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Huntington's Disease Society of America

SAN FRANCISCO BAY AREA CHAPTER

HDSA Volunteer Newsletter - February 2025

Huntington's Disease Society of America

MEET OUR NEW PRESIDENT AND CEO

"I am honored to join the Huntington's Disease Society of America, an organization with a long history of dedication to families and individuals affected by Huntington's disease, I look forward to working closely with the HDSA team, its board, and the broader Huntington's disease community to continue to drive forward progress in research, advocacy, and support for families. Together, we will work toward a brighter future for those living with Huntington's disease."

- Amy Gray

We're thrilled to announce Amy Gray as the new President & CEO of the Huntington's Disease Society of America (HDSA), effective immediately! With over 20 years of experience in fundraising, operations, and patient advocacy, Amy's leadership will enhance our mission to improve the lives of those affected by Huntington's disease. Welcome aboard, Amy—we can't wait for this new chapter! Please click here to read the full press release.

THE HDSA PODCAST

The HDSA Podcast gives listeners an opportunity to meet members of the Huntington's disease community and get a behind-the-scenes look at the Huntington's Disease Society of America. A new episode will be released every month.

CLICK HERE TO ACCESS THE PODCAST!

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!

SOCIAL WORKER CORNER

INTRODUCING YOUR CHAPTER SOCIAL WORKER SATVE ILANGO, MSW

I wanted to use the first social work column to introduce myself to the community and highlight what I can assist you with.

My name is Satve, and I am your Chapter Social Worker! What can I help you with? Well, here are a few things below:

Social Work is available to provide education, information about resources, and support and consultation regarding mental health concerns.

We can help with education and information relating to but not limited to:

- Home caregiver options
- Insurance-related questions
- Assisted living options and adult day programs
- How to access mental health resources
- The components of advanced care planning
- Disability and the application process

Please feel free to give me a call or email me and I would love to help you in any way possible!

Phone: 650-587-0988
Email: silango@hdsa.org

NEW AND NOTEWORTHY IN THE HD COMMUNITY

POWERHD

JOIN THE POWERHD DATA COLLECTION PROGRAM

Patient and Caregiver reported Data Collection is critical to ensure that the patient’s lived experiences are captured to increase the understanding and impact that Huntington’s Disease has on individuals and families. Huntington’s Disease patients, families, and communities are coming together to collaborate and participate in this data collection effort to expand and improve clinical support and medical research.

By coming to the POWERHD Data Collection Program, you can begin the first step in collecting and sharing your insights and making your data available to researchers and other research partners now and well into the future. By generating the most comprehensive patient-driven Huntington's Disease data we can accelerate research and the development of new drugs, devices, or other therapies. You hold the key to unlock future discoveries.
Click here for more information

PLEASE SIGN UP FOR THIS YEAR'S SAN JOSE TEAM HOPE 5K TIMED RUN AND 5K WALK ON SATURDAY, MAY 17, 2025 AT CAMPBELL PARK, CAMPBELL, CA.

- **REGISTRATION OPENS AT 9:00 AM.**
- **RUN/WALK BEGINS AT 9:30 AM.**

SIGN UP HERE!

VOLUNTEER SPOTLIGHT - KEITH MARIN

San Francisco Bay Area Chapter Board member Keith Marin’s family has been personally impacted by Huntington’s disease with the loss of three of his aunts and a biological grandmother. Having a small family, these were important figures in his life growing up. There are two pieces that drive Keith to be a volunteer. One is general awareness. “The individuals who are impacted by this disease are not small and nearly all individuals who I talk to about HD (the first time) have never heard of it,” says Keith. He goes on to point out that “the second piece is one of the last parts of the body to fade with HD is the mind. So you are trapped watching your body decline and cannot change anything. This is heartbreaking and devastating.” He is hopeful that with volunteering we can find a cure.

Keith lives in Novato, California with his wife Frances (also a Board member) and their children, daughter Marlena (3) and son Jamie (15 months). He works in Finance/Analytics and is a beer connoisseur, a self-described “adrenaline junkie” and enjoys mountain biking.

VOLUNTEERS NEEDED - PLEASE CONSIDER JOINING US!

JOIN US IN THE FIGHT AGAINST HUNTINGTON'S DISEASE

“Volunteers do not necessarily have the time; they just have the heart.” - Elizabeth Andrew

VOLUNTEER HERE

UPCOMING HD EVENTS

UCI HD-CARE - *Community Seminar*

Guest Speaker – Dr. Sarah Tabrizi, Director of the University of College London Huntington's Disease Centre, Joint Head of the Department of Neurodegenerative Disease at the UCL Queen Square Institute of Neurology

February 19, 2025

4-5:30 PM - Seminar and Discussion
5:30 -7 PM - Reception
UCI Thorp Conference Center, Room 4001

FEBRUARY 19 AT 4:00 PM - COMMUNITY SEMINAR WITH DR. SARAH TABRIZI
Please join Dr. Sarah Tabrizi at the UCI Sue & Bill Gross Stem Cell Research Center, 4th Floor, 845 Health Sciences Road, Thorp Conference Center - 4001, Irvine, California 92697
SIGN UP HERE

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- Satve Ilango Phone: 650-587-0988

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:
MARCH 5th @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:

Local (San Fran) HDSA Social Worker:
Satve Ilango, HDSA Social Worker
silango@hdsa.org l (650)-587-0988
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...

Our mailing address is:
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