



HDSA Volunteer Newsletter - April 2024



April is National Volunteer Recognition Month

This month is a time to celebrate and recognize the contributions of volunteers who graciously give their time to the San Francisco Bay Area Chapter to help in the fight against Huntington's disease.

If interested in volunteering, the SF Chapter asks for 4-5 hours a month. Check out VolunteerMatch.org where SF Chapter volunteer positions are listed.

IMPORTANT NOTE:

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

NEW AND NOTEWORTHY IN THE HD COMMUNITY

SATVE ILANGO-HDSA SF BAY AREA CHAPTER SOCIAL WORKER

Satve's new HDSA contact information and phone number is:

HDSA Company number is: (212) 242-1968

Extension number is: 604
Direct line is: (650) 587-0988
Email: silango@hdsa.org

Bay area HD families in need of support may call or email Satve for assistance. More information will be coming through our social channels and this newsletter as we get to know this wonderful new resource person for the area.

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

Each week in Huntington's Disease research keeps you up-to-date on HDSA research activities, recently published work about Huntington's Disease, historical moments in HD, research and more.

HDSA NATIONAL YOUTH ALLIANCE (NYA)

Children, teenagers and young adults need support when born into a HD family. NYA is made up of young women and men ages 9-29 that are impacted by Huntington's.

The NYA's Mission is not only support young people within the HD community, but also inspire the youth of HDSA to get involved in the battle against HD and be proactive in this fight. Read more about <u>HDSA NYA</u>.

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. 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

TAKE ME OUT TO THE BALL GAME!

FUNDRAISER NIGHT @ SAN JOSE GIANTS!

On **June 29th**, join HD families at the historic Excite BallPark for a HD fundraiser called the Park Packer - where <u>you use this website link</u> to purchase tickets. The promocode to include is "HDSA". Can't you smell the hot dogs and popcorn already?

SAVE THE DATE FOR EDUCATION DAY - NORTHERN CALIF. CHAPTER!

The HDSA Northern California team have set **May 4th** as the date for the next HD Education Day, and the event is planned to be IN PERSON, in Sacramento. Email Lisa Kjer-Mooney for more information @ lkjer@hdsa.org.

HD AWARENESS MONTH PLANS ARE MOVING AHEAD!

Stanford and UCSF Centers of Excellence presented valuable information on December 2, 2023 and SF Chapter will be hosting a virtual online replay of the educational sessions in May for HD Awareness Month. On May 14th at 7 p.m., Dr. Dietiker's presents <u>Huntington's Disease</u>

Studies and Clinical Trial Updates as of December 2, 2023. On May 23rd at 7 p.m., Dr. Jiao's presents <u>Living Your Best Life with Huntington's Disease</u> and the doctors will be available for questions after each session.

REGISTER FOR THE SAN JOSE TEAM HOPE 10K RUN & 5K TEAM HOPE WALK

Mark your calendars for the 6th Annual San Jose Team Hope Run/Walk on **June 15th**. RecordTiming will time the runners who will start at 9:30 a.m. Walkers will start at 10 a.m. Come and have fun while helping in the fight against HD.

REGISTER FOR TEAM HOPE WALK HERE!

MARCH SUPPORT GROUPS

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

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

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

Leader - Natasha Boissier Phone: 415-476-2904

PALO ALTO HD SUPPORT GROUP

Schedule: Second Tuesday of each month, 7:00 p.m. - 8:30 p.m.

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

Leader- Andrea Hanson-Kahn Phone: 650-725-6571

These support groups are free, but we urge you to register in advance, as space is limited. All our chapter support groups are hosted on Hey Peers. Once you sign up, you can go in and register for any groups you are interested in. Join Hey Peers by clicking the link below and sign up for each group to get email reminders right to your inbox.

Click Here for *HEY PEERS!* Link

OTHER WAYS TO HELP THE HD COMMUNITY

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** (**888-437-2151**). HDSA will tow your vehicle at no cost to you. You will receive a donation receipt and help us in our mission

More Information on Vehicle Donation Here

STAY CONNECTED

JOIN OUR NEXT SF BAY AREA CHAPTER CONFERENCE CALL:

May 1st, 2024 @7pm

Contact Therese Crutcher-Marin for meeting information:

theresecrutchermarin@gmail.com

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

HDSA'S PROGRAMS & SERVICES

Get the help you need from the comfort & safety of your home.

Be sure to take advantage of HDSA's world-class HD programs & services - FOR FREE! Learn more at HDSA.org/support.

New HDSA Programs & Services Document

DOWNLOAD HERE

Click the links below to find support today:

HDSA Social Workers: HDSA.ORG/SOCIALWORKERS

Online Support Groups: HDSA.ORG/OSG

PatientsLikeMe: <u>HDSA.ORG/PLM</u>
Telehealth: <u>HDSA.ORG/TELEHEALTH</u>
HD Trialfinder: HDTRIALFINDER.ORG

HDSA's National Youth Alliance: <u>HDSA.ORG/NYA</u>
Youth Mentorship Program: <u>HDSA.ORG/YMP</u>
Disability Resources: <u>HDSA.ORG/DISABILITY</u>

Locate Resources in Your Area: <u>HDSA.ORG/LOCATERESOURCES</u>

WE CAN NEVER LOSE HOPE...





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