

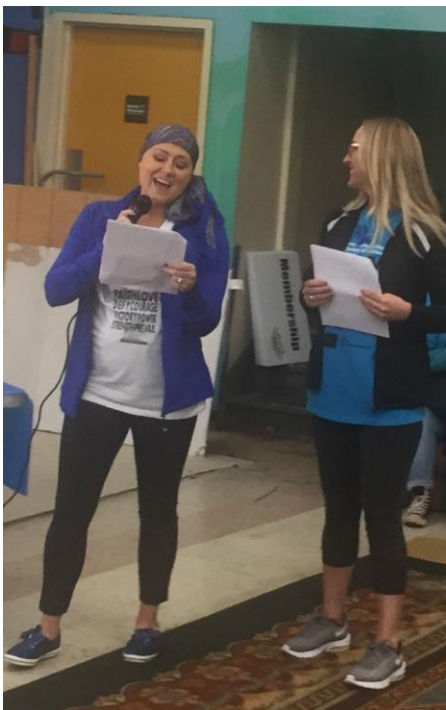
Huntington's Disease Society of America Northern California Chapter

Amy Fedele Named HDSA Person of the Year for 2017

At the June 22-24, 2017, Huntington's Disease Society of America (HDSA) National Convention in Schaumburg Illinois, Bay Area resident and NorCal Chapter Board Member Amy Fedele was named the HDSA Person of the Year.

For the past four years Amy has been a leader in raising awareness and funding for HDSA family services and research. She and her best friend Heidi Ramos met at TEAM HOPE WALK-San Francisco in 2015, and decided to team up to lead the fight against HD in the Bay Area.

She has been active in planning and running major events raising more than \$400,000 including THW-SF, I AM STRONG, The Great Gatsby Gala, Fighting HD One Sip at a Time, The Sacramento Winemaker's Dinner and other events.



Amy Fedele (left) and her friend Heidi Ramos brief hundreds of HD patients and their families at October's Team Hope Walk—SF

The HDSA PERSON OF THE YEAR AWARD symbolizes what HDSA is all about. It honors an individual, usually a person with HD, whose courage, dignity and fighting spirit inspire others living with HD.

Amy's success in fighting HD is even more remarkable considering that she was diagnosed with breast cancer in 2016. Because of her activities and personal health, she was unable to attend the convention so Heidi accepted the award on her behalf. Their teamwork and dedication inspire all who know and work with them.



Heidi Ramos (center) accepts the HDSA Person of the Year Award for Amy Fedele, with HDSA Chairman Arik Johnson and CEO Louise Vetter

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From the President

By RB Hackenberg

At the recent Kaiser Permanente-UC Davis Health HD Education Day in Sacramento I had the privilege of addressing HD families, and I appealed for their participation in Enroll-HD, a worldwide observational study for Huntington's disease families.

There are three goals: (1) to make new discoveries about how HD affects the mind and body; (2) to develop a global database of people with HD or at risk of HD who might eventually be interested in volunteering for studies that test new drugs; and (3) to compare the way people with HD are currently cared for in different parts of the world. You can find more information at <https://www.enroll-hd.org>.

November is when we send our Research Appeal and we hope you, your family and friends will consider a donation for Research Only. You will receive an email and/or direct mail message.

Your contribution will help to fund the HDSA Human Biology Project, a patient-centric research strategy to enable critical HD projects to push the field closer to meeting our goal of identifying effective therapies to slow the progression or onset of HD.

You can send a check or donate online at <https://goo.gl/a5i4jm>

The HDSA NorCal Board thanks you, your families and friends for your participation in care giving, research studies and helping to find a cure. We wish you a Happy Thanksgiving and year-end holiday season.

Warmest regards.
Richard

Did You Know...

- Huntington's disease (HD) is named after Dr. George Huntington, who, in 1872, described it in a paper he wrote called On Chorea.
- Approximately 30,000 Americans have HD, that's 1 in every 10,000 Americans, and more than 250,000 others are at-risk of having inherited it from a parent.
- In 1993, researchers identified the gene that causes HD.
- The Huntington's Disease Society of America (HDSA) was founded in 1968 by Marjorie Guthrie, wife of folk end Woody Guthrie who lost his battle with HD in 1967.
- HDSA is the largest non-profit volunteer organization dedicated to improving the lives of everyone affected by Huntington's Disease.

Sacramento Winemakers' Dinner Celebrates Social Workers and Hope

By Dawn Green

On August 14, four remarkable Huntington's Disease Social Workers were honored for their dedication and hard work to improving the lives of HD families in Northern California.

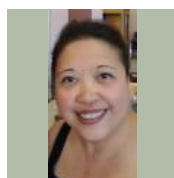
They are Natasha Boissier, UCSF; Amee Jaiswal, Stanford Health; Lisa Mooney, UC Davis Health & HDSA; and Elle Tadina-Siau, Kaiser Permanente.



*Natasha Boissier,
LCSW-UCSF*



*Lisa Mooney,
LCSW-UC Davis and
HDSA Northern CA*



*Elle Tadina-Siau, MSW
Kaiser Permanente*



*Amee Jaiswal,
LCSW-Stanford*

The event raised more than \$7,900, thanks to 75 attendees and generous sponsors: Kaiser Permanente, UC Davis Health, Vicky Wheelock, MD, FusionStorm, TEVA Neuroscience, and Country Club Optimists.



The 12th annual dinner was Emceed by Tina Macuha of Good Day Sacramento.

More than 75 guests enjoyed great food and wine at Rubino's Ristorante in Rocklin.



The evening was joyful and filled with **HOPE**.

NorCal Chapter Convention: A time to Learn and Share Hope

By Andrea Hanson-Kahn

On May 20, 2017, there was hope amongst the HD community gathered in Sacramento. Families came from near and far for the annual Northern California Chapter Convention to meet new people, share in each others' journeys, and learn about a range of topics: managing HD, care giving, genetics, increasing mobility, future planning, being at risk, clinical trials and cutting-edge research. The realities of life with HD were addressed and tackled with honesty and in community.



(l to r) Terry Tempkin, ANP, MSW,
Convention Director Les Pue and
Dr. Vicki Wheelock, UC Davis Neurologist

Keynote Speaker Dr. Vicki Wheelock Neurologist at UC Davis Health gave a HD Research Update: Progress in Disease Modifying Therapies, and now retired Terry Tempkin, ANP, MSN provided Reflections on a Career in the World of HD.

For his courage and community participation, Rick Bielawski was named HD Person of the Year by the Roberson Foundation. NorCal Board Member Martha Lehmann received the George and Marna Parks Award for her service to the Northern California HD Community. And, Past President Les Pue (now retired), was recognized for his decades of service including 20 years as Chapter Convention Director.

One attendee said, "This is the 14th convention I have attended. Every time I go, I meet new people and feel a sense of HOPE. I love seeing the new attendees and knowing they have found a place to learn and find tools to deal with HD."

Another commented, "The convention helps us to stay informed about research, family services and care giving. Additionally, we have met so many brave HD families over the last 10 years and look forward to seeing them each year as well as the medical personnel who provide such wonderful care."



Chapter Secretary Martha Lehman
(right) receives the George and Marna
Parks Award for Service to the
HD Community



Dr. Wheelock with HD Person of the Year
Rick Bielawski

Thank you to the many who helped make the convention a success--the speakers who voluntarily gave of their time, sponsors, those who worked in the background on logistics, setup, food, parking, registration, and to each of the attendees whose presence alone gave hope to others.

We look forward to seeing all of you again at the 2018 Chapter Convention!

RESEARCH UPDATE

(Edited from Scotland's Third Force News)

Cure for Huntington's Disease within reach

Researchers claim they are on the cusp of a cure

By Robert Armour



Dr Ed Wild

A cure for Huntington's disease (HD) is within reach, a charity conference has heard. Dr Ed Wild, one of the world's leading researchers into the degenerative neurological condition said research into treatments for the condition was now on a "knife edge."

Wild outlined how several particularly exciting drug programmes were now moving into advanced stages.

He told the delegates at the annual Scottish Huntington's Association (SHA) conference: "In my career working with HD I've never been more excited," he said. "Not only is research into effective treatment making real progress, but the way the condition is perceived has changed beyond all recognition."

"When I first started working with HD patients it was very much a disease hidden away, people did not want to talk about it. Now people are signing up for worldwide clinical trials and openly sharing their stories to increase understanding. It really is beginning to step out of the shadows."

The latest drugs in development aim to reduce production of the faulty protein created by the genetic change that causes HD. The treatment aims to allow the brain to repair damaged cells; it is hoped this will have the effect of slowing down the rate that symptoms develop... It is estimated there are around 1,100 people living with HD in Scotland and between 4,000 to 6,000 potentially at risk.

"HD is often called the most curable incurable disease, because unlike other neurological conditions, such as Alzheimer's, we know exactly what causes it, we just didn't know how to treat it, I strongly believe we are now moving in the right direction," added Dr Wild.

From the UK, a Poem about HD

The Huntington's Disease Association UK serves England and Wales. At their recent Annual General Meeting, similar to our HDSA National Convention, Lauren Tuhill, 15, from Uckfield, read her poem. Her mother Tracie is a Facebook Friend of Board Member Therese Crutcher-Marin.

By Lauren Tuhill

I was two and a half when my story began,
The day I said goodbye to my beloved nan,
She was only 58 when she passed away,
And this unfortunately happens everyday,

My mum cared for her throughout her childhood,
She did everything for her for as long as she could,
This year she raised exactly £3000,
With family and friends all gathered around.

This disease is cruel and mean,
It all begins with a faulty gene,
It damages the nerve cells that are in your brain,
Attacking and invading them again and again,

It's not like a cough, or an ache or a sneeze,
This is a dreadful hereditary disease,
You lose control, there's no improvements,
A lack of emotion, speech and fidgety movements,

However, you can go into a home,
with support and care,
And nurses, family will always be there,

There will always be people
with experience and knowledge,
And no matter who you are,
you will always be acknowledged,

There are support groups, for family and friends,
So the help provided, will never end,
Look around you now, we have each other,
You have good friends, why not make another?

Huntington's is powerful, there is no cure yet,
But we are all strong, let's not see it as a threat,
If we work together and never give in,
I know that one day it will be us that will win,

You've got to stay strong, put a smile on your face,
You still have a life to live and embrace,
So please, let's all raise a glass,
And kick Huntington's arse!

Life with HD – Audrey Weiland and the K/P NorCal Clinic

By Lynn Mundell

(Used with permission, from Look Inside KP Northern California)

Audrey Weiland has seen 5 generations of her family threatened by Huntington's disease. But her multidisciplinary team at Kaiser Permanente has been there to help her live life to the fullest.



Pictured above, Audrey (in light blue) surrounded by her care team

Audrey Weiland fills each day with giving.

The long-time Vacaville resident, 66, serves meals to homeless people. She joins her church in providing communion to people too sick to attend services.

A few years back, she even donated a kidney to a stranger.

All of this would be commendable in typical circumstances. But Audrey has Huntington's Disease, a fatal genetic disorder passed from one generation to the next like a debt that will never be paid off.

A retired widow who lives independently, Audrey is not alone. She has her remaining family who dodged

Huntington's — and her large team of specialists at the Kaiser Permanente Northern California Genetic Movement Disorder Clinic located in Sacramento.

A 'Cruel' Disease

Huntington's causes the progressive breakdown of nerve cells in the brain. Over time, it affects the individual's ability to reason, walk, and speak. The clinic's coordinator, genetic counselor Mara Sifry-Platt, termed it "cruel."

Every child of a parent with the disease has a 50-50 chance of carrying the faulty gene. If they do, symptoms usually appear between the ages of 30 to 50 and worsen over the next 10 to 25 years. There is no cure. Ultimately, the sufferer succumbs to pneumonia, heart failure, or other complications.

Audrey remembers her family caring for her grandmother. "No one knew what it was or even wanted to talk about it." An aunt and uncle were symptomatic very early in life. Her mother suffered from the disease, and 3 siblings passed away within 15 months.

While 90 to 95 percent of people at risk decide not to learn if they will develop Huntington's, by her early 30s Audrey went to a geneticist and received the tragic news. It wasn't until she was almost 60, however, that the disease's shadow appeared.

"The changes come so gradually, until you realize one day that you have balance issues, cognitive problems, odd facial expressions and hand movements," she said.

(continued on page 7)

(continued from page 6 - Life with HD)

All Care Under One Roof

Audrey is a 30-year Kaiser Permanente member and one of approximately 100 Kaiser Permanente Huntington's patients in Northern California using the clinic. Additional visitors include those who need screening, family members looking for resources, and patients with other genetic movement disorders. The clinic has the prestigious distinction of being a Huntington's Disease Society of America Center of Excellence in partnership with U.C. Davis.

"We have the most extensive multidisciplinary Huntington's Disease clinic in the country, which has been recognized by the Huntington's Disease Association of America," said clinic medical director, neurologist Suketu Khandhar, MD. "Our integrated approach means a multitude of providers can improve upon a patient's condition."

Patients visit a minimum of once a year, but can come more often. Not only do they see neurologists, geneticists, social workers, psychiatrists, and a physical therapist, but they have easy access to other specialists they need: speech therapists, occupational therapists, palliative care professionals, and financial assistance advisors.

"We are trying to keep these patients as well and strong for as long as we can," said Sifry-Platt. "Part of that is our group summary of recommendations tailored for each patient."

The clinic's team has seen Audrey through deepening symptoms, the death of her beloved husband, and now her upcoming decision about what she will do when she can't live alone anymore.

Audrey has even participated in a U.C. Davis research study on the disease — in the hope that there will be a cure one day for a future generation.

"I'm prepared — not scared," Audrey said. "I don't feel angry or bitter. I just want to bring more awareness and help people understand Huntington's."

"I can't describe how inspiring Audrey is to all of us," Dr. Khandhar said. "Whenever I am facing something of great impact, I ask myself, 'What would Audrey do?'"

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

National Youth Alliance–

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

YouTube Videos –

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

Heredity Disease Foundation –

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/>

TEAM HOPE WALK—SAC

A Summertime Success

By RB Hackenberg



*Sacramento DJ Joey Mitchell Starts
Team Hope Walk—Sacramento*

On a beautiful summer morning 120 walkers, 40 volunteers and another 50 plus friends and family members gathered at William Land Park in Sacramento for the annual Team Hope Walk—Sacramento.

The event was emceed by Radio Personality Joey Mitchell, on the air for more than 40 years, and known as "The Best DJ in Sacramento" on station 101.5 K-Hits! His first hand experience with HD is meaningful and reassuring to the HD families of Northern California.

Thanks to hard work by volunteers like Joey whose voice and colorful commentary go along way to making THW-SAC a special event, the NorCal Chapter raised more than \$34,000, achieving 96% of goal, from walk registrations, raffle, silent auction and food service.

The event honored Dr Lorin Scher, MD, UC Davis Health for his commitment to HD patients and families. Dr. Scher's clinical interests include: Psychosomatic Medicine (consultation-liaison psychiatry), Emergency Psychiatry, Behavioral Health Integration within Primary Care, Telepsychiatry Implementation in Primary Care, and Neuropsychiatry, specializing in Huntington's Disease.



*Dr. Lorin Scher (r) is congratulated by
Richard Hackenberg and Dawn Doster*



*The Bosick Family remembers
Emil, Kay and Olivia*

Key sponsors were Kaiser Permanente and UC Davis Health, along with Kohl's, Wal-Mart, Landmark Limited, Country Club Optimists and Tony Graupensberger.

The annual THW-SAC is a major event by the HDSA Northern California Chapter, and we thank everyone who participated as a sponsor, exhibitor, walker, volunteer and supporter.

At The 2017 HDSA National Convention: In The Fight Against HD, Family Is Everything

By Therese Crutcher-Marin, Author, HDSA Northern California Board Member.

The 32nd HDSA National Convention, held in Schaumburg, IL, June 22-24, was the second stop in 15-event book tour my husband John and I made during June-August 2017. We were impressed at the families, the professionals and the workshops—all validating the HDSA mantra Family Is Everything.

Earlier in the year I had published my book “Watching Their Dance,” a tribute to John’s three sisters who had succumbed to HD. In our new RV we traveled the back roads and highways of America’s Heartland; Illinois, Indiana, Iowa, Michigan, Missouri, Ohio, Wisconsin with corn/soybean fields on both sides of the road and many RV Parks in the middle of cornfields.

Friday, June 22, 2017–Convention Day One

The morning session featured Let’s Move With Shana Verstegen, an inspirational speaker who shared her story of how HD brought her family closer together. She’s a fitness guru, focusing on movement, strength and she offers HD Workout Tips on HDSA.org under Living With HD.

<http://hdsa.org/hd-workout-tips/>

Improving Quality of Life Through Healthy Living by Dr. Danny Bega, Director of HDSA Center of Excellence at Northwestern University, emphasized how to take control in your life through healthy living--exercising, staying active, participating in therapies, eating nutritiously and using natural products. <https://vimeo.com/223217810>

There were two sessions on Palliative Care At The End Of Life. Having worked in Hospice, talking about end-of-life is not easy, but families can find comfort knowing hospice services are available when their loved one has six months or less to their life. Here’s a video on Hospice Care.

<https://youtu.be/IFjLGYSOlfU>

Our commitment to donate all book proceeds to HDSA allowed us to sell my book Watching Their Dance: Three Sisters, a Genetic Disease and Marrying into a Family At Risk for Huntington’s. The response was wonderful. To date we have sold 1,300 units (books and Kindle) with approximately \$5,000 in donations to HDSA.

<http://theresecrutchermarin.com>

Late Friday afternoon attendees were privileged to be the first to watch the new hour long HDSA Film: Her Mother’s Daughter. All HDSA Chapters will receive a DVD of the film. <http://hdsa.org/HMDfilm/>

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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.

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

(continued from page 9 - At The 2017 HDSA National Convention:)

Friday evening's National Youth Alliance (NYA) Talent Show was a treat watching the brave, confident young people perform in front of hundreds. The proceeds from this event support NYA Convention Scholarships.

Saturday, June 23, 2017–Convention Day Two

At breakfast we heard–Update on HD Research--by Dr. Ed Wild, MD, PhD and Clinician Scientist, University College of London, Institute of Neurology and Jeff Carroll, PhD, Assistant Professor, Western Washington University. Excellent news from Ionis Pharmaceuticals that the Phase 1 Clinical Trial for gene silencing drug was successful, and the U.S. will be included in Phase 2. Dr. Wild said that in the last 12 months, research has moved closer to a cure.

<http://hdsa.org/about-hdsa/annual-convention/2017-2/>

The Clinical Trials Showcase & Luncheon was about Enroll-HD, WAVE Life Sciences, STAIR, and HD TrialFinder. I attended Meet HDSA's Board of Trustees, and saw a breakout of HDSA 2016 Revenues of \$10.1 Million: Family Services 25%; Research 22%; Education 15%; Management 12%; Chapter Development 12%; and Fundraising 12%.

Many excellent presentations have been posted on HDSA.org for those not able to attend the convention.

(Visit Annual Convention url above to view presentations.)

After the convention, John and I headed to Madison WI to attend the Midwest Log Rolling Championship Fundraiser for HDSA on July 1. Shana Verstegen, who gave the Keynote Address at the convention, hosted the event. John and I continued on our book tour for two more months and had 12 additional book signing events. I can now mark "book tour" off my bucket list, but I may do another next year.

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

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/>

NorCal Chapter Announces Three New Board Members

At its quarterly board meeting in July, the HDSA Northern California announced the election of three new members: Wendy Hill, Heidi Ramos and Amy Fedele.



Wendy Hill

Wendy has a Masters in Health Administration and is a retired healthcare professional having been a manager at Kaiser Permanente for 28 years. She was a Hospice Volunteer at K/P, is a licensed Esthetician and has a Massage Certificate. She cares for her son who is HD-positive.

See the HDSA Person of the Year story (*on page one*) to learn about Amy Fedele and her best friend Heidi Ramos. They are “the dynamic duo” and have teamed up to raise hundreds of thousands of dollars for the HDSA mission of improving the lives of everyone affected by HD.

Heidi works for Pacific Gas & Electric in the Gas Operations Contract Management Department. Amy is an Account Manager for a transcription company and volunteers at the Oak Tree Animal Hospital in Danville.

The Board is better and stronger with Wendy, Heidi and Amy.



Heidi Ramos and Amy Fedele

Honorariums and Memoriams

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.

Louise Freeman in memory of my son Rick and my husband Bob

Tom & Lou Mongan in memory of Barbara Ford Hack

Wanda June Timmons in memory of Joe Del Strickland, James Strickland, & Walter Strickland

Lisa M. Scott in honor of Michael Scott

Susan Lanzinger in memory of James Shearer

Wayne Achziger in memory of Regina Achziger

An anonymous donation in honor of Cheri Harries & Penny McMasters

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

An anonymous donation in honor of Alma Swisher

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

Casey Gagnon in memory of Jeff Johnson

Dale F. Johnson in memory of Maggie Pue

Thank You for your generosity