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.

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
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.

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.

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.

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