GREETINGS FROM THE “BOARD”

SIOUX VALLEY CHAPTER BOARD OF DIRECTORS

It is 2014! Does it feel weird to say “2014”? It does to me! Where does time go and how does it go so fast --- especially since I feel like I move at a “turtle’s pace” sometimes?! The truth is --- we all are moving at “superhero” speeds and we should feel proud and accomplished that we are tackling the world with our “superhero” powers. Our “superhero” powers are the many “hats” that we wear (parent, caregiver, advocate, sibling, employee, etc). You understand what I’m trying to say --- we all are “superhero’s”!

As a board, we plan events for our chapter. The events are educational and fundraising! We are a small group, but a “MIGHTY” group --- part of your Superhero Support Team. We had our first board meeting already – We have set three goals for our chapter in 2014! These goals are lofty goals and exciting goals! We will set goals every year, but know that our goals are going to be a “work in progress”...this just means that we are always working on them and we know that they are “long term goals”!

I want to tell you a little bit about our goals!

We are going to work closely with the Good Samaritan facility for a dedicated HD unit and Sanford Dr. Michael Kruer for HD clinic needs!

This goal is the most exciting and the biggest one...and, it won’t happen overnight. But, we will be able to see a progress! We (board members) are working with Good Samaritan in Sioux Falls to explain the specific needs for our HD families. This will take time but we are working with them.

The second part of this goal involves Dr. Michael Kruer’s team. You will see later in our newsletter that Dr. Michael Kruer is a neurologist at Sanford Hospital in Sioux Falls, SD. He is interested and dedicated in working with our HD families. He is taking appointments now with our HD families.

We want to Increase community education / Creating awareness by speaking to civic groups!

We want to “tell our story” to everyone! Nursing homes, assisted living homes, rotary, and everyone! Help us do this! Let us know if a group in your life would benefit understanding and learning about HD and our chapter! This is a win/win opportunity!

Fundraising!

Fundraising is so important to our local families and our national organization. Our fundraising efforts pay for our Social Worker – Eileen, national convention attendees, educational materials and events, research and much much more. We stay focused in our fundraising efforts. We plan only two big events in 2014 – TEAM HOPE WALK/ RUN and TOUR OF TABLES. Involve your friends, co-workers, and family with our events. It is our goal to make the events rewarding personally just as much as raising money for a cure! Our fundraising events also give us a chance to educate the community.
The board of directors meet six times a year – January, March, May, July, September and November. Everyone is welcome to attend our meetings. Our meeting times are located in “UPCOMING EVENTS”.

I would like to introduce to you your board members (Part of your Superhero Support Team):

Board members: Brenda Gehling, Glenda Obenauer, Peter Anderson, Brad Lingen, Kevin Sandbulte.

Co-Secretary – Cindy Trager / Betty Strom
Treasurer – Noel Lais
Vice President – Margaret Geertsema
President – Debbie Stadley Augustad

One additional note – we are always looking for volunteers for our events! We cannot do these events without you, family and friends. Help us tell our HD story by involving the people in your life. Ask your family and friends to help with an event! They can help in a major or small role – all efforts and help are appreciated, needed and important!

Much love and hugs to all! - Debbie

SIOUX FALLS HYVEE OPERATION HELPFUL SMILE PROGRAM

March 5th – March 11th 2014

SAVE THE WEEK

Hy-Vee has selected our Sioux Valley HDSA organization to participate in their Operation Helpful Smile Program. We are excited to be selected for this event. Here is how the program works --- Donation boxes are placed at the checkout stands of the Sioux Falls Hy-Vee stores. Customers are welcome to donate change, dollars and checks during this week by placing the donations in the DONATION BOX. And, Hy-Vee matches the customer donations up to $1,000! YAY! How easy is this! Please be sure to HIT YOUR FAVORITE Hy-Vee between March 5th -11th, 2014 and donate! Spread the word to your family and friends – every penny counts!!!

SPRING EDUCATION SEMINAR

APRIL 12, 2014
RONNING BRANCH LIBRARY
11:00AM TO 12:30PM SUPPORT GROUP
1:00PM TO 3:00PM FEATURED SPEAKERS
3:00PM TO 4:00PM CAKE WALK

FEATURED SPEAKERS: Dr. Michael Krueger, Neurologist and movement disorders Physician & Lior Borovik, certified genetic counselor

For the cake walk just bring your dollars.

This year the cakes will be provided by Lorraine Sorenson

CHAPTER’S WEBSITE

The chapter’s website has been updated and the content will be kept current so it’s of more value.

If you have items you’d like to find on the website, please let us know and we’ll try to accommodate your request.

If you see incorrect information, please let us know that, too, and we’ll get it corrected. To comment, please contact our webmaster, Margaret Geertsema, at grtzbaby@sio.midco.net or phone 605-338-3396. Check the chapter website: www.hdsa.org/sv

Family Service

As Family Service Chair, Betty Strom works closely with Eileen Krueger the Chapter Social Worker to provide a Support Group setting for family members to meet and share concerns as they deal with Huntington’s disease in their daily lives. Through these meetings family members and caregivers find they are not the only ones impacted with difficulties that are part of HD. We share information on planning ahead, learning coping skills and where to find resources. Support Group also provides a social situation where you can share, without being judged, with others who understand what it’s like to live and cope with Huntington’s Disease. We learn, share, cry and laugh together and become like family. We currently meet at either Caille or Ronning Library in Sioux Falls from 11:00am to 1:00pm on the 2nd Saturday of most months. Monthly reminders can be sent to you by postcard or email if you request to be put on the contact list. Check our facebook page www.facebook.com/SVHDSA or the Chapter website www.hdsa.org/sv or call for the current months meeting information. Come join us.

In addition to Support Group, we provide educational materials about Huntington’s Disease to area physicians offices and HD families, and help the Chapter promote awareness about HD in the community. Eileen also facilitates a monthly telephone support group that you can join. Email or call either of us, if you need information, or just need to talk. Leave a message if you get our voice mail.

Eileen Krueger LSW 612-910-6651 ekrueger@hdsa.org
Betty Strom 605-338-5459 stromb@sio.midco.net

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TEAM HOPE WALK
SAVE THE DATE – SATURDAY, MAY 3rd, 2014
SERTOMA PARK

Our 6th annual TEAM HOPE WALK/5-10K RUN FOR THE CURE is scheduled for Saturday, May 3rd, 2014 at Sertoma Park. Sertoma Park is located at 49th & Oxbow. Registration begins at 9:30 am. Walk/Run starts at 11:00 am.

We are extremely proud of our TEAM HOPE WALK/RUN! This is our BIGGEST fundraising event of the year. It is launching our May Huntington’s Disease (HD) Awareness Month. The funds raised for this event are vital to provide help and hope to those affected by HD. TEAM HOPE WALK raises funds to support the mission of HDSA and raise awareness about HD in our local communities. Many of our important HDSA programs, such as Centers of Excellence, Social Workers and advocacy efforts would not be possible. In addition, this event gets us one step closer to a cure!

This is a great opportunity to unite as friends, family and a community! Be a participant! Form a team for loved ones affected by HD! We’ve made this easy for you to be a part of the cure! Here are the details!

Participant fees
(through Friday, May 2nd)
Adults - $20 each/Under age 12 - $10 each

Day of Walk Registration
Adults - $25 each / Under age 12 - $10 each

Contact Debbie Stadley Augustad for registration forms and to volunteer!
Email – debstadley@gmail.com
Cell – 612-816-0145

Set up your team donation page, pre-register, or donate on-line
www.hdsa.org/thwsiouxfalls
Follow us on Facebook
www.facebook.com/SVHDSA
Chapter website: www.hdsa.org/sv

Along with participant involvement, you may participate in our TEAM HOPE WALK as a sponsor! We are in need of sponsors with cash donations and also prizes/fun items. The following illustrates our cash donation sponsor program.

GOLD SPONSOR - $1,000
Name/Logo on banner displayed at our event
Promotional piece in the participant welcome kits
Name/logo in media advertising as “GOLD SPONSOR”
Opportunity to display product or samples at event

SILVER SPONSOR - $500
Name/logo on banner displayed at our event
Promotional piece in participant welcome kits
Name/logo in media advertising

BRONZE SPONSOR - $300
Name/logo on banner displayed at our event
Promotional piece in participant welcome kits

In addition, there will be drawings of prizes during this event. We are requesting donations of gift certificate(s), and other fun items to use for drawings and our welcome packet. We anticipate 300 participants, but will gladly accept any amount of items that business(es) are able to donate.

For additional donation information – please contact Debbie Stadley Augustad for more details
A NOTE FROM DR. MICHAEL KRUER & LIOR BOROVIK

A new clinic is opening at Sanford Sioux Falls, offering comprehensive diagnosis and treatment for patients with Huntington Disease and their families. The clinic is directed by Dr. Michael Kruer, neurogenetics and movement disorders physician, and Lior Borovik, certified genetic counselor and advocate for HD patients.

The clinic was developed in response to the need for a medical home for patients with HD and related disorders. “Although several HD Centers of Excellence in the Upper Midwest exist, many patients in Sioux Falls and neighboring areas have been receiving care piecemeal, or after traveling long distances,” explained Dr. Kruer. “This clinic is rising up in response to the voices of patients and their families who called for comprehensive, compassionate care closer to home. With the generous support and tireless efforts of our local HDSA chapter, and the commitment of Lior and myself, our goal when beginning our HD Clinic is to become a Center of Excellence serving South Dakota, southwestern Minnesota, northern Nebraska and western Iowa.”

“Our main goal is not only to provide assistance to the patients themselves, but to their families as well,” explained Lior. “Huntington disease diagnosis has an effect on those that surround the person with the disease. Families can be overwhelmed after their loved ones are diagnosed with HD. Our goal is to provide information, guidance and emotional support for everyone. We are here to help and advocate for both the patient and their family.”

The Sanford Sioux Falls Huntington Disease Clinic provides diagnostic testing and comprehensive genetic counseling services. Treatment will focus on the needs of both patients and their loved ones within a family-centered framework. This includes multidisciplinary management of problems related to movement, cognition, and behavior using medical, rehabilitative and behavioral approaches. The clinic plans to offer patients the opportunity to participate in the latest clinical trials. “This latter part will take some time,” Dr. Kruer reported, “as we can’t do everything all at once. However, this is a top priority in order to offer the very latest treatment options for our patients.”

The clinic welcomes referrals from primary care physicians, neurologists, and patients and family members. Both adults and children will be 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

Dr. Michael Kruer attended Arizona State University and the University of Arizona College of Medicine where he graduated with distinction in research. Dr. Kruer is board-certified in both adult and child neurology. He currently serves as a staff neurologist at Sanford Children’s Hospital and as medical director of the Sanford Huntington Disease Clinic. His clinical expertise includes movement disorders and neurogenetics. Michael’s laboratory research focuses on the genetic basis of movement disorders and neurodegenerative diseases. Through the Sanford HD Clinic, Dr. Kruer hopes to offer comprehensive services to HD patients and their families by 1) providing patients with quality care at all stages of the disease; 2) ensuring families have the support they need to care for their loved ones; and 3) providing access to the latest research studies and clinical trials.

Lior Borovik was born and raised in Israel. He attended the University of Nebraska-Lincoln where he graduated with a B.S. in Psychology, and a minor in Biochemistry. Lior later attended the Genetic Counseling program at the University of Wisconsin-Madison, where he graduated with an M.S. in Medical Genetics (Genetic Counseling). During his training at the University of Wisconsin-Madison, Lior took part in additional educational offerings including the Consumer Health Advocacy program through the Center for Patient Partnerships, which combined applied health advocacy training, with an introduction to health systems and health care delivery. Lior is a licensed certified Genetic Counselor (LCGC), and he is currently serves as a genetic counselor at Sanford, and is a part of the Sanford Huntington Disease clinic. Education and advocacy for patients and their families is extremely important for Lior. Through the Sanford HD Clinic, Lior hopes to be a source of education and support for patients with Huntington Disease and their families.
CARE FOR THE CAREGIVER

HD is a complex brain disorder that affects all aspects of life. Providing the best care for a person with HD takes the expertise of many professionals in different areas of medicine and healthcare.

Your loved one may already be seeing a neurologist, psychiatrist or physician who specializes in brain disorders as part of the diagnostic process. Over the course of the disease, this doctor (also called the primary managing physician) may need to call upon other medical specialists and allied health professionals to address the treatable symptoms of HD. As the caregiver, you may be the one to ask the doctor to make referrals for your loved one.

Here are some of the health professionals who may be part of the team:

**Neurologist**

* May be the primary managing physician and team leader
* Provides management of neurological symptoms such as chorea and other movement disorders
* Will provide assessment and counseling about changes to reasoning (cognition).

**Psychiatrist**

* May be the primary managing physician and team leader
* Will address conditions that may be caused by or associated with HD such as: depression, anxiety, behavioral difficulties, obsessions, compulsion or psychosis

**Mental Health Therapist/Psychologist**

* Will provide supportive counseling at initial diagnosis or during difficult transitions
* Will provide assessment and treatment for frequent or severe irritability/anger

**Social Worker**

* Will assist with applications for disability and other benefits
* May serve as the primary therapist an/or supportive counselor
* Will provide guidance, financial planning and advance medical directives
* Helps in accessing community services
* Will aid in finding placement outside the home

**Occupational Therapist**

* Will suggests strategies to increase functional independence in daily life
* Will assess home safety and makes recommendations (furniture placement, handrails, etc)
* Will recommend adaptive equipment for seating, feeding, hygiene etc
Physical Therapist

* Will evaluate difficulties in walking and the need for home mobility equipment (scooters and wheelchairs)

* Develops an exercise program to improve balance, reduce pain, increase flexibility, build strength, improve function and increase range of motion

Speech and Language Pathologist

* Will help address speech difficulties through exercise

* Suggests strategies to reduce choking and swallowing problems

* Will help find and train to use communication devices when needed

Dietician or Nutritionist

* Will review diet to address weight loss or gain

* Adapts diet to address swallowing difficulties

Nurse

- Will provide case management, in-home care and telephone support

Take a notebook to your appointments. It is a great tool to write down questions between your medical appointments. And, it is a great way to take notes while in the appointments with your medical team.

In addition, HD progresses over so many years. Your loved one will need to continue to have general medical checkups, eye care and dental care.

Article taken from “A CAREGIVER’S GUIDE TO HUNTINGTON’S DISEASE” March 2011

ADVOCACY

HUNTINGTON’S DISEASE PARITY ACT – HR1015 and S723

The goal of the Parity Act is to make it easier for people with HD to receive Social Security Disability and Medicare Benefits. The two parts to the Parity Act is:

1. Update guidelines used by Social Security Administration to determine disability for Huntington’s Disease

2. Ends 2-year Medicare wait period for individuals disabled by HD.

There are currently 93 sponsors in the House (HR1015) and 12 in the Senate (S723). You can become an E-Advocate at www.hdsa.org/join to get updates when Congress needs to hear from HD families. You can send a letter to your Representative and Senators by going to www.hdsa.org/takeaction -- add your personal story and “click” SEND!
HUNTINGTON’S DISEASE YOUTH ORGANIZATION

The Huntington’s Disease Youth Organization is entering its third year and is expanding by leaps and bounds. The goal of HDYO is to drastically improve the amount of quality information provided to young people and their families with regards to HD. HDYO also looks to improve support for young people both locally and globally, by collaborating with national Huntington’s disease associations around the world, (including HDSA) to improve youth support in their area as efficiently and appropriately as possible.

HDYO is becoming an extremely effective resource for young people impacted by Huntington’s disease (HD) around the world. Team HDYO now stands at an incredible 120 global volunteers with a variety of roles for young people to engage with. Translation volunteers have made the website content available in 9 different languages and are working on more! HDYO has also recruited two full-time employees: The founder, Matt Ellison as project coordinator and Chandler Swope, as a youth worker to cover the Mid-Atlantic region of the US.

The majority of those taking advantage of our website are young adults. Teens, parents with younger children and professionals are also finding our info on the website and social media (Youtube, Twitter and Facebook) very useful. Their feedback has been overwhelmingly positive.

The educational content on our website is easy for young people to understand and aims to be positive and not scary. There are also safe interactive forums where questions can be answered by professionals. I encourage anyone dealing with any of these issues to check out www.hdyo.org

The National Youth Alliance is a group of youth and young adults from around the United States of America, whose vision it is to make our generation the last to ever have to live with Huntington’s disease. Providing a wide array of support for young members of HDSA, NYA members set out to help one another learn how to cope with the day-to-day struggles we face as children, teens and young adults surrounded by HD. Joining the NYA is fast and easy, go to: www.HDSA.org/nya and click “JOIN THE NYA TODAY!”.

Letter from the social worker - Eileen Krueger

We have some great educational events planned for this year with speakers already lined up. We have Dr. Michael Kruer a neurologist and movement disorder doctor and Lior Borovik, a certified genetic counselor for our spring event and we have Arik Johnson, PsyD for our Fall seminar.

We also have our support group that continues to meet the 2nd Saturday of the month. A reminder email is sent out if you wish or information can be found on the hdsa web site. You may also contact me if you have questions.

Please feel free to email or call if you have questions or just need to talk. ekrueger@hdsa.org or call to 612-910-6651 with a confidential voice mail.

CoRDS Conference

Sioux Valley Chapter HDSA again set up a display and made available Huntington’s Disease information to those in attendance at the 4th Annual Rare Diseases Symposium presented by Sanford Health here in Sioux Falls on February 28th 2014. This event is attended by health professionals from the area.

The previous evening Dr. Michael Kruer gave the opening presentation in conjunction with the Community Lecture Series. His presentation explained his work as a pediatric neurologist and scientist.

Dr Kruer would like to see HD patients and families here in Sioux Falls at Sanford Health. Dr. Kruer, is the recent recipient of the National Institutes of Health’s five-year, $860,000 grant to support his research on genetic forms of juvenile Parkinson’s disease and dystonia.
WE REMEMBER AND HONOR

As a Board, we feel it is important you know that we recognize and appreciate all contributions sent to either SVHDSA or to HDSDA “In Memory of” or “In Honor of” your loved ones. When a specific purpose is designated on how the funds are to be used, we honor that request. Please know that we will never publish individual donor names and/or amounts contributed.

Thank you to everyone who sent these donations. We, too, remember and honor your loved ones.

CONDOLENCES

Along with prayers for comfort, we extend our sympathy to the families of those who sorrow at the death of a loved one.

Ernest “Ernie” Strom, age 47, formerly of Sioux Falls, died December 29, 2013, in Yankton, SD. Ernie is survived by his mother, Betty Strom, and a host of other relatives and friends. Betty is the former board of directors’ president and wears many hats in service to our chapter. Ernie was predeceased by his father, David, and an infant brother, Michael.

Luella Streit, age 84, of Sibley, IA, died January 12, 2014. Luella is survived by four children: Gary (Susan) Streit, Mary (Noel) Lais, John (Jenny Streit) and Nancy (TR) Franklin; nine grandchildren and three great-grandchildren. Noel is the long-time treasurer for our local chapter’s board of directors.

Rena Dragstra, age 90, of Sioux Center, IA, died January 19, 2014. Rena’s former daughter-in-law, Connie, was a sister to Kevin Sandbulte, one of our local chapter’s board of directors. Rena and her family were long-time supporters of our chapter. Rena is survived by five children: Willie Dragstra, Phyllis (Bryce) Fopma, Rose (Bernie) Sichmeller, Carol Dragstra (Lee Jandl), and Ken (Julie) Dragstra; ten grandchildren and nine great-grandchildren.

Lisa Marie Goehring, age 52, formerly of Emery, died January 20, 2014, in Menno, SD. Lisa and her family were long-time supporters of our local chapter. Lisa is survived by her father, Leroy, step-mother, Cheryl and brothers: Leland (Lori) Goehring, Corey (Peggy) Goehring, sister-in-law Dawn Anderson and her daughter Brittany. She is also survived by step-siblings: Kenneth Kayser, Kathy Kayser, David (Lori) Kayser and Todd Kayser. Lisa is predeceased by her mother, Lucille; sister, Laurie and brothers, Curtis and Craig.

Harriet Drury, age 91, formerly of Pipestone, MN, died January 22, 2014, in Springfield, MN. Harriet is survived by four children: Gay Lynn (Jim) Murphy, Hayward “Jay” (Cindi) Drury, James (Sue) Drury, and David (LynDea) Drury. Harriet is also survived by eight grandchildren and seven great-grandchildren. She is predeceased by her husband, Hayward, and two grandchildren.

Kevin Hakeman, age 62, of Watertown, SD, died January 30, 2014. Kevin is survived by his wife, Joan, and two children: Travis (Jen) Hakeman and Megan Hakeman; two grandchildren, Mason and Harlen, his mother, Bonnie Hakeman and two brothers: Keith (Diane) Hakeman and Kim Hakeman. Kevin was preceded in death by his father; one daughter, Erin; one brother, Kent; and his best friend, Larry Wade. Joan and her extended family are long-time supporters of our chapter.

Gregory Barnett, age 44, died February 5, 2014, in Sioux Falls. Greg was a former board of directors’ president during the production of our chapter’s first HD video. Greg is survived by his son, Tommy, and nine siblings: Jeanne Kangley (Dan), Mary Pierce (Rod), Carol Nesbitt (Curt), Tom, Max (Nancy), Mark, Andy (Angie), Jerry (Judy), and Jeff (Jamie) Barnett; many nieces, nephews, and dear cousins. His parents, Tom and Dorothy Barnett, and his brothers, Eddie and Michael, and one niece, Lizzie, preceded him in death.

Sometimes not even
all your love and caring

can make another person’s life easier.

Knowing that
doesn’t take away your sadness

in losing someone special,

but in days to come

it may comfort you to know

that you gave all you could,

with all the love you had,

and no one can do more than that.

HOLIDAY APPEAL

Thank you for your generous support, we raised $1480.00 to date with our Holiday Appeal letter.
UPCOMING EVENTS – MARK YOUR CALENDARS!

MARCH 2014

* SUPPORT GROUP MEETING – SATURDAY, MARCH 8TH AT 11 AM – CAILLE LIBRARY

* CHAPTER BOARD MEETING – SATURDAY, MARCH 8TH – 1:30-3:30 PM

* HYVEE OPERATION HELPFUL SMILE – MARCH 5TH – 11TH AT ALL SIOUX FALLS HYVEE’S

APRIL 2014

* SUPPORT GROUP MEETING & SPRING EDUCATIONAL SEMINAR - SATURDAY, APRIL 12TH AT 11 AM – Location TBD (Check the chapter website)

MAY 2014

* TEAM HOPE WALK/RUN – SATURDAY, MAY 3RD – SERTOMA PARK IN SIOUX FALLS, SD

* SUPPORT GROUP MEETING – SATURDAY, MAY 10TH AT 11 AM – Location TBD (Check the chapter website)

* CHAPTER BOARD MEETING – SATURDAY, MAY 10TH – 1:30-3:30 PM

JUNE 2014

* SUPPORT GROUP MEETING – SATURDAY, JUNE 14TH AT 11 AM – Location TBD (Check the chapter website)

* NATIONAL CONVENTION IN LOUISVILLE, KENTUCKY – JUNE 20-22ND, 2014

JULY 2014

* SUPPORT GROUP MEETING –SATURDAY, JULY 12TH AT 11 AM – Location TBD (Check the website)

AUGUST 2014

* SUPPORT GROUP MEETING-SATURAY, AUGUST 9TH AT 11 AM – Location TBD (Check the website)

* FALL NEWSLETTER WILL BE PUBLISHED AND SENT TO FAMILIES

SEPTEMBER 2014

* SUPPORT GROUP MEETING – SATURDAY, SEPTEMBER 13TH AT 11 AM – Location TBD (Check the website)

* CHAPTER BOARD MEETING – SATURDAY, SEPTEMBER 13TH – 1:30-3:30 PM

* FALL EDUCATION SEMINAR – TBD SEPTEMBER 26-28TH

E-MAIL NEWSLETTER

If you would like to start receiving SVHDSA’s newsletter electronically – or you need to update your address or your e-mail address - please contact Debbie Stadley Augustad at debstadley@gmail.com

Contributing efforts to the Spring Newsletter are Betty Strom, Cindy Trager, Eileen Kruger, Lorraine Sorenson, Margaret Geertsema, Dr. Michael Kruer, Lior Borovik & Debbie Stadley Augustad.

Facebook

Lorraine Sorenson, our fantastic Facebook administrator, reports we have 180 individuals following and reading our chapter’s Facebook page. Lorraine updates this Facebook page almost daily and posts all kinds of interesting stories, video clips and links to other HD materials. Follow us on www.facebook.com/SVHDSA

The 29th annual HDSA convention will be at the Galt House in Louisville, Kentucky on June 20-22nd, 2014. The convention is one of the most rewarding experiences during the year. There are workshops, motivational speakers and most importantly families from around the US affected with HD. It is an incredible opportunity to network and make new HD friends.

We are required to send one chapter representative to participate in Leadership Day training on Thursday, June 19. In addition, thanks to our restricted convention scholarship fund, we have the ability to send one additional volunteer to participate in this training. Funding for this leadership role is 100% paid, including transportation, hotel and registration. (Any sight-seeing or meals not provided for in the registration fee will be at your own expense.) If your schedule permits you to be one of these two volunteers, please contact Debbie immediately.

Book by May 24, 2014 for discounted hotel rooms. The Early Bird discount for convention registration ends May 30. Take advantage of the “family registration fees – see us for details.

National scholarships are available for first time attendees. In addition, our Sioux Valley Chapter is accepting scholarship application for those interested in attending the event. If you are interested in attending, please contact Debbie or Margaret or www.hdsa.org/convention
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_____

*****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