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...  

Continued on page 2  

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

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

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
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

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

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
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

President Continued

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

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

Continued…...
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...
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

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:

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

Convention Report 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


www.helpguide.org/articles/caregiving/respite-care.htm


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.


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 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


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

~•~

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.
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.

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