



# Huntington's Disease Society of America



**SAN FRANCISCO BAY AREA CHAPTER**

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## HDSA Volunteer Newsletter - April 2023



### **HDSA CENTERS OF EXCELLENCE NETWORK HAS EXPANDED TO 67 SITES**

This year the Huntington's Disease Society of America has expanded its HDSA Center of Excellence network of comprehensive care clinics with 56 grants totaling more than \$2 million. In addition to the 56 grant funded facilities, eleven regional partner sites were also named, ensuring expert HD care at 67 distinct medical facilities in 36 states across the nation and Washington, DC.

### **WHAT IS A CENTER OF EXCELLENCE?**

The HDSA Centers of Excellence are institutions that provide an elite team approach to Huntington's disease care and research. Patients benefit from expert neurologists, psychiatrists, social workers, therapists, counselors and other professionals who have extensive experience working with families affected by HD and who work collaboratively to help families plan the best HD care program throughout the course of the disease. Applications to become an HDSA Center of Excellence are open to all clinics in the United States who share HDSA's commitment to high-quality, comprehensive care and access to clinical research. [Learn more.](#)

In our area, we are lucky to have multiple HDSA Center of Excellence clinics — Stanford

University and the University of California-San Francisco. For information about specific study openings or appointments at our bay area clinics, contact UCSF [through their website](#) or by calling (415) 353-2057 and contact the Stanford clinic [through their website](#) or by calling (650) 723-6469.

Stay tuned to our Facebook page for more information, including dates for upcoming HD Education Days in 2023.

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**Make sure that [mail@hdsa.org](mailto:mail@hdsa.org) is added to your email list so that you see all the updates and events in your area!**

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## NEW AND NOTEWORTHY IN THE HD COMMUNITY

### **ALLISON BARTLETT, ESQ. HAS HEALTH INSURANCE TIPS FOR YOU!**

Check out the [blog over on the HDSA website](#) for helpful tips from Allison Bartlett, Esq, our national HDSA Disability Health Insurance expert. She covers what the different kinds of insurance and governmental support are available for our community, and can help clarify what can often be a challenging experience of navigating our healthcare system.

### **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 updates on the last participant completing the PROOF-HD study, compensated research survey opportunities through Rare Patient Voice, and a look back on This Week In HD History.

### **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.

## We want to hear from YOU!

The HD Parity Caucus needs info from those who have experienced applying for disability and the challenge they had.

Too many people living with HD are denied Social Security Disability Insurance (SSDI). HDSA is working to address this with the Social Security Administration and we need your help! Please fill out this survey if you or a loved one has filed for SSDI and share some information about your experience. [Click here to fill out the survey!](#)

Please share this with people you know and the larger HD community! The more people who complete this short survey, the more data we have to inform this work.



[Registration is ALREADY AVAILABLE](#) for our 2023 Team Hope Timed Run and Walk in San Jose on Saturday June 17th! So head over there now and start putting together your team today to start raising those much needed funds for our mission. You can also visit our [Facebook page](#) to stay in touch as we prepare to reveal our THEME for this year's event!!

**Click here to sign up today!**

## UPCOMING HD EVENTS

### REGISTRATION IS OPEN FOR OUR ANNUAL CONVENTION

Join us **June 1-3, 2023** in New Orleans, Louisiana for the **38th Annual HDSA Convention!** Register today to be a part of the magic of the HDSA Convention at the beautiful Sheraton New Orleans. [More information, rates, and registration is available at HDSA.org/convention](https://www.hdsa.org/convention) - we hope to see you there!

### 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 Tuesday of 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:** 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.

[Here is the list of the upcoming meetings for this month.](#) 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! [Click here](#) 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. [More information can be found here.](#)

### **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! Over the next month, we'll reach out and give you the information needed to set up your donations to iGive. In the meantime, you can [get started here.](#)

## SAVE THE DATE

### **SAN JOSE TEAM HOPE TIMED 10K RUN & 5K WALK**

Saturday, June 17th at Campbell Park in Campbell, CA

[Click here to sign up and start your team!](#)

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

Saturday, October 14th at Sports Basement Presidio in San Francisco, CA

Link coming soon!

## STAY CONNECTED

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

**May 3rd, 2023 @ 7pm**

Contact Therese Crutcher-Marin for meeting information: [theresecrutchermarin@gmail.com](mailto:theresecrutchermarin@gmail.com)

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

## ***WE CAN NEVER LOSE HOPE...***



408-253-7100 | [www.hdsa.org](#)

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