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SAN FRANCISCO BAY AREA AFFILIATE

# IDSA VOLUNTEER NEWSLETT OCTOBER 2022

# SAN FRANCISCO TEAM HOPE **5K FUN RUN AND WALK**



#### CONGRATULATIONS FOR A GREAT TEAM HOPE WALK FUNDRAISER!

On Saturday, October 1st, we gathered at Sports Basement: Presidio in San Francisco for the San Francisco Team Hope 5K Fun Run and Walk, supporting HDSA's mission to improve the lives of people affected by Huntington's disease (HD) and their families.

Over 130 people registered in advance and 30 more people registered on the day of the event "I am so proud of the HD community showing up in this way proving once again how resilient, strong, and giving our HD families are," said Therese Crutcher-Marin, HDSA's San Francisco Bay Area Affiliate Chair. "And it was wonderful to be able to see people in person, share a hug and walk together in solidarity supporting HDSA."

We had great representation across all our partners and advisors, with representatives from our area Centers of Excellence, the HD National Youth Alliance, as well as several pharmaceutical companies and sponsors.

We shared a tearful moment when we honored Andrea Zanko for her years of service as a genetic counselor and as a leader of one of our local HD support groups. She touched so many lives, and was moved and touched by them in return. Thank you Andrea for all you've done and continue to do!

We're still tabulating the funds raised, but by the time the walk started we had surpassed our goal for the walk, and were several thousand dollars over the goal by the end of the day. Stay tuned for more information about the final results.

Special thanks go out to all our volunteers, our walkers, runners, donors, sponsors, Centers of Excellence advisors, and supporters! You really made a difference! THANK YOU ALL!

### IMPORTANT NOTE

Make sure that mail@HDSA.org is added to your email list so that you see all of the updates and events in your area!

### NEW AND NOTEWORTHY IN THE HD COMMUNITY

### **NEW CO-SPONSORS FOR THE HD PARITY ACT!**

For too long, individuals with HD have been forced to wait two long years after qualifying for SSDI benefits before they can access Medicare. It's past time we end this harmful policy and make sure that when an individual qualifies for SSDI, they receive all their benefits immediately. We welcome our newest cosponsors in California for the HD Parity Act: Tony Cadenas (D-CA), Jimmy Gomez (D-CA), and David Valadao (R-CA). Take action and get involved at: HDSA.ORG/TAKEACTION

### RESEARCH NEWS ROUNDUP

Get your science on and check out the latest information from HDSA's Dr. Leora Fox on her blog: This Week in Huntington's Disease Research - including a recap of summer HD news, and a discussion on HD research with HDBuzz editors and Help4HD host Lauren Holder.

#### HDSA ONLINE RESOURCES ARE AVAILABLE

HDSA invites you to take advantage of our world-class online support services - FOR FREE! From online support groups to telehealth, you can get the help you need from the comfort and safety of your home. Learn more and get support here.

# **UPCOMING HD EVENTS**



#### HDSA AMARYLLIS SALE BEGINS AT THE END OF OCTOBER

Additional details will be sent out shortly.

#### **UCSF HDSA CENTER OF EXCELLENCE - EDUCATION DAY**

UCSF will host an education day in December. Date to follow.

#### SIGN UP FOR THE RIGHT SUPPORT GROUP FOR YOUR NEEDS

Local HDSA online support groups are available to help families affected with HD.

#### EL CERRITO SUPPORT GROUP

Location: Sycamore Congregational Church - 1111 Navellier St, El Cerrito, CA 94530

Leader: Natasha Boissier 415-476-2904

Schedule: 4th Monday each month, 7:00 pm - 8:30 pm

#### PALO ALTO HD SUPPORT GROUP

Location: First Baptist Church - 305 N. California Street, Palo Alto, CA 94301

Leader: Andrea Hanson-Kahn 650-725-6571

Schedule: Second Tuesday of each month, 7:00 pm - 8:30 pm

These support groups are free, but we urge you to register in advance, as space is limited. <u>Here is the list of the upcoming meetings for this month</u>. Don't see the right one for you? Let us know!

# OTHER WAYS TO HELP THE HD COMMUNITY

#### PARTICIPATE IN HD RESEARCH FROM YOUR HOME

Researchers all over the world are seeking participants from the HD community to participate in survey-based studies on HD. Whether you have HD, are a care partner to someone with HD, a member of an HD family, or at risk for the disease, there is a study for you! <u>Click here</u> to see what survey studies are available and learn more about how you can get involved.

### **HDSA VEHICLE DONATION PROGRAM**

Avoid the hassles of selling or repairing your vehicle altogether when you donate it! All vehicle types are accepted. **Call 888-HDSA-151.** HDSA will tow your vehicle at no cost to you. You will receive a donation receipt and help us in our mission. <u>More information can be found here</u>.

#### AMAZON SMILE. YOU SHOP. AMAZON GIVES.

Shoppers who start at <a href="https://smile.amazon.com/">https://smile.amazon.com/</a> will find the same Amazon they know and love, with the added bonus that Amazon will donate 0.5% of the price of eligible purchases to the charity of your choice. Sign-up today and have your purchases benefit HDSA!

# **VOLUNTEERS NEEDED!**

The Huntington's Disease Society of America is recruiting volunteers for the San

#### Francisco Bay Area Affiliate Team.

If you have some time to give to a non-profit, please consider us! HD is a rare, fatal, genetic brain disorder with no cure. We can use your expertise, ideas, and creativity. Let us know if you'd like to step up and join a committee!

Please reach out to:

Uma Thontakudi, Volunteer Coordinator & Affiliate Co-Chair

Email: <u>umathont@gmail.com</u> Phone: (408) 772-7705

## STAY CONNECTED

### JOIN OUR NEXT SF BAY AREA AFFILIATE CONFERENCE CALL: Wednesday, November 2nd @ 7pm

Contact Therese Crutcher-Marin for meeting information: theresecrutchermarin@gmail.com

If you are interested in doing more for our Affiliate, please let us know!

# WE CAN NEVER LOSE HOPE...





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