

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

### HDSA NorCal Chapter Annual Convention

## Connect, Interact and Learn in Sacramento on May 5

By Andrea Hanson-Kahn, HDSA NorCal Board Member

The 2018 Northern California HDSA Chapter Convention will take place on Saturday, May 5, 2018, at the UC Davis Medical Center in Sacramento.

Families will come from Sacramento, the Bay Area, the Central Valley, and beyond to experience camaraderie, encouragement, and hope, and to learn from experts from UC Davis, UCSF, Stanford, Kaiser Sacramento and Kaiser San Jose. **All are welcome to attend and we hope to see you there!**



You can register at:

<http://northernca.hdsa.org/about/norcal-chapter-convention-2018>

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### HDSA 33rd Annual National Convention in LA, June 7-9, 2018

## Opportunity: Learn, Share and Interact with HD Experts and Families

By Therese Crutcher-Marin, HDSA NorCal Board Member

For the first time, The Huntington's Disease Society of America Annual Convention is in California, June 7-9, 2018, at the Los Angeles Airport Marriott. The hotel is fully renovated and provides a complimentary airport shuttle from LAX.

This year's convention promises to be the most interesting ever as the Research Forum will include the latest about the IONIS/Roche and WAVE Life Sciences gene lowering trails.



You can register at: <http://hdsa.org/about-hdsa/annual-convention/>

*(continued on page 4 - HDSA 33rd Annual National Convention)*

## **Big Day of Giving** May 3, 2018

See page 3 to learn more!

## *Event Calendar*

- May 3 Big Day of Giving
- May 5 Northern California Chapter Annual Convention
- June 7-9 HDSA 33rd Annual National Convention
- Sep. 8 Team Hope Walk, Sacramento
- Oct. 13 Team Hope Walk, San Francisco

(Click event title to learn more)

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## President's Message

By Martha Lehman, HDSA NorCal President

Happy Spring Everyone!

*First, I would like to thank R.B. (Dick) Hackenberg for his past two years of service as the President of the Chapter and continued service on the Board of Directors. Dick did a marvelous job and leaves big shoes to fill.*

And now, I would like to take this opportunity to introduce myself as the new President of the Northern California Chapter.

I have been a member of the Northern California Chapter Board of Directors for the past 15 years. I joined the Sacramento Support group about 2 years prior to that following my mother's diagnosis of HD with a CAG of 40. This was the first we had known of HD in our family since both of my maternal grandparents lived to old age with no symptoms, so I had a lot of adjustments to make and a lot to learn about this disease.

The support group was the best thing that happened to me at that period of my life, and I met the most special people I have ever known. **I continue to marvel at the strength, perseverance, and bravery, of the people affected by this disease, and the families committed to their care. Truly heroes, every one of them.**



**There is a lot to be excited about regarding happenings with HD research.** The IONIS trials have had good and optimistic results in stopping and or slowing the progression of the disease. Hopefully further trials will continue to show positive results and we will have a breakthrough in treatment.

The Northern California Chapter is looking forward to several upcoming events, including the Chapter's Annual Convention on May 5, 2018. It will be held in the same venue as last year at the Education Building at the U.C. Davis Medical Center. **Please put the Convention on your calendar and plan to attend, as it will be a day filled with knowledge, beneficial to those affected and Caregivers. Also, you get a FREE lunch!!!!** There will be a flyer coming out about the Convention very soon so watch for it in your mailbox.

**Another event to save the date for, is the annual Team Hope Walk which is scheduled for September 8, 2018 at the River Walk in W. Sacramento.** We hope to have more information on the Walk to provide you at the Convention. Hope to see you at the walk in September!

*The Northern California Chapter is looking forward to several upcoming events, including the Chapter's Annual Convention*

Lastly, **we are planning a wine tasting event sometime in the fall of this year.** There will be more information forthcoming on this event as we make progress in the planning.

Last but not least, **I am mentioning these fundraising events not only to inform you, but to ask for your willingness to volunteer at one, or all of these events. Volunteers at these events contribute to their success and it is fun to help out.** As you know, the money raised from these events goes to Research and Family Services so we all benefit from the money made from these endeavors.

**If you have a skill or talent you want to share with the Chapter in the course of Fundraising, please let me know.** My email address is [mle1556680@aol.com](mailto:mle1556680@aol.com)

and I would love to hear about your desire to help or consider any ideas you have for other fundraising events.

I am looking forward to the next twelve months as leader of the Chapter and working with such a marvelous group of individuals. **I hope to have an opportunity to meet as many of you as I can and look forward to seeing you at the Annual Convention on May 5th.**

## The Big Day of Giving - May 3, 2018

The HDSA Northern California Chapter requests your support on May 3rd by making a donation to help us continue our mission work. *“To improve the lives of everyone affected by Huntington’s disease.”*

2018 is the first year the chapter will participate in The Big Day of Giving, a 24-hour giving challenge that brings together the region’s nonprofit community to help raise much needed unrestricted funds and shine a spotlight on the work nonprofits do for our community.

### To Donate:

- Please go to:  
<https://www.BigDayofGiving.org/HDSANorCalChapter>
- Click **DONATE NOW** in upper right-hand corner.
- Make your donation.
- An official tax receipt is emailed to you within minutes of the transaction.
- Now smile and know you are helping make a difference in the lives of those affected by HD.

*The Northern California Chapter Board of Directors  
thank you for your support and donation.*



**Big  
Day of  
Giving**  
May 3, 2018

*(continued from page 1 - HDSA NorCal Chapter Annual Convention)*

A complimentary continental breakfast will kick off the event, followed by the first workshops of the day.

### You’ll have four workshop options:

- Discussing how to manage challenging behaviors in HD with Dr. Khandhar, Ameer Jaiswal and Veronica Chanchola.
- Learning about advocacy and clinical trials with Jeanette Garcia and Amanda Martin.
- Talking about being at-risk with Natasha Boissier and Jamie Fong.
- Considering HD and the family: relationship changes and talking to children about HD with Lisa Mooney and Elle Tadina-Siau.

If you’d prefer to engage your body instead, Shannon Fritz will be leading a session called, “Yoga for Every Body.” Bring your yoga mats along!

**The second set of workshop options:** • HD 101 and Genetic Testing by Dr. Witt • Considering what happens after one is gene positive with Dr. Duffy • A session for caregivers about learning to increase your support system with Lisa Mooney and Elle Tadina-Siau • Exploring advanced directives and power of attorney with Kathryn Casey.

The lunch hour will afford opportunities to connect with old friends, meet new people, or perhaps talk with one of the workshop presenters. **Neurologist Vicki Wheelock, from the UC Davis Center of Excellence, will conclude the day by bringing us up to speed on the latest updates in HD research.**

Additional details including agenda, location and parking are available on the Northern California HDSA website at <http://northernca.hdsa.org>. **There is no fee to attend, but advance registration is required.**

**You can register at:** <http://northernca.hdsa.org/about/norcal-chapter-convention-2018>

**Or contact Lisa Kjer-Mooney at (916) 734-6277.**



*(continued from page 1 - HDSA 33rd Annual National Convention)*



*2017 HDSA National Convention*

Last year I represented the Northern California Chapter, and the theme “Family is Everything” resonated with attendees as they interacted with researchers, medical professionals and families who understand the challenges of HD. The feeling of “not being alone” provided the same comfort HD families find at HD support groups and Centers of Excellence.

**If possible, try to attend, as you will walk away with hope in your heart, the latest information about HD and renewed energy to fight this horrific disease.** Video recording and slide presentations from the convention are available following the event. **To view the 2017 presentations:**  
<http://hdsa.org/about-hdsa/annual-convention/2017-2/>

**HDSA offers Convention Scholarship opportunities. But don't wait. Applications must be received no later than midnight, Wednesday, April 4, 2018.** To see if you qualify, go to:  
<http://hdsa.org/about-hdsa/annual-convention/>

- Scroll down to the section titled SCHOLARSHIPS.
- There are two different scholarship applications, one for California residents and the other for non-California residents.

**Here is the 2018 Convention At-A-Glance:** Three Days of Education, Family Fun and Camaraderie. More details regarding the convention will be posted at  
<http://hdsa.org/about-hdsa/annual-convention/>

- **Thursday Evening:** Team Hope Walk; Welcome Reception; Exhibit Hall
- **Friday:** Opening Keynote; Educational Workshops; Community Awards Luncheon; Nya Talent Show
- **Saturday:** Research Forum; Educational Workshops Convention Gala

To get an idea about all the activity, networking, and camaraderie you will experience at the Convention, watch the 2017 convention video in Schaumburg, Illinois: <https://youtu.be/ZLR3M61Q5Uk>

## **Support Group Meetings for Northern California**

### **Chico**

3rd Tue every odd month,  
(Jan, March, May, etc.)  
6:30 pm – 8:00 pm

### **El Cerrito**

*(For Caregivers Only)*  
4th Tue each month,  
7 pm – 8:30 pm

### **Mill Valley**

3rd Thu each month,  
7:00 pm – 8:30 pm

### **Palo Alto**

2nd Tue each month,  
7 pm – 8:30 pm

### **Sacramento**

2nd Wed each month,  
7 pm – 8:30 pm

### **Santa Cruz**

3rd Wed each month,  
7 pm – 8:30 pm

### **Santa Rosa**

2nd Mon each month,  
7 pm – 8:30 pm

### **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 support group information, including address location and facilitator information, visit HDSA-Support-Groups at:**  
[hdsa.org/about-hdsa/support-groups/](http://hdsa.org/about-hdsa/support-groups/)

**Life with HD Series - Part 1****Running for My Life and HD****By Leilani Dunmoyer**

Until about twelve years ago I had a seemingly “perfect” life as a stay at home mom with a wonderful husband and three awesome kids. I enjoyed running and participating in everything from 5k races to marathons as social outlet and to keep healthy. My parents lived nearby and would often help out with the kids so I could get a run in. My mom retired from a lifetime of nursing and being a missionary in South Africa with my dad. It was awesome to have them follow me to California once they left the mission field. My mom worked as a nurse at Mercy San Juan Hospital, eventually starting up their home health program.

Over time I began to see symptoms in my mom, Marian, that I tried to ignore. Things like involuntary movement and slurred speech and behavior out of the norm. I was worried because her sister (10 years older) had similar symptoms that had progressed, and I had vivid memories of my mother’s mother (my Grandma) who had very advanced symptoms when I met her.



*Leilani's Brother Derek and Mother Marian*

I remember a woman who was belligerent, and couldn’t feed herself, dress herself and could only communicate with grunts. This was a far cry from the independent, single 23-year-old college graduate that had traveled to Africa as a pioneer missionary and translated the Bible into several languages.

There had never been a diagnosis for my Grandma. They had called it “hardening of the arteries”, but now that it was impacting my mother and my aunt I was worried that this was something affecting the women in my family. Shortly afterwards, my oldest cousin (the daughter of my mom’s sister) was diagnosed with Huntington’s Disease. Finally, a name was given to

this mystery disease. My relief turned to dread as I read all I could about in on the Internet.

Thankfully I was able to get an appointment with Dr. Wheelock at UCD and her amazing team at the center of excellence. Finally, in the summer of 2009, the HD diagnosis was confirmed. Now I knew I also had a 50% chance of also having HD.

I wrestled with the decision of whether or not to be tested, but for the 50% chance that I didn’t have the gene, I felt it was worth it. Having three kids, I knew how freeing it would be if I found I didn’t have it.

On 12/2/2009 the phone call came confirming my worst fears; I too had the gene, and while not symptomatic, it was a matter of time.

My dad passed away in 2011, and soon after my brother, Derek, was diagnosed with HD (symptomatic). This was especially tragic because he had just celebrated 10 years clean and sober and was working as a drug and alcohol counselor. He was alone and no longer able to work.

I was looking for a way to create awareness for HD and to raise some money for research, but the only thing I really knew how to do was run! I was scheduled to run the Boston Marathon in April 2011, but found out about a “Team HD” that was participating in the San Diego marathon in June of that same year as a fundraiser through the San Diego HDSA chapter.

**[\(continued on page 6 - Life with HD Series - Part 1 - Running for My Life and HD\)](#)**

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I knew I was supposed to do this! It was awesome to put information about HD out there in a “safe” way without being too preachy or obnoxious. Social media was a great resource. The article that my friend (name) wrote for the HDSA San Diego chapter newsletter is reprinted below with permission.

I discovered that running was an amazing outlet for me on many levels. The health benefits are great, and I’m hoping that it will delay my HD symptoms for a long time! Emotionally it also is a great stress reliever. Getting outside and enjoying God’s beautiful creation allows me time to meditate, pray and get my focus right. Being able to raise money and awareness too, is just icing on the cake! The friends I’ve made through running have served as my therapists, my sounding board, and cheerleaders.

I ran the NYC marathon in 2014, this time raising money on my own, and was able to raise \$7,000 for the UC Davis stem cell clinic run by Jan Nolta. She and her team are tirelessly trying to find a cure for HD.

I’ve decided that it’s time to lace up my shoes for HD again, so this year, Lord willing; I plan to run the local Sacramento marathon (California International Marathon CIM) on December 2nd to raise money for HD. I hope to put together a team, so any runners out there, please join us! There is also a relay division so if you don’t want to run 26.2 miles, you can run or walk 6 miles instead.

*I’ve decided that it’s  
time to lace up my  
shoes for HD again, so  
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Sacramento marathon*

Living with HD isn’t the life I asked for or envisioned, but I’m grateful for the gifts it’s brought me. My mother is 85 years old (wow!) and I love being able to read to her, enjoy chocolates with her (her favorite!) and appreciate the good times. I also hang out with my brother each week and marvel at the fact that he still rides his bike 12 miles a day.

I’ve learned I can’t run away from HD, but for as long as I can I’ll keep running to stave off symptoms, bring awareness to HD and try to raise a little money along the way.

## **Life with HD Series - Part 2**

### **San Diego Rock ‘n’ Roll Marathon - Run for Your Life**

**By Don Ford**

Running for your life is a phrase we hear now and then. Lots of different ways we can use it. But for Leilani Dunmoyer, she takes it literally. She ran the San Diego Rock n’ Roll marathon in 2016 to raise money to help find a cure for Huntington’s Disease (HD).

In her own words: “HD has touched me personally in a way that I cannot deny. Almost two years ago my world would forever be changed as I found out that my mother has HD. Her mother died of the disease, and her sister is in final stages. I also have a cousin who is suffering with HD.

After much prayer and support from my husband Dan, I decided to get tested to see if I had the gene. It was worth it for the 50% chance that I didn’t have it. In December of 2009 my worst fears were realized. I have the gene, and now each of my 3 children has a 50% chance of also having it.”

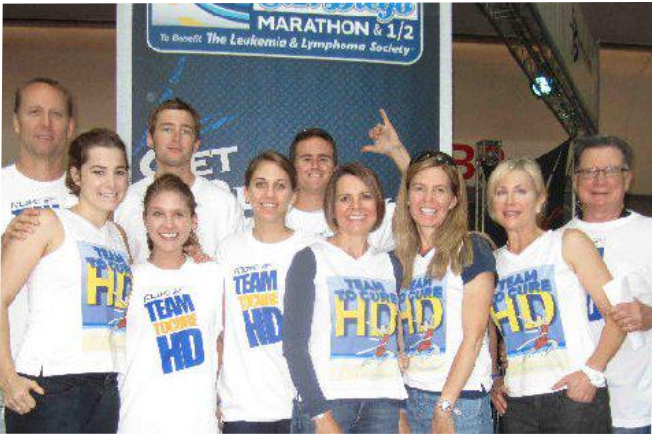
She had run the Boston Marathon six weeks earlier. Her time was 3:42:46. But San Diego was for more than just running a good time. She was running for her life, hoping they will find a cure for HD.

Again she talked about her experience: “I arrived in San Diego and found the “Team HD” folks who I had only met via phone or e-mail. We got our group picture taken and then I was on my way.

*(continued on page 7 - Life with HD Series - Part 2 - San Diego Rock ‘n’ Roll Marathon - Run for Your Life)*



*(continued from page 6 - Life with HD Series - Part 2 - San Diego Rock 'n' Roll Marathon - Run for Your Life)*



*Leilani and Carla*

“Race day came early; up at 4:10 and in the shuttle by 4:45. Skies were clear, and we could tell it was going to be a warm day. I was there with my friend Carla Gottardi who was also running the marathon as a fundraiser for Huntington’s Disease.

“The start went really smoothly, and we never felt like we were in a big crowd. There were several Elvis’ running around us, along with a guy in a bow tie and Speedo. Ah yes, the Rock & Roll Marathon!

“I felt great for the first 17 miles. Even the long climb up the freeway went really well, so my muscle memory of the Boston hills must have come in handy!

Marathon once told me I was running super consistent 8-minute mile splits. I knew I couldn’t sustain that for the whole race, but I enjoyed it while I could! He was running the Galloway method, so I’d see him from time to time. He ended up finishing ahead of me by 1-½ minutes.

“The sun started really hammering away, and my times were slowing. I ended up walking through all the water stops and taking about two one-minute walks per mile. I saw the 3:30 pace group and then the 3:40 pace group pass me.

“I just kept thinking that I was doing this for HD and would remind myself of all the people that had donated a total of \$6,300 for the cause, and that kept me going!

“When finish was in sight I found the strength to kick it and passed a few people. I saw the clock ticking close to 3:40, so even though that time was a minute off my actual time, I was determined to come in under 3:40!

“My actual time was 3:38:47 and I was 8th in my age division. I couldn’t believe that I had run my 2ndmarathon in 6 weeks without getting hurt during the race! I was thrilled to have had the opportunity to do something to raise awareness and money for HD.

“I want to say thanks to everyone on the team for supporting me by spreading the word about HD, encouraging me to persevere, and helping financially. I am proud to be a part of such an amazing group of people.”



*Leilani*

See page 3 to learn more!

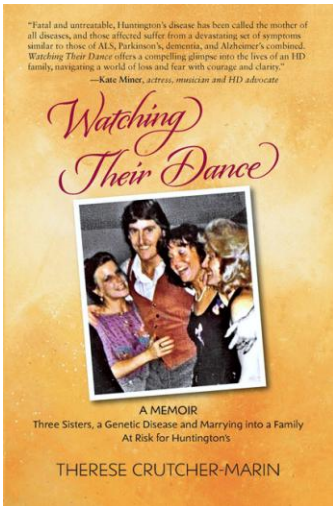
**Book Project Update**

**Watching Their Dance... Earns \$9,000 for HDSA!**

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

Last year I told you about my book project to generate funding for HDSA: *Watching Their Dance: Three Sisters, a Genetic Disease and Marrying into a Family At Risk for Huntington's Disease.*

It's a family love story, chronicled over 38 years of living in the shadow of Huntington's disease. It's about mindfulness, hope, forgiveness, and unconditional love to enrich our daily lives despite the stress and heartbreak of HD. All proceeds are being donated to HDSA.



**Published in April 2017, the book sold 1,577 copies by the end of the year—976 eBooks (Kindle, Nook, Kobo, iBook) and 601 paper books—earning \$9,015 for HDSA.** The goal is 5,000 units via social media platforms (Facebook, Twitter, and Instagram) plus my Author Website blog and book tours. Last summer, my husband John and I traveled the Midwest, and this year we'll promote the book in California, Oregon, Washington, and Canada.

**Here's a special Free Gift offer for 2018: If you purchase the book at [ThereseCrutcherMarin.com](http://ThereseCrutcherMarin.com), you will receive a dozen "Help Fight HD" wristbands and bookmarks to share with family and friends.**

Book marketing experts say word-of-mouth is the number one book selling strategy.

**When HDSA received our check for \$9,015, CEO Louise Vetter sent a thank-you email, and offered us the same opportunity to sell the book at this year's Convention.**

We look forward to seeing you at the HDSA National Convention, June 7 - 9, 2018, at the Los Angeles Marriott.

**In every book I sign, I write:  
We Can Never Lose HOPE.**



***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 # 22-2942362.

**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://facebook.com/hdsanocal/>



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

## Honorariums and Memoriams

An anonymous donation in memory of Lawrence Zaroff, MD • Susan J Lanzinger in memory of James Shearer • Gordan M Stevenson in memory of Thomas Habersack • Edward Cohen in memory of Lynne Cheryl Cohen • Alexandria Manesis in memory of her husband: John A. Manesis • Mary Louise Mongan in memory of Hack, Kadera, & Collins families • An anonymous donation in memory of Wesley A. Paine • Del & Louise Freeman in memory of Bob Nelson and in honor of Rick Nelson • Audie Dahlgreen in memory of Mary Nishihara • Virginia DeSouza in memory of her husband: John DeSouza • Beverly Robertson in memory of David Robertson • An anonymous donation in memory of her father, brother & sister • An anonymous donation in memory of Alma Swisher who died in 2017 • Pauline Giordano in memory of Barbara Lynn Giordano • Keith A. Crowther in memory of Gail M. Lohse • Casey Gagnon in memory of Jeff Johnson • Mary Termini in honor of Tom Miller • Kathleen Romeo in honor of Angie Allen • Don & Gail Wallace in memory of Judy Roberson's Mom and Tim Roberson • Jean Metcalf in honor of Michael Scott • Audie Dahlgreen in memory of Ray Jerry Lane • Jim & Sandi Gettle in memory of Ursula Anzalone

Thank You for your generous support of HDSA  
Your support makes a difference.

 **Big Day of Giving**  
**May 3, 2018**

See page 3 to learn more!