

## Spring/Summer 2016

### Team Hope Walk Raises \$24k for HD Family Services and Research

On a warm spring Saturday morning, June 4, 146 people from the Sacramento area assembled at William Land Park for the Huntington's Disease Society of America (HDSA) Northern California eighth annual Team Hope Walk.

This year's event raised \$24,000 to provide those affected with Huntington's Disease and their families with support services, and the ongoing funding of research programs to find treatments and a cure for this neurological degenerative disease.

Team Hope is HDSA's largest national grassroots fundraising event, with thousands of communities across the U.S. walking together to support more than 250,000 people affected by Huntington's disease (HD).

Sacramento's Team Hope Walk is a family friendly event, with live music, food, ice cream, a raffle and free activities for kids. This year's host emcee was HDSA Northern California Vice President Dawn Doster.

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### Gene Silencing, New Therapies and Gene Editing at HDSA Northern California Chapter Convention

*George and Marna Parks Award to Terry Tempkin, NP-C, MSN*

Sacramento, CA--The 2016 HDSA NorCal Convention held on Saturday, May 21, at UCDMC M.I.N.D Center featured presentations by medical professionals from all three Northern California HDSA Centers of Excellence.

The 2016 George and Marna Parks Award for the most significant contribution to HD family services and research went to Terry Tempkin, NP-C, MSN.

The afternoon Plenary Session began with Alexandra Nelson, MD, PhD, providing an optimistic update on the IONIS Antisense Oligonucleotides in HD clinical trial (gene silencing) in Canada and Europe. This trial may be extended to the U.S. next year.

Vicki Wheelock, MD, at UCDMC reported on new therapies and on PRE-CELL, their observational lead-in stem-cell therapy study, the next step of which may be a large animal trial. Veronica Santini, MD



*HDSA NorCal Presidents with The Marna and George Parks Award winner. From left to right: Richard Hackenberg, current president, Dawn Doster and Les Pue, past presidents; Terry Tempkin and Judy Roberson, past president.*

Convention Continued on page 2

### THW Continued

Other Board members volunteering for this fundraising event included Louise Burke, Martha Lehmann, Max Moon, Mark Stigge and Diane Olsen. If you are interested in volunteering or joining the board please contact Board President Richard Hackenberg, [hackenbergs@comcast.net](mailto:hackenbergs@comcast.net).

*The Huntington's Disease Society of America is the premier nonprofit organization dedicated to improving the lives of everyone affected by Huntington's disease. From community services and education to advocacy and research, HDSA is the world's leader in providing help for today and hope for tomorrow for people with Huntington's disease and their families.*



### Convention Continued

with Laurice Lang, MD presented important values in nutrition and exercise. And Kyle Fink, PhD, presented gene-editing strategies.

The morning breakout sessions included Managing Challenging Behaviors, Juvenile HD, Planning the Future, Challenges in Late Stage HD, Clinical Trials and Advocacy, Mindfulness and Movement-- Yoga for Patients and Caregivers, At Risk Discussion and Considerations for Predictive Testing.



### President's Corner

*By Richard Hackenberg, Chapter President*

#### **NorCal HD Convention Reflects Positive Progress; Consider ENROLL-HD**

The 20th annual NorCal Chapter Convention at UCDMC on May 21, was a big success with presentations by professionals from all three Northern California HDSA Centers of Excellence. The presentations are available on the UCDMC website --

<https://www.ucdmc.ucdavis.edu/huntingtons/patients.html>.

Board Member Les Pue, doing his usual excellent work, has managed all 20 conventions. It was my first as President having succeeded Dawn Doster, currently our Vice President. I joined the Board after my late wife Mary was diagnosed HD positive in 2010. It was a surprise as we did not know it was in her father's family, since he was not symptomatic.

Sadly, Mary left us last August, but the progress we've seen in the past several years is amazing, and while we provide Help for Today, there are very HIGH HOPES for tomorrow.

One of the reasons for the high HOPES is that awareness of HD has grown exponentially as have the research efforts during the past five years. May was HD Awareness Month, and we hope many of you shared your stories in ways that worked for you.

**Continued...**



*Members of Team Mark Vincent Palmer Walking at the 8<sup>th</sup> Annual Sacramento Team Hope Walk on June 4, 2016.*

## Resources for HD Families

### Information/Research

- HDSA Research--  
<http://hdsa.org/hd-research/a-leader-in-global-hd-research/>
- Enroll-HD--  
<https://www.enroll-hd.org/learn/about-hd/?enrollid=43be5528e3e364de124a0d460afb7bc1>
- 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--  
<https://hdinsights.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)

### HDSA Centers of Excellence in Northern California

- UC Davis Huntington's Disease Center of Excellence
- Alexandra Nelson, MD, PhD | UCSF Memory and Aging Center
- Stanford Center of Excellence/Huntington's Outreach Project for Education at Stanford  
<http://hopes.stanford.edu/>

### Documentaries

- The Lion's Mouth Opens (2014)  
<http://www.hbo.com/documentaries/the-lions-mouth-opens>
- <https://vimeo.com/ondemand/amindinquicksand>
- <http://twitchdocumentary.com/>
- <http://aliveandwellthefilm.com/>
- <http://www.doyoureallywanttoknowfilm.com/>
- <http://www.wehaveaface.org/#!/documentaryinformation/chqk>  
(The Huntington's Disease Project Removing the Mask—2015)

### Amazon Charity Program

- <http://smile.Amazon.com> search for Huntington's Disease Society of America N. California Chapter
- .05% of price of eligible purchases will go to the Chapter



### Convention Report Continued

The first reaction following an HD diagnosis is usually denial, but we all do better when we confront the reality. On this page of the newsletter is an HD Information Handout with many useful resources including six documentaries, all worth your time to see how others are confronting HD.

One relatively simple, yet important, way to participate in the process is to join ENROLL-HD. This worldwide study is for those who are HD positive and their families. You can enroll at UCDMC or UCSF. Here's a FAQ --  
<https://www.enroll-hd.org/learn/enroll-hd-faq/>.

Another way to participate is to volunteer to help at chapter fundraising events like the recent Team Hope Walk—Sacramento, and autumn fundraisers like Hounds for Huntington's and the Holiday Amaryllis Sale. We also hope that you and your friends will contribute to our Family Services and Research Appeals.

Enjoy the summer, watch for the Family Services Appeal and we'll provide another update in the Fall/Winter Newsletter. Thanks for all you do to take care of each other as together we seek more effective HD treatments and a cure.



## 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.*

Terry Ball in memory of Jim Gannon ~•~ David Yount in memory of Susan Yount ~•~ M. Lou Mongan in memory of Josie Hack ~•~ Marina Fernandez in memory of Beatriz, Fred & Horacio Flores ~•~ Arturo Mercado in memory of Gloria & Sarah Mercado ~•~ Katherine B. Liddington in memory of Ludger, Paul, Philip Leger and in honor of Philip Leger ~•~ Mark Stigge in memory of Melinda Rosenthal and in honor of Mary Stigge ~•~ Pamela & James Self in memory of Herbert Hillard and in honor of

Jan Hunter ~•~ Gordon Stevenson in memory of Tom Habersack and in honor of Charles of Alameda ~•~ Lucille Towner in memory of Lucille's sisters: Frances & Inez ~•~ Koaki B. Harris in memory of Karen E. N. Bailey & Edward W. Bailey ~•~ An anonymous donation in memory of Tim Roberson ~•~ Larry Sherwood in memory of Jerry Cake and in honor of John Cake ~•~ Chris Pfeifle in memory of Peter and Patti Pfeifle and in honor of Steve Pfeifle & Julia Pfeifle ~•~ An anonymous donation in honor of Cheryl Harries ~•~ Lisa M. Scott in honor of Michael V. Scott ~•~ Marilyn Walker in memory of Stanley & Dennis Walker ~•~ An anonymous donation in memory of Dale Seybold ~•~ Lois Smrtnik in memory of Bill Smrtnik ~•~ Virginia Desouza in honor of Strickland-DeSouza Families ~•~ Maureen Cornelia in honor of Dean Link & Mary Jane Genochio ~•~ Jeanette Schneider in memory of Jeanette's father and in honor of

her sister ~•~ Diana L. Gordo in memory of Jim D. Beasley and in honor of James V. Beasley ~•~ Mary E. Johnson in memory of Stan, Beth & Jeff Johnson ~•~ Alyosha Zim in memory of Joshua Zim ~•~ Jean Metcalf in memory of Martha, William, James & Lynne ~•~ Sandy Lazarz in honor of Tom Zahuranec ~•~ Jaqi Thompson-Ashgedon in memory of V. Opal Thompson ~•~ Susan Senser in memory of Janice Senser ~•~ Gordon and Lori Steel in memory of Margaret Pue ~•~ Douglas and Teri Devitt in memory of Karen Bjorklund ~•~ Justin Espinoza in memory of Papa Bill and our Mother, Janet ~•~ Wanda Timmons in memory of The Strickland family ~•~ Jane S. Miller in memory of Esther Shingledecker ~•~ Christian Roa in honor of Team Hedi Ramos ~•~ Christian Roa in honor of Team Hedi Ramos ~•~ Dawn & Ron Doster in memory of Mark Palmer ~•~ Shannon Fritz & Mark Stigge in memory of Mark Palmer.



## HDSA Northern California

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