

# SAN FRANCISCO BAY AREA CHAPTER

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# HDSA Volunteer Newsletter - July 2023

THANK YOU SAN JOSE TEAM HOPE WALK VOLUNTEERS!



YOU did it! Our first major fundraising event of 2023 is in the books! On Saturday, June 17th, we gathered in Campbell Park to hold the San Jose Team Hope Timed 10K Run & 5K Walk. We had over 100 participants, 15 event volunteers, and raised \$27,000.00 dollars to support our mission - to improve the lives of everyone affected by Huntington's disease and their families through our local support.

Above is a photo of some of our volunteers for the day. We just want to say a big "Thank you!" to each and every one of you who helped make the event a success. Check out more pictures of the event on <u>our Facebook page</u>, including pictures of us honoring Dr. Sharon Sha from the HDSA Center of Excellence at Stanford University. <u>SPECIAL SHOUT OUT TO OUR</u> <u>SPONSORS</u>! Thank you to all who helped sponsor this event.

Our next amazing IN-PERSON event will be held Saturday, October 14 at 9:00 AM at the Sports Basement: Presidio - 610 Old Mason Street in San Francisco, California. You won't want to miss

#### CLICK HERE TO REGISTER OR DONATE FOR THE UPCOMING SAN FRANCISCO WALK EVENT

For any questions, please reach out to Christine Greve, especially if you'd like to volunteer!

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

# NEW AND NOTEWORTHY IN THE HD COMMUNITY

#### **RESEARCH NEWS ROUNDUP**

Get your science on and check out the latest information from HDSA's Dr. Leora Fox on her blog: <u>This Week in Huntington's Disease Research</u> - including HD research updates for the HD Data Collection Initiative and HD Trialfinder, an article about A Golden Age for Biomedical Innovation, and a new entry of This Week in HD History.

#### NOW IS THE TIME TO REGISTER FOR THE 2023 NYA RETREATS

The National Youth Alliance Retreats are being planned for 2023. You can <u>find out more on their</u> <u>website and register there</u>. There are retreats planned in Louisville, KY, Denver, CO, and one in California (November 10, 2023 - November 12, 2023), but the location of the California retreat is not known at this time.

#### 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. <u>Learn more and get support here</u>. Not sure where to start? Reach out to one of our board members and we'd be happy to listen to your needs and point you in the right direction.

### **UPCOMING HD EVENTS**

#### MARK YOUR CALENDARS FOR THE 2023 HD EDUCATION DAY!

Our two area HDSA Centers of Excellence are combining forces for a blow-out 2023 Education Day Event on Sept 30th: it will be in person, but the location is still to be determined. There will be educational sessions, break out sessions, and some time to visit and network. Look out for more information about registration to come - we hope to see you there!

#### NORTH BAY, LET'S GET READY TO RUN/WALK - IN COSTUME!

<u>Registration is AVAILABLE</u> for our 2023 San Francisco Team Hope 5k Walk & Fun Run in San Francisco on Saturday October 14th. Our theme will be Heroes and Villains, so head over there now and set up your team today to start raising those much needed funds for our mission. You can also visit our <u>Facebook page</u> to stay in touch.

## Click here to sign up today!

#### 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: <u>Natasha Boissier</u> 415-476-2904 Schedule: 4th Tuesday 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: <u>Andrea Hanson-Kahn</u> 650-725-6571 Schedule: 2nd 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 THE HDSA DISABILITY/ADVOCACY SURVEY

We are still looking for MORE family's experiences with Social Security.

IF YOU or someone you know has applied, or IS applying for SSI or SSDI (Disability) we would like to know your experiences <u>via this survey</u>. Anyone can fill it out, even if they did not file for SSDI, but the more people who do, the more data we collect.

This data will be used to convince Congress to help with the administrative process, issues, concerns, challenges, etc. Its hard enough to have HD, love someone with HD, care for someone with HD or be at-risk for HD; that the disability process shouldn't add to that.

Please share with other family or friends that can offer their experience. Thank you in advance for you time and help in advocating for the HD community via this survey.

#### 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>.

#### SUPPORT HDSA WHILE YOU SHOP!

We have a partner in iGive that has been supporting HDSA and the nonprofit community for more than 20 years and we hope you'll give them a try! iGive allows you to shop at more than 2,000 stores online that provide DONATIONS to HDSA, just for doing your shopping with the iGive plug in on your browser! Later this year, we'll provide you the information needed to set up your donations to our chapter. In the meantime, you can <u>get started here.</u>

# STAY CONNECTED

#### JOIN OUR NEXT SF BAY AREA CHAPTER CONFERENCE CALL:

August 2nd, 2023 @ 7pm

Contact Therese Crutcher-Marin for meeting information: <u>theresecrutchermarin@gmail.com</u>

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

# WE CAN NEVER LOSE HOPE...



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