



Fall 2015

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President's Corner

Dawn Doster, Chapter President

This will be my last column as President of the NorCal Chapter as I am stepping down from my position at the end of December after serving for more than four years. It has been a truly amazing journey and I have so many wonderful memories. During the last five years, I have attended four National Conventions and met so many brave families from all over the country.

Ron and I attended the HDSA Convention in Dallas, Texas in June and we thought it was an outstanding event. We learned about HD research that is currently happening all over the world and feel sure a cure will be discovered soon or at least a better quality of life for HD patients.

During my term, the Chapter has provided HD families with many services as well as providing funds for HD research. We have had

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Emotional Aspects of Huntington's Disease

By Diana Wertz, MD, PhD and Sepideh N Bajestan, MD, PhD

Huntington's disease (HD) can produce a combination of neurological, cognitive, and psychological symptoms that can lead to a range of emotional challenges for people with HD as well as family, friends, and primary caretakers.

This article will discuss common emotional and psychiatric issues that may be part of the nature of HD or that may result from the challenges of either living with the disease or of taking care of those with HD. In one large study of 1993 individuals carrying the mutation for HD, the most common psychiatric issues experienced were **apathy, depression, irritability/aggression, and obsessive behaviors** while psychosis was rarely seen (Van Duijn, et. al., 2014).

The emotional experience of those with HD as well as family and

friends may include feelings of loss and confusion related to changes in behavior and personality. These changes in behavior and emotion likely occur due to changes in brain areas, and are not volitional or character flaws, but are more accurately viewed as neurological side effects of the illness.

For example, studies indicate that **aggression and irritability** become problematic for between 22%-65% of people with HD and that these issues are among the most common reasons for hospitalization (Fisher, C., et. al., 2014). Fisher's review of several case studies suggests that behavioral plans, searching for and eliminating triggers for irritability, as well as medications such as buspirone or dopamine blockers may be helpful in reducing aggression and impulsivity.

Emotional Aspects Continued on page 2

President's Corner Continued

success in our advocacy efforts for the HD Parity Act as well as bringing awareness to HD through fundraising events and media blasts.

For the last 20+ years, our annual convention on the 1st Saturday in May remains the best educational event in HDSA and is attended by around 200 people in Northern CA.

During my time the Chapter has provided HD families with many services as well as providing funds for HD research.

The Chapter also continues to sponsor eight support groups in Northern CA. I attend the Sacramento Support Group and know how much these groups mean to HD families. While Lisa Mooney is on maternity leave, I look forward to helping facilitate the Sacramento group with Martha Lehman.

At the National Convention in Dallas, our Chapter won the award for Outstanding Board Development. It was wonderful to be recognized and I am honored to lead this board of highly qualified and diverse board members. At our board meeting in September we added two new members, Diane Olsen and Louisa Burke. They have connections to HD and understand the importance of helping families through services and research. They also bring specialized skills to our board. Diane is a graphic artist and Louisa is a Wells Fargo team member, experienced in banking and financial management. We are

Continued...

Emotional Aspects Continued

Behavioral support plans have been very helpful in specific situations and often include an element of highly structured daily routines, minimization of triggers, sensory agents such as weighted blankets and handheld puff massagers, and rewards to reinforce positive behaviors.

Apathy is the most common psychiatric symptom experienced and up to 70% of people with HD will struggle with it at some point (Krishnamoorthy and Craufurd, 2011). Apathy may lead to isolation and a lower quality of life for both patient and caregivers. At this time there are no well-controlled trials of medications or behavior therapies for apathy in HD.

However, treatments such as cholinesterase inhibitors and behavioral therapies may eventually prove helpful as there are studies showing efficacy for relieving apathy in Alzheimer's disease and several case reports where these interventions have been helpful for apathy in patients with HD. For patients struggling primarily with apathy as a symptom, it may be helpful to avoid dopamine blockers and sedating medications.

The key neurotransmitters that have been implicated in leading to the symptoms of HD are dopamine, glutamate, and gamma-aminobutyric acid. Many of the drugs that have been studied as potential treatments modulate one of

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HDSA 30th Annual Convention Report – Need More Research Volunteers; Chapter Recognized

By Ned Cohen, HDSA NorCal Board Member

The 30th HDSA National Convention was held in June in Dallas, Texas. Northern California Chapter, President Dawn Doster, and Board Member Ned Cohen attended. The Chapter received the award for Best Chapter Board Development.

Many convention sessions related to current research, and the need for volunteers for future research. Some of the major studies include:

Legato-HD Trial by Teva, Huntington Study Group (HSG), and the European Huntington's Disease Network (EHDN) to investigate Laquinimod. Laquinimod has been investigated for MS, as it acts on both the immune system and within the central nervous system. May have an effect on progression of HD. The trial is in Europe and will take 52 weeks.

Monoclonal antibody by Vaccinex. A phase 2 drug trial has started. May delay or slow progression of HD. One year study.

ISIS-antisense oligonucleotide. Delays loss of brain mass. Study

Continued...

President's Corner Continued

pleased to welcome them to the NorCal Board.

Richard (RB) Hackenberg has been voted in as our President for 2016. He is a retired marketing, advertising and communications executive and has held senior management positions with advertising agencies and advertisers in Chicago, Los Angeles and San Francisco. RB has been a member of our Board for several years and drafted several policy documents. He has also served on our communications and advocacy committees.

RB understands how devastating an HD diagnosis is to a family. He was a 24/7 caregiver for his wife until she lost her fight with this horrific disease in August. In order for the transition to be as seamless as possible, I will take the position as Vice President in 2016 and look forward to working with RB at the helm.

In July, we had a successful Sacramento Team Hope Walk in Land Park. The day could not have been more beautiful. Mark Palmer and I were on Fox 40 morning show several days before to advertise our walk and also to bring more awareness about HD.

During that broadcast, Mark, who has HD, was kind enough to discuss the symptoms and problems that occur after onset. What a trooper! I keep telling him we are going to take our show on the road to bring awareness all over the country. Additionally, Good Day Sacramento interviewed me the day of the walk about HD and took

Continued...

Emotional Aspects Continued

these three neurotransmitters. High levels of some neurotransmitters can lead to the involuntary movements seen in HD.

In fact, some medications that can help the neurological aspects of HD by decreasing levels of these neurotransmitters can lead to psychological side effects such as **depression**. For example, tetrabenazine is a drug that causes depletion of dopamine within the brain. Tetrabenazine is FDA approved to treat chorea as lowering levels of dopamine has been shown to reduce involuntary movements.

However, dopamine is very important in maintaining normal mood, interest in life, and motivation to carry out enjoyable activities. Low dopamine levels can lead to depression, thoughts of suicide, as well as profound apathy. Not all people taking tetrabenazine experience these psychological side effects, but it is important to monitor mood and seek the help of your neurologist and a psychiatrist if sadness or apathy worsen after starting tetrabenazine. Antidepressants may be helpful in lifting mood so that tetrabenazine can be continued.

For some individuals, the use of dopamine blocking agents may offer some control of chorea without the mood side effects of tetrabenazine. For example, a

Continued...

Convention Report Continued

would affect wild HD gene and mutant HD gene. Thus, the study will seek 50% reduction in both to decrease anxiety, improve activity, and improve motor control. The study has started. It will take 2 to 5 years to complete if the study goes through phase 3 of drug testing.

UCD stem cell to block BDNF from cortex to striatum.

Waiting for FDA approval for human trials.

CHDI Genetic Modification Consortium has found that chromosomes 15 and 8 affect the mutant HD protein with 15 being the more important.

This explains why there is up to a 20 year range around each repeat set. Thus for 47 repeats the range is age 32 to 52 for age of onset. Degrees of symptoms are also affected. Thus, CHDI is looking for the gene variance to either mimic the positive effects or to anti-mimic the negative effects of these two genes.

Dr. Ed Wild of Britain, who is the HDBuzz.net developer, stated that the critical problem is signing people up for drug trials. He encouraged people to go to www.enroll-HD.org. The goal is 25,000-30,000 people worldwide. CHDI pays a stipend to Centers of Excellence when people enroll.

Dr. George Yorling from HDSA also advised people that the government website on HD research is not current. He urged people to use the new trial

Continued...

President Continued

pictures of our walkers as they prepared to start.

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/>

Recently Ron and I spent a week with our daughter and son-in-law and found Yvette to be in good health and spirits. Every time I meet her plane, I am worried that I will see more HD symptoms. We feel blessed to have her doing well; however, we know at some point she will get worse. It is the fear all HD families face as they constantly worry about their loved ones.

My work with the Chapter has helped me get through this long and difficult journey. I am grateful for all the avenues of help that are there when the time comes. It is extremely important for us to continue providing family services to HD families in Northern CA as well as make donations to research.

We will be mailing our Research Appeal letter in late November. Please participate with a contribution to HD research. We must keep the

Continued...

Emotional Aspects Continued

few small, non-placebo controlled studies suggested that aripiprazole (and other dopamine blockers) may provide some relief of chorea and aggression without increasing depression or irritability (Reilmann, R., 2013).

In addition, there is a once monthly injectable form of the medication for people who do not want to take another daily pill. Van Duijn's 2014 study indicated that only 54% of patients with severe depression were receiving antidepressant treatment and that depression may be underdiagnosed and inadequately treated in patients with HD.

Because depression so severely impacts quality of life, a trial of an antidepressant may be worth considering in certain situations. Certain antidepressants may also help the obsessive thoughts and behaviors that can be seen in HD (Morreale, M. K., 2015). Obsessions can manifest in many ways such as: performing the same action repeatedly, having to follow a very specific ritual to reduce anxiety, collecting items, being unable to throw things away, needing things to be arranged in a very specific way, asking the same question repeatedly, and getting stuck on the same idea repeatedly. This aspect of HD has been shown to be undertreated according to HD studies. However, it is important to mention such obsessions to your doctor as treatment can

Emotional Aspects continued...

Convention Continued

finder developed by HDSA: HDTrialfinder.org

The National Youth Alliance had a great showing in numbers and spirit. The NYA has 550 members, ages 9 to 29. Was great to see many young people, who have tested negative for HD and have lost a parent, are active in HDSA and NYA!

The Chair Person for the HDSA Board, Jang-Ho Cha (MD, PhD, Roche Pharmaceuticals) said that HD research developed the way for all genetic diseases to find genes. HD research was the basis for the human genome project. Because it is a forefront disease, it attracts researchers.

In trying to expand and centralize HDSA efforts, one activity is to try and bring out people who are known to tell about their experience with HD. For example, Joe Smith, pitcher Los Angeles Angels; Geoff Schwartz, NY Giants football; and Marianna Palka, author of "The Lion's Mouth Opens".

On an organizational level, those who attended leadership day, the day before the convention began, were introduced to a restructuring effort the HDSA Board is hoping to implement for existing chapters and affiliates by January of 2017.

The incoming President of the Northern California Chapter, Richard Hackenberg will attend a meeting in December to learn

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President Continued

research dollars coming in order to find a cure for this devastating disease.

Thank you for supporting us and making a significant difference in the lives of HD families in Northern CA! I am fortunate to have a wonderful family and I send out a special thank you to my husband Ron and my children, their spouses and our grandson for their help.

Since I became President, Travis and Bonnie have provided many hours of help because they are local. Yvette, Todd & Haydn are in GA, but they support me in many ways from across 3,000 miles.

I look forward to working with the board, the HD Centers of Excellence, the support groups and all of you in 2016.

Save the Dates:

March 13, 2016—HD Day at the Sacramento Kings playing the Jazz (We get a discount on the tickets so stay tuned for more information) Great awareness for HD!

May 7, 2016—Annual local convention

June 4, 2016—Sacramento Team Hope Walk in Land Park

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



Emotional Aspects Continued

make a big difference in terms of quality of life.

In addition to depression, **mood swings** may become problematic for some people with HD. There are several case studies that indicate early success with mood stabilizing agents such as lamotrigine or valproic acid (Scheuing, et. al., 2014). In some cases, improvement of chorea was seen in addition to the beneficial effect on mood (Shen, Y. C. 2008).

The combination of neurological and psychiatric symptoms can overwhelm not only people with HD but also family and primary caretakers. A recent study that focused on caretaker wellbeing reported that caretakers were often told by professionals to make sure they take time to care for themselves, however, many caretakers reported a need for specific strategies for easing caretaker burnout.

Helpguide.org, a nonprofit devoted to mental well-being, suggests that primary caregivers let friends and family know the day to day needs of both the person with HD and the caregiver. Family and friends not involved on a day to day basis may not understand the extent of time and energy involved in being a primary caretaker. They may want to help but may feel they don’t have the skills to help.

Therefore, caregiver advocates have suggested that caretakers

Emotional Aspects continued...

Convention Continued

more about the proposal. The National Convention was well attended, very informative, and enjoyable.



DNA Direct: DNA and Love

By Andrea Zanko, MS, LCGC

After more than three decades of working at UCSF, as many of you know, I have been 90% retired for just over one year. My 10% commitment has been with HD families in partnership with the UCSF Memory and Aging Center and I have continued to contribute to our newsletter with my DNA Direct musings for 20 years. Certain truths have withstood time.

We are all at risk for something – remember 100% of us carry multiple potentially harmful (deleterious) genetic changes (mutations). If we are fortunate, we are also all aging. And, trust me, that process can be both wondrous and disturbing!

Family and friends are the treasures in our lives. Cherish the people in your life and your community and treat them with respect and affection. Never take them for granted.

Balance is essential. Use your brain – challenge yourself to focus and calculate and solve problems. Use your muscles every day to maintain flexibility

DNA Continued...

Mindfulness in Care Giving

by *Natasha Bossier, LCSW, UCSF*

Here are some highlights from a Mindfulness presentation by Marguerite Mantau-Rao, LCSW, ATR at the East Bay Support Group earlier this year.

Mindfulness is being fully aware of the present moment, on purpose and without judgement—Jon Cabot-Zinn.

Mindfulness is a powerful stress reduction tool and can be a big help in caring for a loved one. The symptoms and reality of Huntington's Disease invites a mindfulness practice.

When the care giving experience becomes difficult and stressful, here's a mindful way to proceed—STOP--Stop. Take a breath. Observe. Proceed.

When a loved one is physically still there, but psychologically disappearing, use mindfulness to notice and to make room for all emotions in your heart.

There are three hindrances: (1) Wanting what cannot be; (2) Resenting what is; and (3) Worrying about the future. It's good to focus on the hindrance itself, not the object of the hindrance.

(Note: From a UCSF Care Givers Conference, a good way to stay mindful when stress hindrances

Continued...

Emotional Aspects Continued

make a list of specific actionable to do items that would bring comfort to patient and caregiver. For example, a recent study by Rothing, et. al., reported that sadness related to isolation is the most common concern of primary caretakers. Extended family and friends may wish to help but may live too far away to routinely visit, or may mistakenly believe they are not in a position to help.

They may, however, still be able to participate in care by calling the patient/caregiver, ordering needed care equipment to be delivered to the home, arranging for meals to be delivered to the home, visiting via skype to decrease isolation, or offering financial support to pay for respite care so that the primary caregiver has time for self-care.

If friends and relatives are reluctant to help, support groups, individual therapy for the primary caretaker, or family therapy may be important to address feelings of resentment, isolation, and frustration. Helpguide.org (cited below) gives specific ideas for how to pay for respite care and access resources. In addition, Huntington's Disease Society of America offers a searchable database of support groups as well as links to other resources.

Citations:

Fisher, C. A., Sewell, K., Brown, A., Churchyard, A. "Aggression in Huntington's Disease: A Systematic Review

Emotional Aspects Continued...

DNA Continued

and strength. Be serious when appropriate and be silly when possible. Be cerebrally still while you meditate mindfully and move and dance with abandon when the music starts.

Be safe – use your seatbelt and carry a whistle and a flashlight in the dark. Wear a helmet when biking and slow down around corners. Avoid unhealthy habits – moderation when appropriate.

A recent question by a delightful young man reminded me that in all this time, I have never written about **DNA and LOVE**. The young man and I were talking about how he would feel about himself if he learned that he has the Huntington disease-causing gene mutation.

During our pre-test discussion, we typically talk about the **VALUE** of information – particularly when considering education, career, relationships, reproduction and practical issues, such as type of home one rents/buys and stairs and community access.

But probably the most profound consequence of **KNOWING** is trying to define the effect on **SELF** – self-image, confidence, competence, and role in family, community and in society. **This young man questioned whether he would still be LOVABLE if he has the HD gene mutation.** Clearly this is a deeply personal issue. And, thus, the reminder that we are all

DNA Continued...

Mindfulness Continued

and obstacles occur—Relax in the present. Do not rehash the past. Do not rehearse the future.)

Compassion is good for everyone. Notice the loss of decision-making, apathy and depression. Then lend your executive function to jumpstart thinking, dialogue and engagement.

Practice mindful “Sitting Together,” a good way to care for our loved ones and ourselves at the same time. Ask permission to sit. No agenda. Take a breath. Observe. Introduce a topic or task.

Practice mindful “Walking Together” is another way to care for each other.

Again, relax in the present. Let go of past practices of relating to yourself and your loved one. Focus on what needs to get done right now. This is the ultimate mindfulness practice.



Remembering Roberta Van Nortwick

*By Les Pue, HDSA NorCal Vice
President*

Those of you who have attended the Northern California HD convention in Sacramento in recent years will likely remember the lovely lady who sold the beautiful sweaters, caps, scarves, etc. that she had knitted and donated the proceeds to HDSA. That was Roberta Van Nortwick and,

Remembering Continued...

Emotional Aspects Continued

of Rates of Aggression and Treatment Methods.” (2014) *Journal of Huntington’s Disease*, 3, p. 319-332.

www.helpguide.org/articles/care-giving/respice-care.htm

Krishnamoorthy, A. and Craufurd, D. “Treatment of Apathy in Huntington’s Disease and other Movement Disorders.” (2011) *Current Treatment Options in Neurology*, 13, p. 508-519.

Morreasle, M. K. “Huntington’s Disease: Looking Beyond the Movement Disorder” in Balon and Wise’s “Clinical Challenges in the Biopsychosocial Interface.” (2015) *Adv Psychosom Med*, 34, p. 135-142.

Reilmann, R. “Pharmacological Treatment of Chorea in Huntington’s Disease: Good Clinical Practice versus Evidence-Based Guideline” (2013) *Movement Disorders*, 28(8), p. 1030-1033.

Rothing, M., Malterub, K., Frich, J. “Balancing Needs as a Family Caregiver in Huntington’s disease.” (2015) *Health and Social Care in the Community*, 23(5), p. 569-576.

Scheuing, L., Chiu, C-T., Liao, H-M., Linares, G.R., Chuang, D-M. “Preclinical and Clinical Investigations of Mood Stabilizers for Huntington’s Disease: What Have We Learned?” (2014) *Int. J. Biol. Sci.*, 10 p. 1024-1038.

Emotional Aspects Continued...

DNA Continued

– 100% of us - at risk for something.

Of course this young man is lovable. At age 23, he is bright, engaging, funny, creative, silly and sensitive. Even if we learn that a gene mutation is present, he likely has untold years of adventures ahead.

Can I promise him that? No. Can I promise ANYONE that? No. Can I predict how many years of ‘quality’ life he has ahead? Only in the vaguest of terms based on highly variable factors.

Can I predict how many quality years ANYONE has? No, of course not. Therefore, do not dare allow such genetic information to make you feel unlovable. Some of us (you know who you are) are finding love well into our 40’s, 50’s, 60’s and beyond. Being lovable is possible for all who have a twinkle in their eyes and a smile in their heart.

We know that loving changes over time. As we all age, as we mature, with the passage of life events – our loving changes. And, yes, LOVING may evolve into CARING – if we are lucky enough to have people CARE about us throughout our lives, we are lucky indeed.



Remembering Continued

sadly, we will not be having Roberta and her knitting at future conventions. In late August she passed away in her sleep from the effects of HD.

Roberta was an amazing person. In addition to her wonderful knitting, she had been active for several years in a ballroom dancing group and continued dancing until the very end although her HD required her to arrive at the dancing venue in a wheelchair.

Roberta was a charming, vivacious and energetic lady who lived alone in her condo in Rohnert Park as she dealt with the challenges of HD. She will be sorely missed.

Fittingly, Roberta’s ballroom dancing group sent a very generous donation to HDSA in her memory.



Emotional Aspects Continued

Shen, Y. C. “Lamotrigine in Motor and Mood Symptoms of Huntington’s disease” (2008) World J. Biol. Psychiatry, 9(2), p. 147-149.

Van Duijn, E., Craufurd, D., Hubers, A. A. M., et. al., “Neuropsychiatric Symptoms in a European Huntington’s Disease Cohort (REGISTRY)” (2014) J. Neurol. Neurosurg. Psychiatry, 85, p. 1411-1418.

Dr. Wertz is a San Mateo based private practice psychiatrist who is anticipating joining the Huntington’s disease clinic at Stanford Hospital and Clinics.

Dr. Bajestan is an attending neuropsychiatrist in the Department of Psychiatry at Stanford Hospital and Clinics.



Honorariums & Memorials

The Northern California Chapter has only been able to provide services such as eight support groups, funding for cutting edge research, as well as informative conventions with the generous support and donations from Northern California and beyond. It is with great honor and respect that we continue to say thank you for all of the donations that we continue to receive.

Gertrude Shearer in Memory of Betty Benedetto ~~ An anonymous Fidelity Charitable Donor in memory of Craig Carll ~~ An anonymous donor in memory of Martha, William, James, Lynne ~~ An anonymous donor in memory of Loraine Larsen ~~ John and Therese Marin in memory of Phyllis Cahoon-Marin ~~

Honorariums Continued...



Participants from the Northern California Annual Team Hope Walk (left) and the San Francisco Team Hope Walk (right) show off their Team Hope pride! The Sacramento Walk was held July 25th and the San Francisco walk was October 24th.

Honorariums Continued

Barbara Geisler in honor of Lou Mongan ~•~ James and Doris Lloyd in honor of David Taunton ~•~ An anonymous donor in memory of James Shearer ~•~ An anonymous donor in memory of Michael Resch ~•~ Katherine B. Liddington in memory of Ludger, Paul & Philip Leger ~•~ Charles Pue in memory of Margaret Pue ~•~ An anonymous donor in honor of Cheri Harries ~•~ Sherry Taylor in memory of husband, Bob, son, Seamus & in honor of children living with HD ~•~ An anonymous donor in memory of Jim Roberson ~•~ Tom and Darlene Johnson in memory of Stan, Beth and Jeff Johnson ~•~ An anonymous donor in memory of Stephen Rauen ~•~ Richard Dalby in memory of Paula Dalby ~•~ Jeanette Schneider in memory of her father and sister in honor of Myrtle Page ~•~ Beverly Ann Gooch in memory of Donald Gooch ~•~ David Yount in memory of Susan Yount ~•~

Donald DeBerry in memory of Charlotte T. Smith ~•~ An anonymous donor in honor of Marilyn & William Wilson ~•~ Bonnie Venkatesan in honor of T. Venkateson ~•~ Carl and Sharon Nordstrom Family in memory of Douglas J. Nordstrom ~•~ Douglas and Teri Devitt in memory of Karen Bjorklund ~•~ Lois Smrtnik in memory of Bill Smrtnik - deceased 12/2009 ~•~ Wayne Achziger in memory of Regina Achziger ~•~ Michael and Karen Rogge in honor of Alma Swisher/Swisher Family ~•~ Connie Hurst in honor of Sharon Renato ~•~ Nora McGuinness in honor of Vicki Wheelock, M.D. ~•~ Del and Louise Freeman in memory of Bob, Rick & Sandy ~•~ Kaoki Bailey Harris in memory of Edward W. Bailey and Karen E.N. Bailey ~•~ Peter Sheremeta & Maureen Cornelia in honor of Dean Link & Mary Jane Genochio ~•~ Betty J. Miller in honor of Tom C. Miller ~•~ Sherry Taylor in memory of Robert and Seamus Taylor in honor of Jacelyne and

Brent Taylor ~•~ An anonymous donor in honor of Les Golembo ~•~ An anonymous donor in honor of Dr. Wheelock's Group, Dorothy Foster, Santa Rosa Facilitator ~•~ Mary Johnson in memory of Jeff, Stan & Beth Johnson ~•~ Jean Metcalf in memory of Martha, William, James and Lynne ~•~ Mrs. Alexandria A. Manesis in memory of John A. Manesis ~•~ Wayne Achziger in memory of Regina Ellan Achziger ~•~ Sheryl and Boone Seto in memory of Tim Roberson ~•~ An anonymous donor in honor of Vicki Wheelock, M.D. ~•~ John W. Ross & The Ballroom in memory of Roberta Van Nortwick ~•~ Byron and Gloria Petersen in memory of Mary Hackenberg ~•~ Jack and Maryellen Langley in memory of Betty Miller ~•~ Mary Termini in memory of Betty Miller ~•~ Doyle and Debra Pease and Family in memory of Betty Jeanne Langley Miller



Northern California & UCD Med Center HD Center of Excellence News

October / November / December 2015

National:

- HDSA has HD Identification bracelets for sale, \$10. The idea is to help prevent law enforcement interactions from escalating and inform medical professionals with your new Huntington's disease ID bracelet! Bracelet features: Adjustable wristbands are a soft, latex-free elastic. Lightweight, nylon plastic compartment is highly water resistant. Includes 4 waterproof Tyvek inserts to write your medical background & emergency contact information. Visit <http://hdsa.org/shop/accessories/> to order yours today. HDSA does not profit from the sale of these bracelets, but offers as another tool and resource for families.
- The 2015 HDSA National Convention presentations are now available at <http://hdsa.org/about-hdsa/annual-convention/2015-convention/> for viewing. Each year there are new speakers, innovative

research and updates relevant to HD discussed. While you may not have been able to travel to Dallas, you can still be up to date with the information shared!

Local:

Helpful Links

Additional information, news and events for local resources can be found at the following websites.

HDSA Northern California Chapter Website or Facebook page:

<http://northernca.hdsa.org/> or www.facebook.com/hdsanocal

HDSA Center of Excellence @ UC Davis Medical Center website:

www.ucdmc.ucdavis.edu/huntingtons/index.html

HDSA Pacific Southwest Regional Facebook page:

<https://www.facebook.com/pages/Huntingtons-Disease-Society-of-America-HDSA-Pacific-Southwest-Region/115252895152973>

Chapter Social Worker: Lisa Kjer-Mooney is out of the office on extended leave until the end of January. Jill Olmstead, LCSW will be available Mondays at 916-734-6277.

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	4 th 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	3 rd 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	3 rd 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	2 nd Tuesday each month, 7pm-8:30pm	First Baptist Church 305 N. California , Palo Alto
Sacramento	Dawn Doster & Martha Lehman during Lisa Kjer-Mooney's absence	2 nd 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	3 rd Wednesday each month, 7pm-8:30pm	Unitarian Church 6041 Freedom Blvd, Santa Cruz
Santa Rosa	Dorothy Foster, MFT dfoster@sonic.net	2 nd Monday each month, 7pm-8:30pm	576 B Street, Suite 1-A, Santa Rosa
Youth Support & Information	On-Line Support http://en.hdyo.org/		

NorCal Chapter Treasurer

By Dawn Doster, HDSA NorCal President

On September 30th, Mary Harris stepped down as the Treasurer for the NorCal Chapter Board. She was an excellent treasurer and a caring volunteer for three years. Although not directly connected to Huntington's Disease, she was tireless in her efforts to help HD families in Northern CA. Mary joined the Board in Spring 2012 after Dawn Doster asked her to help with the golf tournament at Rancho Murieta. Friends for 20+ years, Dawn knew of her impressive organizational skills

and dedication to any project she tackled. Mary has done a remarkable job as Treasurer, and she has helped on fundraising projects, which she will continue to do. We wish her the best and thank her for the many hours she dedicated to improving the lives of HD patients and families. Her successor is Board Member Mark Stigge, who has been active in Chapter communications and fundraising.



Mary received beautiful flowers from President Dawn Doster at the last board meeting.



Vice President Les Pue was recently presented a gift by President Dawn Doster and the NorCal Board for his many years of dedicated service to the chapter.

HDSA Northern California

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