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STXBP1 disorders

— Science + L♥ve = Cure —

**Welcome to the August issue of the
STXBP1 Foundation Newsletter**

STXBP1 Meeting with



On October 20, the STXBP1 Foundation is bringing the STXBP1 patient community together for a first ever Externally-Led Patient-Focused Drug Development Meeting (EL-PFDD), to inform the FDA and other stakeholders about the patient perspective of living with STXBP1-related disorders. **We need testimonials from our community; we need to hear your voice!**

We are holding an informational session to help prepare our community for this important meeting, on September 7 at 4 pm ET. **Register [HERE](#) and learn how you can participate to make this meeting a success.**

More information on the EL-PFDD meeting can be found [HERE](#).



Move to Cure STXBP1 Disorders

[Register or Donate HERE!](#)

Be part of the global movement as the entire STXBP1 Community gathers near and far to **Move to Cure STXBP1 Disorders!**

Families and friends are encouraged to walk, run, hike or bike right in their own neighborhoods, at the end of September as part of STXBP1 awareness month. Keep it simple, and get Moving for a Cure!

Start a Team or Join a Team! Each individual registration includes Move to Cure STXBP1 Swag including new STXBP1 Socks!

Our goal is to raise \$100,000...with your help we know we can get there!

*Registration is open now through the month of September. To receive STXBP1 swag by the last week in September registration needs to be received by 9/18. Swag will be mailed after this deadline, but is not guaranteed to be received by the last week in September.



Custom Move to Cure STXBP1 Disorders Team Shirts!

Create custom team shirts (including toddler tees-option 2) [HERE!](#)

Share your custom team shirt link with friends and family, and get ready to Move to Cure STXBP1 Disorders at the end of September!

*To receive shirts by the last week in September, **orders need be placed no later than September 10th.**



Why September? September is the 9th month and the STXBP1 gene is on the 9th chromosome.

Follow us on social media and join in all month long as we spread awareness for this rare

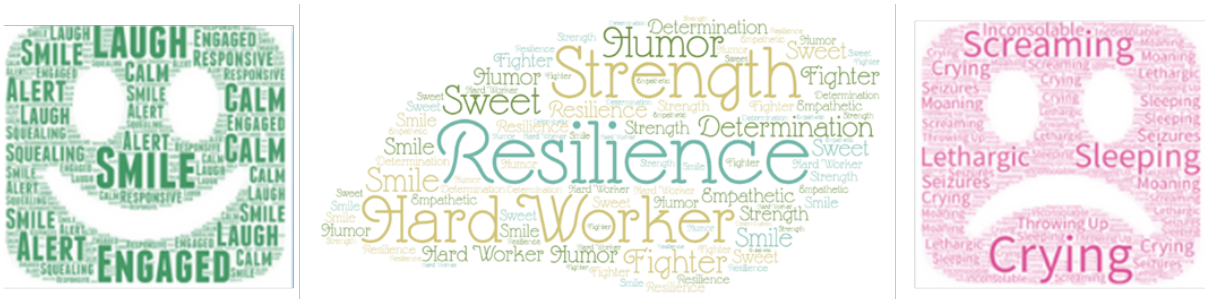
genetic disorder, keep up with the latest research, and bring the community together throughout the month with webinars, special content & the Move to Cure Event as the grand finale of [STXBP1 Awareness Month](#).



CALLING ALL RESEARCHERS!

Thanks to Lulu's Crew & The Million Dollar Bike Ride, two \$75,460 grants are available to advance research that supports therapeutic development for STXBP1 Disorders.

Letters of Intent DUE SEPT 15! More Info [HERE](#).



Inchstone Project Survey

The DEE-P research project, [The Inchstone Project](#), has launched a survey to identify the priorities of families who have a loved one severely impacted by a developmental epileptic encephalopathy. The goal is to better measure when our children achieve inchstones of progress in response to new therapies.

The project is specifically focused on meeting the needs of children and young people with severe to profound impairment, and therefore looking to hear from families whose children are:

a) Are at least 1 year old

AND

b) Have very **severe communication challenges** (largely or completely nonverbal and cannot communicate effectively even using nonverbal means)

And have either or both of the following:

c) **Severe challenges in mobility** (require a stroller or being carried, even in the home)

d) **Dependence on a feeding tube** for nutrition or **dependence on someone else to feed them.**

- Survey link is: <https://screen.inchstoneproject.org/>
- Our PAG access code is: PACT



Recordings available [HERE](#)

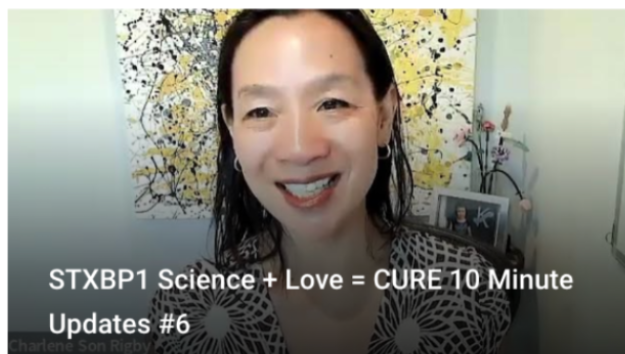
We are excited to share the recordings from the STXBP1 Summit+ Family Meeting in

Colorado...with the option of closed captioning.

So much GREAT information, and so much HOPE for the STXBP1 community!

Thank you again to all of our Amazing Sponsors, Volunteers, Presenters, Research Partners & Families who made this event truly memorable!

Science + Love = CURE Podcast Series



Our July Podcast #6 is Available to watch on YouTube >>>

Watch [HERE](#)

In this podcast, news on: the STXBP1 Family Summit in July, our new STARR STXBP1 Natural History Study, a call for additional Board Members, and a look forward to our annual Move to Cure fundraising event.



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