comment, please contact our Webmaster, Margaret Geertsema, at grtzbaby@sio.midco.net or phone 605-338-3396. You'll find the chapter's website at www.hdsa.org/sv.

Also check out www.hdsa.org for other valuable information and resources. Check back often as it's frequently updated. To access webinars and other HDSA information, you will want to select Extranet (found in the bottom of the screen – see below for sample). The username is Chapters; the password is hdsa. Note: both are case sensitive!! To view information for chapters, select CHAPTERS, and then scroll down to find a topic of interest. For information on Team Hope, select TEAM HOPE. Log out when finished.

HELP FOR TODAY, HOPE FOR TOMORROW

| | | |
|----------------|-------------|------------|
| New to HD | About HDSA | Physicians |
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212-242-1968
hdsainfo@hdsa.org
505 Eighth Avenue
Suite 902
New York, NY 10018

SUPPORT

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QUALITY PATIENT CARE
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Facebook

Lorraine Sorenson, our Facebook administrator, reports we have 196 followers, with 18 consistently reading the contents on our chapter's Facebook page. Lorraine reports lots of activity to view the 2014 Team Hope Walk/Run photos. If you've not yet seen them, checkout the photos by following us at www.facebook.com/SVHDSA.

FUTURE NEWSLETTERS – GOING GREEN!

In an effort to recycle and "**GO GREEN**" --- This will be our last printed newsletter. Our next newsletter will be in the Spring, March/April 2015. Our newsletter will be available on our website, our Facebook page and we will send to you electronically. If you already receive emails from us --- you are ready to receive our newsletters. If you don't think we have your emails, please send to Debbie at debstadley@gmail.com

Special Lambs May Hold Promise for Huntington's disease Treatment

Ag Product for Pharmaceutical Use

What would you do as an HD community member if you met a scientist(s) who thinks he/she has a prospective therapeutic drug for HD – and/or possibly a cure?

I hope your answer would be similar to mine – start supporting them in any way a person can!

A four-member cohort of scientists: Dr. Holler (South Dakota State University), Dr. Hersch (Harvard/Massachusetts General), Dr. Frey (University of Minnesota), and Dr. Shaw (Avanti Polar Lipids, Inc. – AL) are leading the way to get GM1 for HD into human clinical trials.

For the past 2 decades the Holler's have maintained a flock of sheep that contain a specific genetic trait that results in the accumulation of a natural molecule, GM1 ganglioside. GM1 is the short name for GM1 Ganglioside. Dr. Holler originally got excited about the idea of pursuing ovine (sheep) GM1 application to HD because data was published in Spring 2012 that showed **GM1 had reversed HD symptoms in a mouse model within 60 days** (<http://en.hdbuzz.net/072>). And in addition, he knew of published data that showed GM1 had already been in human clinical trials for application to Parkinson's disease (PD), Alzheimer's Disease (AD) and other neurological diseases (<http://www.glycoscienceresearch.com/references-2/>). Safety in humans had already been proven. For the laypeople in the HD community, this is all very exciting! So what happened? Why is there not a human clinical trial yet?

Short answer: politics and money.

Long answer with some history: Last January in conjunction with Dr. Hersch a project proposal was submitted to The National Institutes of Health (NIH) National Center for Advancement of Translational Science (NCATS) Therapeutics for Rare and Neglected Diseases (TRND) to help get GM1 from basic science research into clinical trials for HD. While the proposal made it through multiple rounds of scientific scrutiny, it was rejected in late April 2014. After reviewing current trends in the US sheep industry, the NCATS reviewers concluded that although they were impressed by the science, they determined it was impossible to raise enough lambs to treat HD patients, and that it may be necessary to wait until the scientific community figures out how to synthesize the molecule.

Currently there are about 30,000 HD patients in the US. Using current estimates, it would take 1 to 2 lambs to treat an HD patient for 1 year. To date, Dr. Holler currently has capacity to treat approximately 300 HD patients. However, money is needed so that Dr. Holler can ramp up the number of sheep to 30,000 sheep. A good faith initial estimate is that he needs about 1- 2 million dollars over the next 2-3 years to help get GM1 into human clinical trials and into the pharmaceutical market.

These scientists need our support through the HD grassroots level to help GM1 gets it turn to prove itself in a human clinical trial. And for approximately 2 years, that is what I have been doing on a volunteer basis. And we need more grassroots support. If you are motivated and want to help, please call Dr. Larry Holler, Sue Holler, or myself directly if you have any questions or simply want to learn more. Families who struggle with HD, we urgently need a treatment! **And please do what you can to help get GM1 for HD into human clinical trials. GM1 needs its turn to prove itself!**

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CONDOLENCES

We extend our deepest sympathy to the families of those who have lost a loved one:

Julie (Dummer) Nelson, died June 18, 2013, in Remsen, IA. Julie is survived by two children: Kristine (Joe) Mohning and Keith (Becky) Nelson. She is also survived by four grandchildren; two brothers: Mark (Deb) Dummer of Franklin, MN, and Paul (Deb) Dummer and family of Lesterville, SD. Julie was predeceased by her parents Donald and Valeria Dummer and brother Gary, all of Franklin, MN.

Arnie Ver Hoef, age 80, Sioux Center, IA, died March 14, 2014, in Sioux Falls, SD. Arnie is survived by his wife Ardene; three children: son Jay (Mary) Ver Hoef and daughters Anne (Mike) Schroder and Kathy (Kembe) Hulstein; seven grandchildren and one great-grandchild. He is also survived by his sister Mary (Hoyt) Acuff and brother Bruce (Marty) Ver Hoef. He was preceded in death by his parents Bernard and Alvina Ver Hoef. Arnie was a long-time President, Board member and loyal supporter of Sioux Valley HDSA.

Deborah (Zarecky) Ekern, age 55, formerly of Colman and Flandreau, SD, died March 19, 2014, in Houston, TX. Deb is survived by two daughters: Samantha Headrick and Pamela Ekern; and two grandchildren. She is preceded in death by her parents Richard and Helen Zarecky and brother, Richard.

Stephen (Steve) Elliott, age 58, Sioux Falls, SD, died June 29, 2014, in Sioux Falls. Steve is survived by his wife Cindy; son Michael; father Wendell (Dee); sisters Wendy Jo Elliott and Jane (Ken) McGrew; brother David (Suzan Lorenz); special friend Mary Merrill; and a host of other friends and relatives. He is predeceased by mother Joanne Elliott and father-in-law Don Merrill. Steve was a long-time supporter of Sioux Valley HDSA.

Upcoming Events

SEPTEMBER 2014

- ✓ Saturday, September 13th – 11 am to 1 pm
 - Support Group Meeting at Caille Library (49th Street – across from Sertoma Park)
- ✓ Sunday, September 28th – Noon to 4pm
 - Fall Seminar At Schroeder Auditorium / Sanford Hospital
- ✓ Monday, September 29th
 - USD Panel in Vermillion, SD

OCTOBER 2014

- ✓ Saturday, October 11th – 11 am to 1 pm
 - Support Group meeting at Caille Library (49th Street – across from Sertoma park)
- ✓ Amaryllis Campaign
- ✓ First ever Wind Tasting Event -- Fall Fundraising Event - TBD

NOVEMBER 2014

- ✓ Saturday, November 8th – 11 am to 1 pm
 - Support Group Meeting at Caille Library (49th Street – across from Sertoma Park)
- ✓ Saturday, November 8th – 1:30 – 3:30 pm
 - Board Meeting (Caille Library)
- ✓ Wednesday, November 19th
 - Menno-Olivet Care Center Inservice

DECEMBER 2014

- ✓ Saturday, December 13th – 11 am to 1 pm
 - Support Group Meeting

We are grateful for your support to our chapter. Please continue your support to our chapter.

All proceeds support efforts to provide help for today, hope for tomorrow for families affected by HD.

ENCLOSE THIS FORM SO WE CAN UPDATE OUR RECORDS:

_____ \$15.00 Friend _____ \$25.00 Family

_____ \$50.00 Angel _____ \$100.00 Century Club

_____ \$ Other amount enclosed

Name _____ Phone _____

Address _____ City _____ State _____ Zip _____

Email address _____

*****VIDEO ORDERS*****

_____ VHS copies @ \$25/copy &/or _____ DVD's @ \$30 each of "Huntington's Disease: Living with Knowledge."

_____ DVD @ \$30 each of "Huntington's Disease: Living with Care." _____ Viewer's guide for "Living with Care." DVD @ \$5.00 ea. Send payment to: Sioux Valley Chapter HDSA PO Box 2675 Sioux Falls, SD 57101



PO Box 2675

Sioux Falls SD 57101-2675