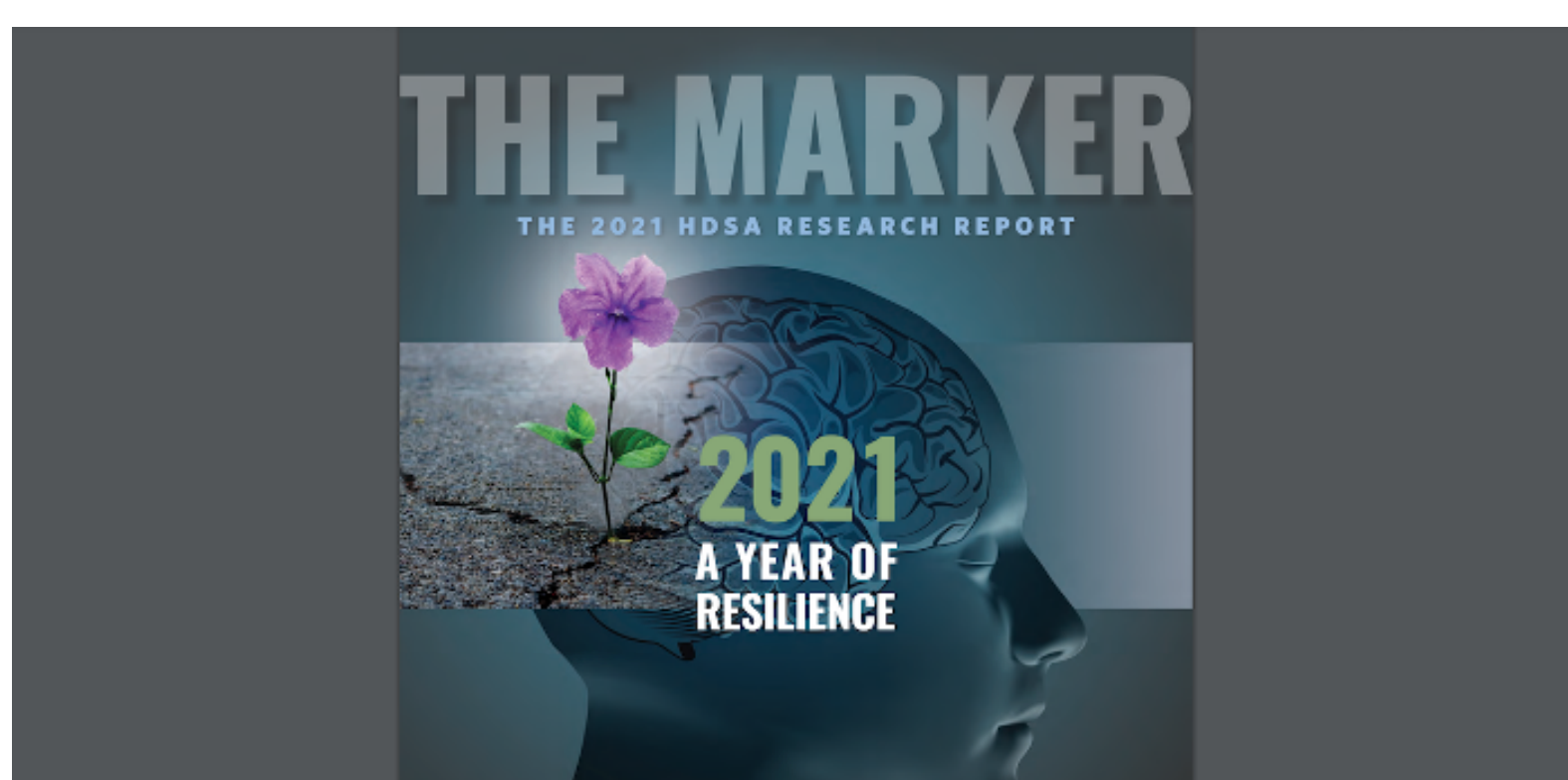




HDSA Volunteer Newsletter - February 2022



THE 2021 HDSA RESEARCH REPORT IS NOW AVAILABLE

Each year, HDSA creates a comprehensive end-of-year report about HDSA research activities and advancements in HD science, compiled in a downloadable resource called [THE MARKER](#).

The 2021 report contains a message from Louise Vetter, the President & Chief Executive Officer of HDSA, as well as news about fellowships, new programs, partnerships, updates from HD researchers, new therapy investigations, and other research underway - much of which is funded by HDSA or our industry partners.

From Mrs. Vetter's letter: "We hope that this 2021 edition of The Marker provides a renewed sense of optimism about the year to come and the scientific developments on the horizon."

Download your copy of the 2021 report on our national site at [HDSA.org](#).

NEW AND NOTEWORTHY IN THE HD COMMUNITY

THANK YOU TO ALL WHO PARTICIPATED IN OUR TOFFEE FUNDRAISER!

This January, [Kate's Toffee](#) and the San Francisco Bay Area Affiliate partnered in a 5-day fundraiser, the first of its kind for us. It was inspired by Therese Crutcher-Marin and her friend Kate - thinking that they could promote a small business in the SF North Bay while raising funds for HDSA and heightening awareness. After a short promotion period on Kate's website, Therese and her family mailed out 125 boxes of delicious toffee. All told, we raised \$1,050.00 to help in the fight against Huntington's disease for our Affiliate.

Thank you to all who participated, and if anyone has connections with another small business that would like to donate to a program like this in the future, just [let us know!](#)

THE LATEST ABOUT TOMINERSEN AND BRANAPLAM TRIALS

In a community letter released January 18th, Roche announced plans to continue developing the huntingtin-lowering drug tominersen. Read the [full announcement from Roche here](#), and watch the video of the [Community Presentation of New Tominersen Data here](#). HD Buzz also [published a great summary here](#). And in a community letter on January 27th, Novartis provided an update on the status of the VIBRANT-HD trial, which will test branaplam, an oral huntingtin-lowering drug, in people with Huntington's Disease. [Check out the community letter here](#).

TAKE ACTION TO INCREASE MEDICARE ACCESS FOR HD

In October of 2021, advocates from across the country met virtually with 34 Members of Congress, but their work alone won't win this fight. We need YOU to help build momentum. We need YOU to help finally pass the HD Parity Act. Sign up to show your support [on our Action Center page](#) now!

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 about Novartis's Trial of Branaplam and Roche's continued development of tominersen.

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](#).

UPCOMING HD EVENTS

SAVE THE DATE FOR OUR 37TH ANNUAL HDSA CONVENTION

Join us on June 9-11, 2022 at the Marriott Marquis in Atlanta, Georgia for our 37th annual convention! Following COVID-19 safety recommendations, we will be capping the number of in-person attendees and providing mandatory safety protocols. And if you are not able to make it to Atlanta, you'll be glad to know that every session throughout the HDSA Convention will be live-streamed - FOR FREE! For more information and to register for in-person attendance/hotel/scholarship, please visit [HDSA.ORG/CONVENTION](#).

STANFORD EDUCATION DAY COMING UP IN MARCH 2022

Stanford University will be hosting an HD Education Day/Session near the end of the first quarter of 2022. This educational event will contain valuable information about Huntington's disease, its progression and clinical presentation. The final date of the event is not yet decided, but is currently planned to be a virtual event. So [stay tuned to our Facebook page](#) to hear more information about the content and how to register closer to the event.

SIGN UP FOR THE RIGHT SUPPORT GROUP FOR YOUR NEEDS

HDSA online support groups are available to help families affected with HD. [Here is the list of the upcoming meetings](#) for this month. These support groups are free, but we urge you to register in advance, as space is limited. 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](#).

AMAZON SMILE. YOU SHOP. AMAZON GIVES.

Shoppers who start at <https://smile.amazon.com/> will find the same Amazon they know and love, with the added bonus that Amazon will donate 0.5% of the price of eligible purchases to the charity of your choice. Sign-up today and have your purchases benefit HDSA!

VOLUNTEERS NEEDED!

The Huntington's Disease Society of America is recruiting volunteers for the San Francisco Bay Area Affiliate Team.

If you have some time to give to a non profit, please consider us! HD is a rare, fatal, genetic brain disorder with no cure. We can use your expertise, ideas, and creativity. Let us know if you'd like to step up and join a committee!

Volunteer Coordinator: Uma Thontakudi

Email: umathont@gmail.com

Phone: (408) 772-7705

STAY CONNECTED IN THE NEW YEAR!

JOIN OUR NEXT SF BAY AREA AFFILIATE CONFERENCE CALL:

The First Wednesday of Each Month @ 7pm

Contact Therese Crutcher-Marin for meeting information:

theresecrutchermarin@gmail.com

If you are interested in doing more volunteering, please let us know!

WE CAN NEVER LOSE HOPE!



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