

## **Huntington's Disease Society of America** Northern California Chapter

### **Northern California Chapter Convention: Keynote: HD Update – Disease Modifying Therapies – Vicki Wheelock, MD**

*By Andrea Hanson-Kahn, MS*

**You are invited to join this community at the HDSA Northern California Annual Convention, Saturday, May 20th, 2017, at the UC Davis Medical Center in Sacramento.**



**If you've attended an HDSA National or Chapter convention** you know that Huntington's disease affects all kinds of people at all stages of life, and that caring for those with HD is all consuming.

In the prime of life, a wife and mother is diagnosed with HD. Her changes in mood, facial twitching and difficulties at

work are concerning. Her husband feels like he is losing the person he's known and loved, and wonders how to care for the kids.

At age 75, a successful engineer is diagnosed with HD after a full and rewarding life. None of his forbearers or siblings were known to have HD. He and his wife are especially concerned for their children (none of whom have tested for HD) and for their grandchildren.

In the midst of these challenges, we have a community of support. There are husbands, wives, parents, children, siblings and friends whose lives are impacted by HD.

Those spearheading the fight against HD will be there to share experiences and give their support. **Neurologist Vicki Wheelock, MD**, will present the latest findings in the search for treatments for HD. **Terry Tempkin, ANP, MSA**, will provide perspective discussing her Career in the World of HD.

You will learn practical ways to care for loved ones and for yourselves. Other experts will share advice on physical therapy, genetic testing, living at-risk, clinical trials and long term planning. There is something for everyone! The entire convention; including registration, workshops, and lunch is free.

### **To Register for the Convention:**

**Contact Lisa Mooney, LCSW,**  
Email: [lkjer@hdsa.org](mailto:lkjer@hdsa.org) or  
Phone: (916) 734-6277

**HDSA Northern California Chapter Convention**  
Saturday, May 20, 2017  
9:30 am - 3:30 pm

#### **— New Location —**

UC Davis  
Health Education Building  
4610 X Street  
Sacramento, CA 95817

[Download Convention Brochure](#)

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## Join the 9th Annual Team Hope Walk – Sacramento, June 24

By Theresa Bielawski, HDSA NorCal Coordinator

**The annual Huntington's Disease Society of America Team Hope Walk – Sacramento**, is an opportunity to raise awareness and funding for this neurological scourge often described as having Alzheimer's, Parkinson's and ALS at the same time.

Too many people are unaware of this genetic, debilitating disease, and how it affects families today, and for generations to come. We have lofty goals for our walk this year, and we hope you will be a part of our success.

**At HDSA, Family is Everything**, so people of all ages are encouraged to participate. You can help by participating as an individual or getting a team of family and friends together.



**To register as an individual or team use this link:**  
[www.hdsa.org/thwsacramento](http://www.hdsa.org/thwsacramento)

The walk is Saturday, June 24, at William Land Regional Park. Sign-in/registration begins at 8 am, and the walk starts at 9 am. Activities after the walk include a raffle, a silent auction, great food, face painting for the kids, and an all-around fun time.

**We will be honoring Dr. Lorin M. Scher from UCDMC.**

We will also have an awards ceremony recognizing top fundraisers for the event. Prizes include an iPad Mini, Disneyland Park Hopper passes, restaurant gift certificates, and more.

**In addition to participating, there are other opportunities for you to help:**

- "Like" us on Facebook at <https://www.facebook.com/hdsanocal/> and invite your friends too. Help us spread awareness about HD and the Team Hope Walk.
- Sponsorships of different levels are available to anyone interested in helping fund the event.
- We are also collecting donations for our raffle and silent auction.
- Many different volunteer positions need to be filled.
- Lastly, we have an **Amazon Wish list for HDSA Northern California** where you can purchase items we need the day of the walk. The list can be found at <https://smile.amazon.com/ch/22-2942362>

If you have any questions or are interested in helping in any of the ways listed above, please contact Theresa at (916) 864-4336 or [theresaszoal@yahoo.com](mailto:theresaszoal@yahoo.com)

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**We hope you will join us for the 9th Annual HDSA Team Hope Walk – Sacramento.**

**You can register on the HDSA Team Hope Walk – Sacramento webpage: [www.hdsa.org/thwsacramento](http://www.hdsa.org/thwsacramento)**

For those that cannot participate but still want to help, donations may also be made at this link. All proceeds from the HDSA Team Hope Walk – Sacramento will help provide family services in Northern California and support research to find a cure. With your help, we can help find a cure for HD.

## **HDSA 32nd National Convention June 22-24, Schaumburg, IL Hear and Ask the Experts at the HDSA Convention**

By Richard Hackenberg



The Annual HDSA National Convention is the world's largest Huntington's disease family event bringing together the best of education, advocacy and research to create three days of family-focused learning for the Huntington's disease community.

And this year's 32nd Annual Convention Thursday-Saturday, June 22-24, at Marriott's Renaissance Schaumburg Convention Center Hotel near Chicago looks to be the best ever with eleven information tracks and 60+ speakers.

You'll hear the latest on HD research from what's going on worldwide to clinical trials that are currently or may be recruiting shortly. Workshops include an introductory session for anyone who is new to HD so they may have a greater understanding of what is discussed during Saturday's Research Forum. Also scheduled are sessions on specific research approaches including Huntingtin gene lowering, genome editing and drug discovery.

Information tracks include Living with HD, New to HD, Juvenile HD Parenting, Youth-Teens-Young Adults, Caregiving, Volunteer Engagement, End of Life, and several general sessions with HDSA Leaders, MD and PhD speakers from around the world.

HD Buzz Founders Jeff Carroll, PhD, Western Washington University, and Ed Wild, MD, Clinician Scientist at University College of London Institute of Neurology "Ask The Scientists, Anything" session is a convention highlight.

*The Annual HDSA  
National Convention is  
the world's largest  
Huntington's disease  
family event*

**This year HDSA is offering a new app to follow all the Convention activities** via your smartphone, laptop or tablet devices. The HDSA Convention App features venue maps, schedules, communication tools and much more!

**To learn more or to register, go to: <http://hdsa.org/about-hdsa/annual-convention/>**

## Life with HD Series – Remembering the Marin Sisters

By Therese Crutcher-Marin, Author, HDSA NorCal Board Member

It's been said, "If you have one true friend in your lifetime, you are lucky". With that, I have been extraordinarily lucky! When I met John in 1976 and we became a couple, I quickly learned that being with him meant having his three older sisters in my life as well. The four siblings had had a difficult upbringing and were exceptionally close and I was thrilled when they welcomed me.



Like their brother, Lora, Marcia and Cindy were kind, positive, unselfish individuals and I became closer to them than I was to my own sisters. Through the years, I would count my blessings for the loving relationship the three sisters and I shared, as they became tried and true friends. These brave, gentle souls would inspire and teach me many lessons that would enrich my life.

When the sisters discovered the Marin family secret in 1978, their mother had Huntington's disease, I struggled with my commitment to John, broke off our engagement and walked away. But, after much soul searching, and deciding life was too short to leave the man I loved, John and

his sisters welcomed me back with loving arms. John and I married in 1980.

Thus began our journey into the uncharted world of living AT RISK for Huntington's disease. Though we didn't speak about living in the shadow of Huntington's, I acknowledged the possible consequences of my decision to marry into a family where four individuals had a 50/50 chance of inheriting the mutated Huntington gene.

In my mind, based on statistics, this inherited neurological disease with horrible odds, translated into the fact that probably two of the four Marin's would eventually show symptoms of the disease. It was a coin toss that we all tried to ignore.

Through the years, John and I shared many good times with his sisters playing softball, having barbecues and parties, camping, taking vacations together, and just hanging out at Lora's house in Citrus Heights.

*(continued on page 5)*

## Resources for HD Families

### HDSA Webinars –

<http://hdsa.org/hd-research/hd-research-webinar-series/>

### Clinical Trials –

<http://hdsa.org/hd-research/enroll-in-a-clinical-trial/>

### Huntington's Study Group –

<http://huntingtonstudygroup.org/>

### HD Buzz –

[www.hdbuzz.net](http://www.hdbuzz.net)

### National Youth Alliance–

<http://nya.hdsa.org/>

### YouTube Videos –

<https://www.youtube.com/channel/UCbjowsMQBkoj8TJbjsxPdaw>

### Heredity Disease Foundation –

[www.hdfoundation.org](http://www.hdfoundation.org)

### Stanford Center of Excellence/Huntington's Outreach Project for Education at Stanford –

<http://hopes.stanford.edu/>

### Amazon Smile Charity Program

<https://smile.amazon.com/ch/22-2942362>

0.05% of price of eligible purchases will go to the Chapter

### Additional resources can be found at:

#### NorCal Chapter Homepage

<http://northernca.hdsa.org/>

#### NorCal Chapter Facebook page

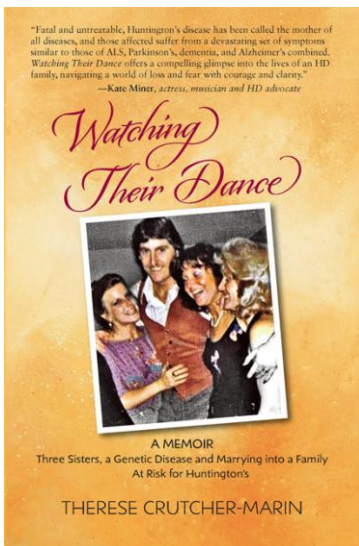
<https://www.facebook.com/hdsanocal/>

(continued from page 4 - *Life With HD Series* –)

Unfortunately, in 1984, Huntington's began its attack on the Marin women.

Lora was the first to fall prey to HD with severe, deep depression that led her to self-medicate with alcohol, and she was stolen from us at age 41 in 1989. Marcia was diagnosed in 1986 after a terrible car accident that seemed to trigger and exacerbate HD symptoms and she died at age 49 in 1999. Cindy, who we thought was free from the disease, began showing symptoms at age 41 and died at age 54 in 2008.

Because of our close relationship, all three sisters lived with John and me at particularly hard times in their lives and I cared for Marcia for many years until I needed to return to fulltime work.



John and I miss them terribly and we wish we all could have grown old together, celebrating birthdays and the holidays together and sitting on the deck at our cabin in Lake Tahoe sipping wine and watching the sunset. Forty years ago, I took the biggest gamble of my life by keeping these people in mine, and it has made me the person I am today.

I have published a memoir, "*Watching Their Dance: Three Sisters, a Genetic Disease and Marrying into a Family At Risk for Huntington's*" to accomplish several goals. My hope is that the book will heighten HD/JHD awareness, as it will be

promoted around the world. The book serves to honor my three sisters-in-law and will generate a continuous revenue stream to HDSA for years to come. (John and I are donating 100% of the books proceeds to HDSA.)

I request folks in the United States, to purchase the book/eBook from my Author Website, [ThereseCrutcherMarin.com](http://ThereseCrutcherMarin.com). The reason for this request is that there is no middleman, i.e. Amazon, allowing the highest profit, approximately \$7.00 per book, to donate to HDSA. In order to promote the book worldwide, it will also be available on Amazon.

I encourage HD families, communities and Chapters to use *Watching Their Dance* as a personal fundraising tool, promoting it to friends and family because each time the book is purchased a donation will be made to help in the fight against Huntington's disease.

## Support Group Meetings for Northern California

### Chico

1st Wed each month,  
6:30 p.m. – 8:00 p.m.

### El Cerrito

*For Caregivers Only*  
–no meetings in Nov or Dec  
4th Tue each month,  
7 p.m. – 8:30 p.m.

### Lodi

3rd Tue every other month:  
Feb, Apr, Jun, etc;  
6:30 p.m. – 8:30 p.m.

### Mill Valley

3rd Thu each month,  
7:30 p.m. – 9 p.m.

### Palo Alto

2nd Tue each month,  
7 p.m. – 8:30 p.m.

### Sacramento

2nd Wed each month,  
7 p.m. – 8:30 p.m.

### Santa Cruz

3rd Wed each month,  
7 p.m. – 8:30 p.m.

### Santa Rosa

2nd Mon each month,  
7 p.m. – 8:30 p.m.

### National Youth Alliance

For Ages 9-30  
Chapter Events may have  
additional youth programs  
available.

### On-Line Support

Huntington's Disease Society  
of America Forum  
Huntington's Disease Youth  
Organization

**For address location and  
facilitator information, visit  
UCDavis Health HDSA Clinic at:**  
<https://www.ucdmc.ucdavis.edu/huntingtons/calendar.html>

## Les Pue Retires from HDSA

### Honoring Twenty-Four Years of Outstanding Leadership and Service



*Les Pue, right, is recognized by HDSA NorCal Chapter President Richard Hackenberg, for his 24 years of outstanding leadership and service to the Huntington's Disease Society of America.*

In the envelope was a **L-19 Bird Dog commemorative coin**, the plane Les owned and flew until a few years ago (see inset.) Les and his late wife Margaret who died four years ago from HD complications were founders of the chapter that began in 1993 when UCDMC became a HDSA Center of Excellence. Les' life of service – military, airline and HDSA—is an inspiration to all who know him. We wish Les and his wife Barbara a happy retirement.



*Les with his beloved Cessna L-19 Bird Dog*

## DNA DIRECT – April 2017

### Update on the Marin HD Support Group – Strangers and Family

By Andrea Zanko, MS LCGC

First, let me say that after facilitating this support group for ~ 25 years, I am still deeply moved, thrilled and in awe of the courage, resilience, creativity, intelligence, compassion, energy and thoughtfulness of the participants. I think you get the picture. I am grateful and honored to know each and every one.

In April we had over 20 people in attendance and we welcomed several new people, including a representative from TEVA pharmaceuticals. We shared introductions and brief bios, realizing that HD is common ground but not our only challenge...life inserts obstacles of all shapes and sizes.

*The ‘stranger’ becomes family as an HD background unites us, but it is the warmth and kindness of the members that holds the ‘new’ person close.*

and brought to group.

Therefore, one of the messages this month that became so clear to me:

The ‘stranger’ becomes family as an HD background unites us, but it is the warmth and kindness of the members that holds the ‘new’ person close.

There has never been a more important time to stay connected personally and to keep apprised of the current research and science. Please stay focused on medical issues and health care - we cannot lose ground now.

Research is productive – we are seeing innovation all the time. Please continue to offer compassionate support for each other and to ‘raise your voices’ to insure support of research, education and our health care needs. Please stay inspired and continue to inspire others.

Heading into Spring – til next time.

Warmly,  
Andrea Z

These challenges bring out the warrior – and we have people in our group who are fighting multiple battles with grace and humor while still finding the energy to reach out to others (eg. provide rides for members who don’t drive, offer meals to those who are hungry).

We had people present who live far far away but happened to meet one of our awesome ‘emissaries’ (you know who you are!) – and were embraced

## About The Nucleus and Northern California Chapter

The Nucleus Newsletter is a publication of the Northern California Chapter of the Huntington's Disease Society of America.

The Nucleus is published twice a year, once in the Spring/Summer and again in the Fall/Winter.

The Nucleus provides items of interest related to individuals with Huntington’s Disease and their families, friends, health care professionals and other support organizations.

The HDSA Northern California Chapter provides services to the local HD community through advocacy, education, information and referral, and support groups.

Donations are tax deductible to the extent permitted by law. Our Federal tax ID is # 13-3349872.

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### HDSA Northern California Chapter

P.O. Box 161238  
Sacramento, CA 95816

Email questions and comments to:  
[northernca@hdsavolunteer.org](mailto:northernca@hdsavolunteer.org)

**For additional information, visit our website and Facebook page.**

**NorCal Chapter Website**  
<http://northernca.hdsa.org/>

**NorCal Chapter on Facebook**  
<https://www.facebook.com/hdsanocal/>

## Honorariums and Memoriams

*The HDSA Northern California Chapter provides services to eight support groups, funding for cutting edge research, as well as informative conventions. We could not do this without the generous support and donations of caring people. It is with great honor and respect that we continue to say "Thank You" for all the generous donations that we continue to receive.*

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Tracy Vera in memory of Charlotte Perry

Jaqi A. Thompson in memory of Jaqi Thompson's Mom

Jeanette Schneider in memory of Myrtle Page and Wesley Kuehn

Pam Mastelotto in memory of Dorothy Buchner

David Yount in memory of Susan Yount

Geraldine A. Martin in memory of Mary Ellen Martin Petersen

Katherine Liddington in memory of Ludger A. Leger, Paul A. Leger, & Philip J. Leger

Mary E. Johnson in memory of The Johnsons, Stan & Jeff

Dolores Paine in memory of Wesley A. Paine

Lucretia & Dale Johnson in memory of Margaret Pue

Alexandria J. Manesis in memory of My Husband: John A. Manesis

Don & Gail Wallace in memory of Tim Roberson

Keith A. Crowther in memory of Eugene E. Crowther and in honor of Gail M. Lohse

Wayne Achziger in memory of Regina Achziger

Paul & Brittany Heyn in memory of Nancy, Deborah, & Steve Heyn

Cathie Lesjak in memory of Doris Lesjak

Nora McGuinness in honor of Vicki Wheelock, UC Davis Center of Excellence

Shannon Hatfield in memory of Joshua & Lynne Cohen

Therese Crutcher-Marin in memory of Lora, Marcia, & Cindy Marin

Maryanne Clark in memory of Timothy Roberson

Alyosha Zim in memory of Joshua Zim

Natalio DeLaTorre in memory of my wife: Virginia DeLaTorre

Mary Louise Mongan in honor of David Hack, Pam Silverwood, & Rae P. Haynes

Mary Termini in honor of Tom Miller

Richard Marasso in memory of Joshua & Lynne Cohen

Bette Watkins in honor of Pam Cochrane

Susan Gubisch in honor of Dean Link

Connie Hurst in honor of Sharon Schaeffer