The Nucleus

Late Spring, Early Summer 2015

Huntington's Disease Society of America

Northern California Chapter

President's Corner

Dawn Doster, Chapter President

I hope you enjoy your mid-year copy of the Nucleus. It is almost officially summer and time for picnics, hikes, swimming, vacations and just being lazy in the warm weather. I am looking forward to the HDSA Convention in Dallas, Texas on June 26th through 28th. Hopefully, some of you will be attending and we can have a nice visit while in Dallas. I always enjoy the convention as I get to spend time with so many brave Huntington Disease (HD) families from around the USA. The speakers are topnotch and the gala on the final night is so inspiring that I come back to Northern CA renewed and ready to get busy with the Chapter mission for the second half of the year. This year I will return to Carmichael to help finalize our plans for the **Sacramento Team Hope Walk on July 25th** (See article below). The Northern California Chapter has done well thus far in 2015 as we continue to honor our responsibilities to the HD patients and families in Northern CA.

I just mailed our Family Services Appeal letter and hope you make a generous donation in order for us to continue providing support and services to our families. As I state in my letter to our families and friends, our Chapter provides so many areas of care and support, including an annual educational convention; support to the three Centers of Excellence in Northern CA; a Chapter Social Worker (Lisa Mooney) who manages our helpline; 9 support groups (including the NYA); a visiting nurse in the Bay area; participation in the Kaiser HD Ed Day and the UCSF Research Symposium; semi-annual Chapter newsletter; a Webpage and a Facebook page. As an HD family member, I certainly understand the importance of these vital services to a family in the throes of an HD diagnosis.

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Annual Team Hope Walk July 25, 2015

By Martha Lehman

Save the date and join us on July 25, 2015 for the seventh annual Team Hope Walk at William Land Park in Sacramento, Ca. Registration begins at 8:00 am followed at 9:00am by a pleasant shaded 1 mile walk through William Land Park. This year we are again proud to have local celebrity Joey Mitchell as the MC for the event.

The walk is followed by a raffle drawing and silent auction, events for kids including face painting and other activities, and the chance to view vintage cars and a fire truck which will be on display. Also, there will be a presence from the Sacramento Kings.

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Mindfulness Practice: A Powerful Tool for Caregivers

By Natasha Boissier, LCSW
HDSA Center of Excellence @ UC San Francisco and Facilitator of El Cerrito HD Support Group

At our HD Caregiver Support Group meeting in El Cerrito, CA this past month, we were fortunate to receive a presentation on Mindful Meditation by Marguerite Manteau- Rao, LCSW. Ms. Manteau-Rao, a seasoned social worker, leads mindfulness-based care workshops for professional providers and family caregivers providing care to people living with dementia and other neurodegenerative illnesses. She is also the founder of the Presence Care Project, a non-profit organization with the mission to "promote greater ease – less stress and greater well-being – in dementia care, both at home and in care settings". Ms. Manteau-Rao offered three main benefits for caregivers in practicing mindfulness: 1) it reduces stress, 2) it makes your job as a caregiver easier and 3) it allows you to provide better care.

How does mindfulness practice help with stress reduction?

John Kabat-Zinn, the creator of the Stress Reduction Clinic and the Center for Mindfulness in Medicine, Health Care, and Society at the University of Massachusetts, helped bring mindfulness to the mainstream, starting with patients suffering from chronic pain and looking to reduce their stress. Mindfulness is now applied to many different populations and types of problems, including depression, anxiety and pain. It is being taught in many different environments such as schools, prisons, health centers, and the workplace. Kabat-Zinn defines mindfulness as: "Mindfulness means paying attention in a particular way; On purpose, in the present moment, and nonjudgmentally." The practice itself is meant to be simple. It involves sitting comfortably, breathing in and out at a normal rate, and noticing what sounds, feelings, sensations and thoughts come up. There is nothing more "to do" as can be part of other meditation practices – the goal is not to clear the mind or reach any particular state. When one encounters

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"Mindfulness means paying attention in a particular way; on purpose, in the present moment, and non-judgementally."

Challenging Behaviors in Huntington's Disease: Strategies for Patients and Families

By Barbara J. Kocsis, MD
HDSA Center of Excellence at UC Davis Medical Center

Huntington's disease (HD) is a *neuropsychiatric* illness, which means that people with HD suffer from both physical symptoms, like chorea, and mental symptoms, such as depression or problems with thinking and memory. Research tells us that psychiatric symptoms in HD often arise years earlier than physical symptoms, and that psychiatric symptoms are frequently the most distressing symptoms for both patients and families to cope with. This article provides an overview of behavioral symptoms common in HD, and suggests strategies for how to best manage them.

Psychiatric problems are extremely common in those suffering from Huntington's disease; in fact, almost all patients with Huntington's disease will have at least one psychiatric symptom during their lives, and most patients will have multiple symptoms. Behavioral symptoms in HD are a direct result of changes in the brain caused by the illness. This happens because Huntington's disease damages important structures and pathways in the brain—and this damage causes the problems with movement, thinking, and behavior we see in Huntington's patients. Though the psychiatric problems common in HD can be challenging for patients and families, it's important to remember that these problems are *caused by the illness,* and not by the person suffering from Huntington's disease. Additionally, it's crucial to keep in mind that people with HD face many losses, including loss of independence, health, and eventually, their lives. These losses burden HD patients with

Though the psychiatric problems common in HD can be challenging for patients and families, it's important to remember that these problems are caused by the illness…

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Life with HD and a Dog Named Flo

By RB Hackenberg

After noticing some unusual mental and physical behavior, appointments with and tests by a neurologist, we got the startling diagnosis of Huntington’s Disease (HD) in March 2010. It was an unwelcome surprise as we were not aware that this genetic brain disease was in her father’s family. Mary’s reaction was, “I don’t want to know that…” but now, five years later, she’s resigned to her fate.

I was glad to know what we were dealing with, but had no idea that I would spend my retirement as a 24x7 caregiver. We’ve been married 54 years, and had plans to continue the world travel that began in Japan after our marriage. But it was not to be. Our new adventure is learning about and managing the symptoms for this neurologically degenerative disease for which there is no cure.

Although our family has been shocked, and we are grieving for the Mary we knew, we are encouraged by the significant progress in research during the past five years, and the increasing national awareness of HD in documentary filmmaking like *The Lion's Mouth Opens*.

HD often first shows up with involuntary movement known as chorea (Greek for dance) and/or tentative gait. Mary had begun to walk very slowly, pulling me back if I had her arm. And, as home manager, she was having difficulty making decisions, paying bills, handling checks and compulsively collecting newspapers. In the last year she has become more emotional—sudden crying, anger, angst.

The diagnosing neurologist referred us to the Huntington’s Disease Center of Excellence at UCDavis where we met with the HD team for an evaluation. A year later we switched to the UCSF Memory & Aging Center that takes a more horizontal approach to neurological diseases and was geographically closer.

We met with several team members for observation and consultation. The prognosis was annual observation that has become semi-annual, and for the past 12 months the anti-anxiety drug Mirtazapine before lunch and bed. If she’s still agitated and unable to sleep we back up the Mirtazapine with Melatonin.

As it turned out the most significant meeting was with the physical therapist, who, after a brief interview, showed us strength and balance exercises, and how to get up after a fall. But, her most important recommendation was: *“Get a dog!”*

It had been about 18 years since our last dog. We had enjoyed a Black Lab, then a Siberian Husky while our two daughters were growing up, but they had gone off to college and out into the world, so we did not get another after the Husky died.

Our younger daughter had been advocating a dog for several years and Mary, who had been our leader in acquiring dogs, had said she would like a lap dog that would sit with her in the car or next to her on the couch while she watched TV. I had balked at the idea thinking it

Continued…

Mindfulness Continued

thoughts and feelings as they arise during the meditation, one is asked to notice them and return their focus on the breath.

Sit, Breathe, Listen

Ms. Manteau-Rao led us through a 5 min mindfulness meditation practice as a group. As luck would have it, there was a car alarm making all sorts of sounds throughout the 5 minutes! This was incredibly annoying, but we were instructed by Ms. Manteau-Rao to continue breathing and to gently bring our focus back to the breath regardless of what noises we were hearing or how we were feeling about them. It was very interesting to note which thoughts came up, what our mind tells us when we tune in to it, and discover what sensations we feel in our bodies. How easy it is to get wrapped up in our endless to do lists and negative thoughts! Simply by returning to the breath, we begin to break this cycle and to train ourselves to choose where we put our attention. It is with this acquired awareness that we are able to lessen our anxieties, stresses and worries.

Our group members summed it up well in their comments after the practice: “I had a chance to relax for 5 minutes without being interrupted!”, “I felt peaceful.”,“I realized the car alarm is not such a big deal.”, “I feel more energized!”, “It was so nice.” Not bad for 5 minutes!

Mindfulness in Caregiving

Ms. Manteau-Rao explained that mindfulness allows us to choose and incorporate the qualities we want to bring to providing care. We are more likely to provide compassionate care in a calm manner if we are attentive to the moment. She suggested that before we ask our loved ones to do a specific task, we take a few minutes to just be with them. By taking this time, we acknowledge their presence and allow for a mutual moment of connection. In many situations, by taking a few minutes ahead of the task at hand to connect, we are actually more likely to succeed in getting the task completed in a shorter amount of time and with less frustration. We can also be mindful when we walk with someone who has a neurological condition by matching their pace; this again allows us to connect with the person while sending them the message that we see them and are with them on a physical and emotional level.

> *We are more likely to provide compassionate care in a calm manner if we are attentive to the moment.*

There are multiple opportunities throughout the day for both ourselves and our loved ones to slow down, breathe and notice. Enjoy!

If you want to try a mindful meditation now, you can download one of Ms. Manteau-Rao’s podcasts for free at:

http://www.presencecareproject.com/podcasts

For more information on Mindful Meditation:

Center for Mindfulness:
http://www.umassmed.edu/cfm/Stress-Reduction/History-of-MBSR

Presence Care Project:
www.presencecareproject.com

On Carergiving and its challenges:
http://www.yogajournal.com/article/philosophy/because-you-care

Dog Named Flo Continued

would just be more work for me.

While thinking about a dog, we joined two HD Support Groups, one for caregivers only, the other for caregivers and patients. Both formats are good, but I found the combined group to be more helpful as hearing from those affected and those who care for them was usually enlightening. And it didn’t seem that caregivers held back in talking about their challenges, problems and successes.

We connected with some distant relatives and learned about other family members who had been affected. I talked with the niece of one of Mary’s father’s nieces who was just 50 and was about to enter a care facility. She has four children, a husband who has left, but a loving sister who has taken care of her.

I reached out to Care.com and posted a physical exercise job, got amazing response and found a professional caregiver who began a weekly Walk &Talk with Mary getting her out of the house without me—good for both of us.

I met with Family Caregivers Alliance to learn about their services, educational programs and workshops. I asked our housekeeper to come every week and do some part time care giving. She, in turn, introduced me to a caregiver relative who comes weekly for six hours so I can see my grief counselor and meet up with friends. And, a year ago, we engaged hospice services—really helpful.

In September 2012, just after her 75th birthday, Mary said, “Let’s go to Berkeley Humane,” a place we often passed. When we told the attendant that we were looking for a small dog, 20 pounds or less, 1-2 years old, she

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President's Corner Continued

On May 2nd, we had our annual educational convention at the MIND Institute on the UCDMC campus. Les Pue, who has flawlessly organized the convention for 20 years, was unable to manage it this year because of a serious surgery. Mary Jane Genochio with the help of Terry Tempkin and the Chapter Board took over this year and did a great job. Les is doing well and will be joining us for our Board meeting in July. As usual, the morning and afternoon breakout sessions were informative. Dr. George Yohrling, Senior Director, Mission and Scientific Affairs of HDSA, traveled from New York to be our keynote speaker. He provided us an excellent and detailed update on the HD research taking place in so many areas in the US and around the globe. The Chapter also awarded the first annual George and Marna Parks Award. It will be given each year at the local convention to a Northern California family that makes a substantial contribution to the Chapter. It does not have to be a monetary donation, but can be given to a family who has supported the Chapter by hosting a fund raiser, volunteering many hours to the Chapter, etc. The first award was given to George and Marna Parks who donated over $52,000 during our research appeal. Their donation was greatly appreciated and will go to HD research.

The NorCal Chapter Board is a talented and diverse group. Since October, we have added two excellent board members:

- **Max Moon** is a 15-year veteran of the Real Estate & Mortgage business. He was inspired to volunteer after learning that HD is overlooked and underfunded. He has contributed from the sidelines since 2012, but wanted to do more so in early 2014 as an advocate was able to help secure Rep. Doris Matsui as a co-sponsor of the HD Parity Act/Bill. Max was voted in as a board member in October 2014. He has been on the Sacramento TEAM HOPE Walk committee for two years helping with fundraising and sponsorship.
- **Edward (Ned) Cohen** is a former HDSA National Campaign for Help and Hope committee member. An attorney with managerial, trial, and appellate experience, he is active in local and state politics, and served fifteen years on the Sierra Community College Foundation Board. Ned cared for his HD afflicted mother-in- law, who passed away in 1990. He cared for his beloved first wife Lynne, who suffered from HD for thirty years, and passed away in 2012. He joined the Board in January 2015, to work on fundraising and advocacy.

If you are interested in becoming a board member or helping with our fund raisers, please let me know at dawn.doster@sbcglobal.net.

On February 10, 2015, the Huntington's Disease Society of America announced twenty-nine outstanding HD care facilities were awarded the designation of HDSA Centers of Excellence. During the selection process, forty-two grant applications were received from top-notch medical centers in the US. The twenty-nine newly designated centers share a commitment to bringing more comprehensive care to more HD affected families, including ten states that did not have a Center of Excellence program. After a rigorous selection process, the NorCal Chapter was elated to learn three Northern California medical institutions were designated: University of CA Davis Medical Center; University of CA, San Francisco and Stanford University. Congratulations to these three outstanding institutions.

Don't forget to get in touch with your congressional representatives and encourage them to sponsor the HD Parity Act, or just get out in your community and make people aware of HD and how they can help through volunteering and donations! In order to find out more about the HD Parity Act and how to contact your Congressional representatives, go online to HDSA at http://hdsa.org/about-hdsa/advocacy/.

For the last seven years, my life has been blessed by the NorCal Chapter and the families of Northern California. My daughter Yvette, who has HD, came from Georgia for a nine day visit in May. She came without her family and is doing well. She is proud of her parent's involvement with the NorCal Chapter and HDSA. Volunteering our time and energy is a way we can feel a part of Yvette's journey and keep abreast of what is going on all over the country and the world to fight this devastating disease.

Thank you again for supporting us and making a significant difference in the lives of HD families in Northern CA!

"Snowflakes are one of nature's most fragile things, but just look what they can do when they stick together." ~Vista M. Kelly~

Challenging Behaviors Continued

frustration, anger, and grief in addition to any psychiatric symptoms they may have from the illness. Understanding that behavioral issues in HD stem from a combination of brain changes and the effects of profound loss helps to guide coping strategies for patients and families. The table below summarizes common behavioral symptoms in HD.

Strategies for problems with executing functioning and apathy

Problems with executive functioning (thinking, planning, and organizing) and apathy (loss of motivation to initiate or complete activities) can significantly impact the lives of people with HD and their families. Fortunately, similar strategies are helpful for managing both of these problems. HD patients with apathy or deficits in executive function may benefit dramatically from *having a regular routine*. Having a predictable schedule (e.g. regular meal and bed times, chores completed at same time each day, etc.) is helpful because it reduces the amount of new information and change the person with HD faces. This is especially helpful for individuals experiencing problems with thinking and memory. The familiarity of a routine is also soothing for some, and can reduce anxiety and irritability. Additionally, patients and families may find the use of *cues and prompts* helpful. Cues and prompts help the person to remember and pay attention to his or her responsibilities and routine. Examples include using cell phone alarms, calendars, and gentle verbal prompts to remind individuals with HD that it's meal or medication time, or that a chore needs completing. *Additional helpful strategies* include speaking in short sentences that give 1-2 pieces of information at a time, or offering choices instead of open-ended questions (e.g. "Do you want oatmeal or eggs?" instead of "What do you want for breakfast?").

Strategies for inappropriate anger and unawareness

Sometimes, individuals with HD may experience inappropriate anger that seems out of proportion to the situation at hand. Individuals may lose patience more quickly than they used to, or may not be able to "shrug off" minor irritations. The person's anger may escalate quickly, and they may yell, slam doors, throw objects, or even hurt others. This can be especially challenging if the person with HD also suffers from unawareness, or the inability to recognize their symptoms or declining functioning. One important strategy is to *avoid direct confrontation*, and adopt a

Common Challenging Behaviors in Huntington's Disease
Unawareness: Failure to recognize or notice problematic behaviors or the declining ability to function. *Examples: Person doesn't notice worsening performance at work, person fails to recognize they are no longer a safe driver.*
Declining executive function: Problems with speed of thinking, planning, prioritizing, organizing, concentration, decision-making, flexibility, or creativity. *Examples: Poor performance at work, inappropriate behavior, impulsive decision-making*
Apathy: Loss of motivation to attend to responsibilities, basic needs, and things the person used to think were important. *Examples: Difficulty getting out of bed or starting the day, neglecting household chores or personal hygiene*
Irritability and disproportionate anger: Often stems from frustration about losses (e.g. abilities, independence) combined with brain changes that decrease the ability to regulate emotions. *Examples: screaming, swearing, threatening, slamming doors, hitting walls, pushing, striking or hurting others*
Obsessive thoughts and compulsive behaviors: Recurrent, intrusive thoughts paired with repetitive behaviors that reduce inner discomfort. *Examples: Over-concern with germs/contamination, fixation on past insults/injustices (thoughts); repeated hand washing, compulsive eating or drinking (behaviors)*
Depression and suicide: pattern of low mood and poor energy that can lead to feelings of hopelessness and thoughts about ending life. *Signs: Persistent sadness, irritability, or low energy; changes to appetite and sleep patterns; preoccupation with or frequent thoughts about death or suicide*
Anxiety: Intense feelings of inner discomfort, worry, panic, or restlessness. *Signs: Frequent worrying about minor or everyday things, fear of losing control or "going crazy," preoccupation with perceived judgment or scrutiny from others, obsessions/compulsions (see above).*

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Challenging Behaviors Continued

helpful stance when possible. For example, instead of saying "You can't drive because you have Huntington's—your attention and motor skills aren't good," try, "I'll drive you—I was going there today anyway." This helps the person to maintain a sense of dignity and control, and is less likely to trigger anger. Another critical strategy for preventing anger outbursts is for the person with HD to *stop all use of alcohol and recreational drugs*. Though someone using these substances may feel better in the moment, substance use increases the risk of dangerous behavior and is not safe for people with HD. For particularly sensitive issues, such as approaching the person about declining work performance or unsafe driving, *involving outside agencies* is helpful (e.g. work performance evaluation, driver evaluation through DMV) because it shifts confrontation away from family members. If the person suffering from HD does become inappropriately angry, *de-escalation technique*s such as using soft voice, kind words, and giving space may help. If the person threatens or uses violence, it is crucial to *get away and call for help* (e.g. police). Do not attempt to touch or restrain the person yourself. Any HD patient with frequent or severe inappropriate anger should see their HD care team right away, because they may need *medications* to help reduce anger. *Additional important strategies* include minimizing stress, removing any weapons from the home, and maintaining a calm, predictable environment whenever possible.

Strategies for depression, anxiety, and other psychiatric syndromes

In addition to the above behavioral challenges, people with HD often suffer from distinct psychiatric syndromes, such as depression and anxiety. The presence of these types of syndromes can worsen challenging behaviors, so recognizing and treating them is critical. Treatments may consist of medications, counseling or psychotherapy, and other interventions. In addition, some of the above strategies, such as maintaining a consistent routine, can be helpful for depression and anxiety. Lastly, it is important to be aware that *suicide is unfortunately common* among those who suffer from HD. Suicidal thoughts and statements in patients with HD should always be taken seriously and addressed immediately. *If someone with HD voices an intent or plan to commit suicide, it is an emergency*, and those around them should take actions such as calling a suicide hotline, or 911.

Social Security DISABILITY Tips

By Lisa Kjer-Mooney, LCSW

Applying for Social Security Disability Income (SSDI) can be a frustrating and challenging process. Listed below are some tips and suggestions about what information to gather before starting your disability application. All HD persons applying for disability should have a close loved one (spouse, sibling, adult child, etc) assist with the application process to ensure that applications are completed thoroughly the first time to hopefully avoid any unnecessary delays in processing.

The information shared here was gathered from ***2014 HDSA National Convention Workshop: Assessing Disability -- "When It's time to apply for Social Security Disability Insurance"***, by Art Spencer. You may watch the archived presentation in its entirety at http://hdsa.org/about-hdsa/annual-convention/2014-convention/.

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HD Documentaries & Books

A Mind in Quicksand

It was six years between the time Kim felt there was "something wrong" with her health to her diagnosis that she had the degenerative brain disorder Huntington's disease. While coping with the challenges of her new reality she began to uncover questions about her past and come to grips with her future.

www.amindinquicksand.com

Twitch: A Documentary

Twitch follows 18-year-old Kristen Powers as she undergoes genetic testing for the disease that killed her mother. This documentary will highlight the pressures people, especially young adults, face when given the chance to be handed their medical fate.

twitchdocumentary.com

Continued…

Documentaries & Books Continued

The Lion's Mouth Opens

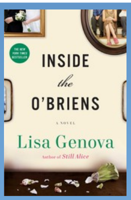
This verité documentary is about confronting life's most daunting moments with purpose and grace, and about the impact of genetic bonds and genetic testing on the people we love and on how we face our destiny.

www.lucywalkerfilm.com/THE-LION-S-MOUTH-OPENS

Huntington's Dance

This intensely personal window into one family's struggle with a devastating genetic disease, Huntington's, invites the viewer to experience their own vulnerability to the human condition.

www.huntingtonsdance.org



Inside the O'Briens

From the *New York Times* bestselling author of *Still Alice* Lisa Genova comes a powerful and transcendent new novel about a family struggling with the impact of Huntington's disease.

www.books.simonandschuster.com/Inside-the-OBriens/

Flo Continued

said, "You should meet Flo who's in the next room."

It was love at first sight. Flo is a tan Border Terrier-Dachshund mix with brown eyes, black eyebrows and muzzle. We took her for a walk and said we'd like to "rescue" her. After two hours of paperwork we got in the car and took our new little friend home. I told Mary that she still had good dog karma.

Flo was just one-year old, in late puppy-early maturity development, and after some environmental adjustment was just fine. With our daughter and son-in-law we took her to a park and to everyone's delight she loved to run and fetch a ball, bringing it back most of the time. She has become a great little retriever, but most of all she's become a comfort to Mary and a little pal for me.

Having a "third party" helps us keep a positive outlook, and she is a great stress reducer as she loves to play with a ball or chew toy in the house, then curl up in Mary's lap when we go out in the car. Mary has become less mobile so holding the dog in her lap allows me to run into stores for quick errands.

Flo is a great little watchdog barking when the doorbell rings, then settling down after the guest enters our home. And, she likes TV. Her favorite program is the PBS Nature series, and she'll often watch an entire show, charging the screen and barking at animal close-ups, but just watching during the long shots.

One of the most rewarding dog values is dog owner sociability. During our early morning and late afternoon walks we have met nearly a dozen new neighbors down the street and around the block because the dogs react to each other and dog owners often talk, get acquainted and sometimes become friends. These daily encounters are welcome mini respites.

One dog walker has become a part-time caregiver. She and her dog come four days a week for two-hour periods allowing me to do some work around the house, run errands and attend my Tai Chi class. The dogs play to everyone's delight. We now have part time caregivers everyday but Sunday.

We caregivers need to take care of ourselves so we can be effective in helping our loved ones. Even with our hospice team, part time caregivers, support groups, workshops and professional guidance, I have a long way to go to become a better caregiver as I get frustrated, fatigued and angry.

Care giving is more art than science. An unconditionally loving, four-legged friend can make a big difference.

DISABILITY Continued

Eligibility

- You have to have paid into the SSA system for at least 40 quarters (10 years)
- You must have worked at least 20 quarters (5 years) in the last 40 quarters (10 years).
- If you did not pay into the system for 40 quarters or have been self-employed or not working you may be eligible for Supplemental Security Income (SSI), please visit www.ssa.gov or your local Social Security Branch for more information about the SSI program.

What you have to PROVE:

- You need to prove that you have the disease by

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either medical & family history or genetic testing results, AND
- Demonstrate how the HD symptoms prohibit your ability to work and meet employer expectations.
    - Symptoms can include: movement disorders, cognitive difficulties and behavioral and emotional symptoms.

<u>Compassionate Allowance Listing Designation:</u>

- To ensure your application is flagged as Compassionate Allowance you must use the "right" words:
    - When entering your disability state:
        - "Huntington's Disease with increasing limitations"
        - "Juvenile Huntington's Disease or Early-Onset HD"
- When an application is flagged in the system as Compassionate Allowance, it should not ask lengthy questions about past employment history.

<u>Documentation needed to PROVE disability:</u>

MEDICAL DOCUMENTATION

- Any medical documentation from your General Practitioner/Primary Care Physician, Neurologist, Psychiatrist/Psychologist, Genetic Counselor and etc. that demonstrates that you have HD symptoms AND details what those symptoms are.
- Ask your MD to discuss in the medical notes how the symptoms are preventing you from working and/or completing activities of daily living.

PERSONAL & FAMILY DOCUMENTATION

- Keep an "Activities of Daily Living" journal:
    - Describe how the HD symptoms are preventing you from completing everyday tasks such as cooking, cleaning, paying bills, driving, managing medication, dressing, bathing, housekeeping, caring for children, etc.
- It may be best for FAMILY MEMBERS to keep the diary as they can often see subtle changes that may be happening.
- Keep the journal as matter of fact as possible and SUMMERIZE the symptoms/changes caused by HD.
- Submit the journal with your application.

EMPLOYMENT DOCUMENTATION

- If you have any employment records that demonstrate a decline in performance or change in your work responsibilities due to not meeting expectations make sure to get copies and submit with your application.
    - This can include: e-mails, formal disciplinary action or write ups.
    - If only verbal meetings were held to discuss your work performance, you can include the date, time, staff/supervisors present and details of the discussion in your journal to submit with your application.

<u>Submitting the Application and Approval/Denial:</u>

- Keep copies of everything you submit to SSA.
- If SSA refers you for a DDS consult/Medical Relations Officer or Professional Relations Officer, you can request to have the evaluation completed by your MD and SSA has to comply and allow your doctor to complete the evaluation.
- For additional assistance with submitting or reviewing your application, Caring Voice

Continued…

Language Do's & Don't's

DO Say	DON'T SAY
• I am limited by balance from doing any work around dangerous machinery, etc	• I can't work
• I have troubles with fine motor making <u>*(list activity here)*</u> difficult and unsafe.	• I am totally disabled
• Due to HD I am experiencing impulsivity (or other behavioral symptom – depression, anger outbursts, irritability, etc) which is causing difficulties in getting along with co-workers and customers.	• I should be awarded benefits
• I am limited by cognitive decline and I am unable to learn new tasks and take on new responsibilities.	• NONE of this column tells the assessor what is happening with you and this information will cause the application to be denied.

Kaiser HDSA Center of Excellence

By: Susan Dorenfeld, LCSW

Kaiser Permanente Medical Center in Sacramento is very honored to be among the HDSA Centers of Excellence in the United States. In collaboration with the Center of Excellence at UC Davis, we offer our Kaiser Permanente members a coordinated, collaborative and multi-disciplinary approach to care that includes the best in clinical, social services and research available. We believe our collaborative approach provides the best opportunity to educate, support and improve the lives of our members.

The Kaiser Permanente multidisciplinary team includes Mara Sifry-Platt, MS, LCGC, Clinic Coordinator/Genetic Counselor; Suketu Khandhar, MD, Neurologist; Mark Lipson, MD and Kamer Tezcan, MD, Geneticists; Karen Brookhyser, MS, LCGC, Katie Jones, MS, LCGC, and Jake Massa, MS LCGC, Genetic Counselors, Brad Briercheck, MD, Psychiatrist; Jeanine Perry, PT, Physical Therapist and Susan Dorenfeld, MSW, LCSW, Genetics Social Worker.

Each medical professional provides a unique set of skills that contribute to the patient's care plan. Patients are provided education about the disease, a clinical exam and assessments, treatment and research options, therapies to improve quality of life and enhance coping with the adjustment to living with a progressive disease and ways to communicate needs, feelings and concerns.

Once a year, we provide a day of education for all those affected by HD. The presenters represent all of the professionals on our team. It's a great opportunity to learn, share and meet with others living with HD. Both Kaiser members and non-members are very welcome to attend.

Our clinic is held every other month at the Kaiser Permanente Point West facility in the Genetics Department. Most patients come to the clinic every 6 or 12 months but the team is also available at any time for questions or concerns. Our patients can contact us by telephone or by sending a Secure Message through their HealthConnect computer record. To contact the team or schedule an appointment call the Genetics Department at (916) 614 4075.

Team Hope Walk Continued

You will probably work up an appetite from the walk and the other events so there will be plenty of food options available to curb that appetite. You can purchase a barbequed hot dog or hamburger meal including chips and a drink for $5.00 and for desert indulge in ice cream from Vic's. Jamba Juice will also be available.

To form a team and pre-register for the walk please go on line and register at www.hdsa.org/thwsac/! You can also register the day of the walk.

The cost of registration is Adults: $25.00 and Children over 7 yrs. Old $10.00. The registration fee is a donation to the Northern California HDSA and includes a goody bag.

Our honoree this year is Lisa Kjer Mooney, LCSW, Center of Excellence Social Worker. Please plan to come out and thank her for all she does to help and support HD families.

We are hoping to make this the biggest and best walk yet so let's all turn out to support our local HDSA Chapter.

DISABILITY Continued

Coalition (non-profit agency) has lawyers and advocates that can review applications and provide recommendations on how to make the claim stronger and more likely to be approved.

- If denied, you have the opportunity to appeal within 60 days. At that time you should contact Caring Voice Coalition for additional support for the appeal process.

Additional Resources:

- **Caring Voice Coalition: http://www.caringvoice.org/2014/04/understanding-your-disability/**
- **Social Security Administration: http://www.ssa.gov/disabilityssi/**
- **Chapter Social Worker: Lisa Kjer-Mooney @ 916-734-6277 or lkjer@hdsa.org**

HDSA Northern California Support Groups

By Lisa Kjer-Mooney, LCSW

Did you know that the **HDSA Northern California Chapter** has a total of 8 support groups to support you? All groups are professionally facilitated and most meet monthly. Support groups are a great way to meet others living with HD, feel part of the HD community and receive information and education about HD from other families in similar situations. They offer each person an opportunity to share frustrations, challenges, joys, triumphs, etc in regards to your HD journey. You will meet caring and compassionate individuals that understand what you are going through and can offer advice on how to cope and overcome challenges, they will listen to you and most of all help you feel like you are not alone. All support groups are FREE of charge and serve HD persons, at-risk individuals, family members and care partners. Visit your local support group next month to get the support and compassion you deserve.

City	Facilitator	Meeting Dates/Times	Location Address
Chico	Lori Rollin lorirollin@gmail.com (please put HDSA in the subject line) 530-896-0257	1st Wednesday each month 6:30pm-8:00pm	Enloe Regional Cancer Center 265 Cohasset Road, Chico
El Cerrito (For Caregivers Only)	Natasha Boissier, LCSW nboissier@memory.ucsf.edu 415-476-2904	4th Tuesday each month 7pm -8:30pm (No meetings in Nov or Dec)	Sycamore Congregational Church 1111 Navellier Street, El Cerrito
Lodi	Lisa Kjer-Mooney, LCSW lkjer@hdsa.org 916-734-6277	3rd Tuesday every EVEN month (February, April, June, etc) 6:30pm-8:30pm	First Baptist Church of Lodi 267 N. Mills Ave, Lodi
Mill Valley	Andrea Zanko, MS Genetic Counselor zankoandrea@gmail.com	3rd Thursday of each month, 7:30pm-9pm	Westminster Presbyterian Church 240 Tiburon Blvd, Tiburon
Palo Alto	Andrea Hanson-Kahn, MS Genetic Counselor andreak@stanford.edu	2nd Tuesday each month, 7pm-8:30pm	First Baptist Church 305 N. California , Palo Alto
Sacramento	Lisa Kjer-Mooney, LCSW lkjer@hdsa.org 916-734-6277	2nd Wednesday each month, 7pm-8:30pm	UC Davis Medical Center Ellison/ACC Building 4860 Y Street, Sacramento Suite 3030C
Santa Cruz	Jan Raffety jannybraffety@gmail.com	3rd Wednesday each month, 7pm-8:30pm	Unitarian Church 6041 Freedom Blvd, Santa Cruz
Santa Rosa	Dorothy Foster, MFT dfoster@sonic.net	2nd Monday each month, 7pm-8:30pm	576 B Street, Suite 1-A, Santa Rosa
Youth Support & Information	On-Line Support http://en.hdyo.org/		

HDSA Northern California

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hdsa.org/nocal