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Huntington's Disease Society of America



SAN FRANCISCO BAY AREA CHAPTER

HDSA Volunteer Newsletter - September 2023

JOIN US AND STRIDE WITH PRIDE!

If you were waiting
for a sign...
THIS IS IT.



On Saturday, October 14 at 9:00 AM we will gather for our 2023 San Francisco Team Hope 5k Walk & Fun Run at the Sports Basement: Presidio - 610 Old Mason Street in San Francisco, California.

Registration & Breakfast begins at 9:00 AM, with the Walk & Run kicking off at 10:00 AM. We will host a raffle and silent auction just as in years past, so come ready to peruse the items and pick your favorites!

Our theme is Heroes and Villains! So come dressed to impress (or distress!) as your favorite superhero/supervillain, or fairytale hero/heroine. After the run/walk returns to the Sports Basement, we will host a short program, and award the raffle and silent auction winners.

[CLICK HERE TO REGISTER OR DONATE](#) And visit our [Facebook page](#) to stay in touch.

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

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 HD research updates about Brain Donation for HD Research, Researchers at University of British Columbia studying new ways to deliver ASOs, and Ken Serbin, also known as Gene Veritas, discusses the FDA approval of INGREZZA.

DO YOU HAVE QUESTIONS ABOUT SOCIAL SECURITY AND DISABILITY INSURANCE?

Head over to the [HDSA YouTube channel](#) and check out Allison Bartlett, ESQ. - HDSA's Manager of Disability Programs. In the video called "Here's The Deal With Disability," In this episode, Jennifer Simpson, LCSW, sits down with Allison to discuss Social Security Disability Insurance (SSDI) & HD. Allison can be contacted at abartlett@hdsa.org to answer your questions about disability or visit [Ask Allison on the HDSA website](#).

TIME TO REGISTER FOR THE 2023 NYA RETREATS

The National Youth Alliance Retreats are being planned for 2023. You can [find out more on their website and register there](#). 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. [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

HDSA FOUNDERS DAY FUNDRAISER COMING UP!

56 years ago, on September 18, 1967, the Committee to Combat Huntington's Disease (CCHD) - which later became Huntington's Disease Society of America (HDSA) - was incorporated in New York state. At the helm, Marjorie Guthrie, the widow of folk musician Woody Guthrie, began a movement that continues to this day. Please [join us on September 18, 2023 for a special 24 hour giving day](#) dedicated to the legacy that Marjorie Guthrie left, the same one that continues for the entire HD community.

MARK YOUR CALENDARS FOR THE 2023 HD EDUCATION DAY on December 2nd!

Our two area HDSA Centers of Excellence are combining forces for a blow-out 2023 Education Day Event, but we've had to move the timing from September to December - so please adjust your calendar reminder to December 2nd. The day's program 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!

2023 SAN FRANCISCO TEAM HOPE 5K WALK & FUN RUN - HEROES AND VILLAINS!

Saturday, October 14 at 9:00 AM we will gather for our annual fundraiser for SF at the Sports Basement Presidio - 610 Old Mason Street in San Francisco, California. [Sign up today!](#)

SEPTEMBER 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

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

Leader: [Natasha Boissier](#) 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: [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

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! Later this year, we'll provide you the information needed to set up your donations to our chapter. In the meantime, you can [get started here.](#)

STAY CONNECTED

JOIN OUR NEXT SF BAY AREA CHAPTER CONFERENCE CALL:

Sept 6th, 2023 @ 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 AND SERVICES

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

Be sure to take advantage of HDSA's world-class HD programs & services - FOR FREE!

Learn more at [HDSA.org/support](https://www.hdsa.org/support).

[Download the new HDSA Programs & Services document here](#)

and click the links below to find support today:

[HDSA Social Workers: HDSA.ORG/SOCIALWORKERS](https://www.hdsa.org/socialworkers)

[Online Support Groups: HDSA.ORG/OSG](https://www.hdsa.org/online-support-groups)

[Patients Like Me: HDSA.ORG/PLM](https://www.hdsa.org/patients-like-me)

[Telehealth: HDSA.ORG/TELEHEALTH](https://www.hdsa.org/telehealth)

[HD Trialfinder: HDTRIALFINDER.ORG](https://www.hdsa.org/hd-trialfinder)

[HDSA's National Youth Alliance: HDSA.ORG/NYA](https://www.hdsa.org/national-youth-alliance)

[Youth Mentorship Program: HDSA.ORG/YMP](https://www.hdsa.org/youth-mentorship-program)

[Disability Resources: HDSA.ORG/DISABILITY](https://www.hdsa.org/disability-resources)

[Locate Resources in Your Area: HDSA.ORG/LOCATERESOURCES](https://www.hdsa.org/locate-resources)

WE CAN NEVER LOSE HOPE...



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