



Huntington's Disease Society of America



SAN FRANCISCO BAY AREA CHAPTER

HDSA Volunteer Newsletter - March 2024



WELCOME TO OUR CHAPTER SOCIAL WORKER!

The HDSA SF Bay Area Chapter is pleased and excited to welcome Satve Ilango, our new social worker for the Chapter. She has taken on this new role in combination with her social worker position at the Huntington's Disease Center of Excellence at Stanford.

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

We're so glad to have her join us! Bay area families in need of support may begin reaching out to Satve for assistance. More information will be coming through our social channels and this newsletter as we get to know the wonderful new resource person for the area.

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

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 information about new HD research studies being conducted by Design Science, Dr. Jody Corey-Bloom from the UC San Diego Center of Excellence provided some advice for the community around overcoming the bumps on the way to HD therapies, and the FDA granted orphan drug designation to SAGE-718.

MAKE A DIFFERENCE THROUGH ADVOCACY

It is not too late to participate in the HDSA Congressional Awareness campaign by writing a letter to your U.S. Representative and two Senators educating them about Huntington's disease and the challenges you and your family face. HDSA has made the process easy for you. Follow the link below to be taken to a letter template and guidance to assist you in writing your letter. The template provides an opening paragraph. Be sure to add your personal story below this opening.

Letter Template Available Here

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

MAY 4th DATE SET FOR EDUCATION DAY FOR NORTHERN CALIFORNIA!

The HDSA Northern California team is looking to host their next HD Education Day on the first weekend of May, and the event is planned to be IN PERSON, in Sacramento (details still being arranged). Our own HD Education Day for our local Bay Area Centers of Excellence has not yet been set, but we be sure to bring you news as soon as details are decided.

HD AWARENESS MONTH PLANS ARE MOVING AHEAD!

We had a few families turn out for our own HD Education Day in December last year at Stanford, but to make sure that the valuable information can still reach all our families, we will be hosting a virtual online replay of the educational sessions in May for HD Awareness Month. One video broadcast with Dr. Dietiker will be during the week of May 14th and the other one with Dr. Jiao will be the week of May 23rd. Final dates are not set but both broadcasts will begin at 7 pm. Dr. Dietiker's video is an update on clinical trials and Dr. Jiao is on Palliative care and the doctors will be available for questions after each video. Stay tuned to register and get all the details for the sessions we will be rebroadcasting for the community.

DO YOU WANT TO GET YOUR GAME ON?

Rebekah Granlund has secured June 29th for a fundraiser at the San Jose Giants for our Chapter! The fundraiser is called the Park Packer - where you purchase tickets in order to gain contributions allocated to our Chapter.

The promocode to include is "HDSA" and there will be a QR code available shortly!
June 29th is the date of the big game - don't miss it!

[Purchase Park Packer Tickets Here](#)

REGISTER TODAY FOR HDSA's FIRST QUARTERLY CEO WEBINAR OF THE YEAR

Join HDSA's President & CEO Louise Vetter on Wednesday, March 27th at 3pm (ET) for the first Quarterly CEO Webinar of the year!

[Register for CEO Webinar Here](#)

ARE YOU GOING TO CONFERENCE THIS YEAR?

Mark your Calendars for the 39th Annual HDSA Convention in Spokane Washington, May 30-June 1, 2024. *Registration is officially open!*

Register today to be a part of the magic of the HDSA Convention at the beautiful Davenport Grand Hotel in Spokane. We hope to see you all there!

[HDSA Convention Information + Registration 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.

PALO ALTO HD SUPPORT GROUP

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

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

Leader- Andrea Hanson-Kahn

Email: andreak@stanford.edu

Phone: 650-725-6571

EL CERRITO SUPPORT GROUP

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

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

Leader - Natasha Boissier

Email: natashaboissier@berkeley.edu

Phone: 415-476-2904

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:

April 3rd, 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: HDSA.ORG/PLM

Telehealth: HDSA.ORG/TELEHEALTH

HD Trialfinder: HDTRIALFINDER.ORG

HDSA's National Youth Alliance: HDSA.ORG/NYA

Youth Mentorship Program: HDSA.ORG/YMP

Disability Resources: HDSA.ORG/DISABILITY

Locate Resources in Your Area: HDSA.ORG/LOCATERESOURCES

WE CAN NEVER LOSE HOPE...



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