



#TSCstrong



Community Programs and Support Services in the Face of COVID-19

April 27, 2020



The Tuberous Sclerosis Alliance's Mission

The TS Alliance is dedicated to finding a cure for tuberous sclerosis complex, while improving the lives of those affected.

ESSENTIAL BUSINESS

Online Resources: www.tsalliance.org/COVID-19

WE'LL GIVE EVERYTHING. BUT UP.



Tuberous Sclerosis Alliance

HOME **EN ESPAÑOL** INTERNATIONAL REQUEST INFORMATION DONATE

ABOUT TSC NEWLY DIAGNOSED INDIVIDUALS & FAMILIES HEALTHCARE PROFESSIONALS RESEARCHERS DONORS



INDIVIDUALS & FAMILIES



COVID-19 & TSC Resources

Welcome to the Tuberous Sclerosis Alliance's (TS Alliance's) COVID-19 & TSC Resources page for people with tuberous sclerosis complex (TSC), their families and loved ones, healthcare professionals and others. Please visit this page often as we will continually update it as needed.



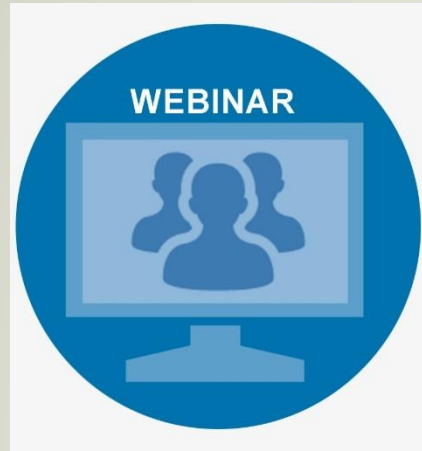
COVID-19 Community Education, Support and Awareness

Virtual Town Halls

- **March 20: TSC/LAM Virtual Town Hall: COVID-19 Update**, co-hosted with The LAM Foundation, featuring some of the world's top TSC and LAM physicians.
- **April 10: Virtual Town Hall: Accessibility to Care**, co-hosted with the Child Neurology Foundation and Dup15q Alliance.
- **May 1: Virtual Town Hall: Accessibility to Treatments (including Drug Supply)**, co-hosted with the Dravet Syndrome Foundation and LGS Foundation.
- **May 15: Virtual Town Hall: Rescue Meds, Seizure Tracker and a Future Glimpse at Forecasting Seizure Risk**, co-hosted with Seizure Tracker.



COVID-19 Webinars, Open Forums and Podcasts



Webinars

- **Topics:** Schooling at Home, Anxiety, Self Care, Research Updates, Remote Behavioral Interventions



Open Forums

- **Connect Online:** Platforms for caregivers, teens and adults with TSC to openly discuss issues related to COVID-19 and TSC



Podcasts

- **TSC Now Podcasts:** Updates on COVID-19 and interviews with the TSC community

Other Digital Initiatives During COVID-19



#TelecommutingTuesday

- **See Where We Work:** Each week a different staff member shows how we're working from home during the pandemic.



TSC Academy

- **Learn more about TSC and Research:** Online learning platform open to the entire TSC community. Learn more: www.tscacademy.org.



TSC Matters and Email

- **TSC Matters:** E-newsletter featuring news from the TS Alliance, TSC research updates, TSC clinical trials, upcoming TS Alliance events and more. Subscribe: tsalliance.org/tsc-matters/

Community Programs

Community Programs



Calendar of Events



| Event Date | NEW Date | State |
|----------------|-------------------------------------|----------------------------|
| April 4, 2020 | Saturday, September 12, 2020 | Scottsdale, Arizona |
| April 25, 2020 | Saturday, November 7, 2020 | Houston, Texas |
| April 26, 2020 | Sunday, October 4, 2020 | Seattle, Washington |
| May 2, 2020 | Saturday, September 26, 2020 | Manchester, Connecticut |
| May 3, 2020 | Virtual Walk – TBD | Washington, DC |
| May 9, 2020 | Saturday, September 26, 2020 | West Chester, Pennsylvania |
| May 9, 2020 | Saturday, September 26, 2020 | Carrollton, Texas |
| May 16, 2020 | Saturday, October 10, 2020 | Dacula, Georgia |
| May 16, 2020 | Saturday, October 3, 2020 | Galesburg, Illinois |
| May 17, 2020 | Sunday, October 4, 2020 | Middleton, Ohio |
| May 17, 2020 | Sunday, September 27, 2020 | Michigan |
| May 30, 2020 | Saturday, October 3, 2020 | Westmont, Illinois |
| June 6, 2020 | Virtual Walk – July 2020 | Muscle Shoals, Alabama |
| June 13, 2020 | Saturday, October 24, 2020 | Long Beach, California |

Visit www.stepforwardtocurets.org to register today!

RESCHEDULED



Benefiting
Tuberous Sclerosis Alliance

Sunday, October 18, 2020

Academy LA
6021 Hollywood Blvd., LA 90028
www.comedyforacure.org



Save the Date

4th Annual Minnesota Sound Bites
An Evening of Food, Libations and Music

Friday, November 20, 2020
@ 6 pm

The Metropolitan Ballroom & Clubroom
5418 Wayzata Blvd.
Golden Valley, MN 55416

For more information, please visit:
www.tsalliance.org/MNSoundBites

RESCHEDULED

Community Programs

TSC Awareness Month of Caring

launching May 1

<https://give.tsalliance.org/TSCstronger>

TSC Awareness Month of Caring

Fundraising Options



TSC Global Awareness Day

Visit tscglobalday.org for information on how you can raise awareness on May 15.



Shop TSC Swag Store



Visit

<https://www.kayedesignstudio.com/collections/tsc-swag-store>
to place your order!

Film and Share

#WearBlueChallenge



Upcoming Events



2020 Conference Series

August 1 – Memphis, Tennessee

October 17– Gainesville, Florida

October 24 – Denver, Colorado



Official Charity Partner of the
50th TCS New York City Marathon
Sunday, November 1, 2020

2020 Team TSC Members

Amanda Alberts, Shalonda Alexander, Bridget Faria, Jennifer Kuehn, Bridget Lucas, SHELLY MEITZLER, Heather Morris, Taylor Ryan, Sara Skelton, Elizabeth Taber, Suresh Thomas

Visit and Support

Team TSC

<https://give.tsalliance.org/TeamTSC>

Getting the Help You May Need

Peer Support Options

- Adult Regional Coordinators
- Dependent Adult Transition Resource Coordinators
- Education Parent Mentors

Newest Publication

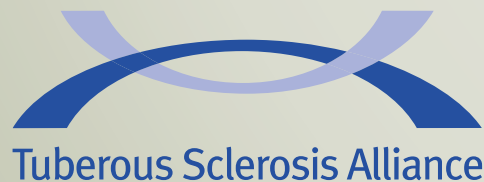
- Book of Sample Letters to Build a Paper Trail

Dust Off

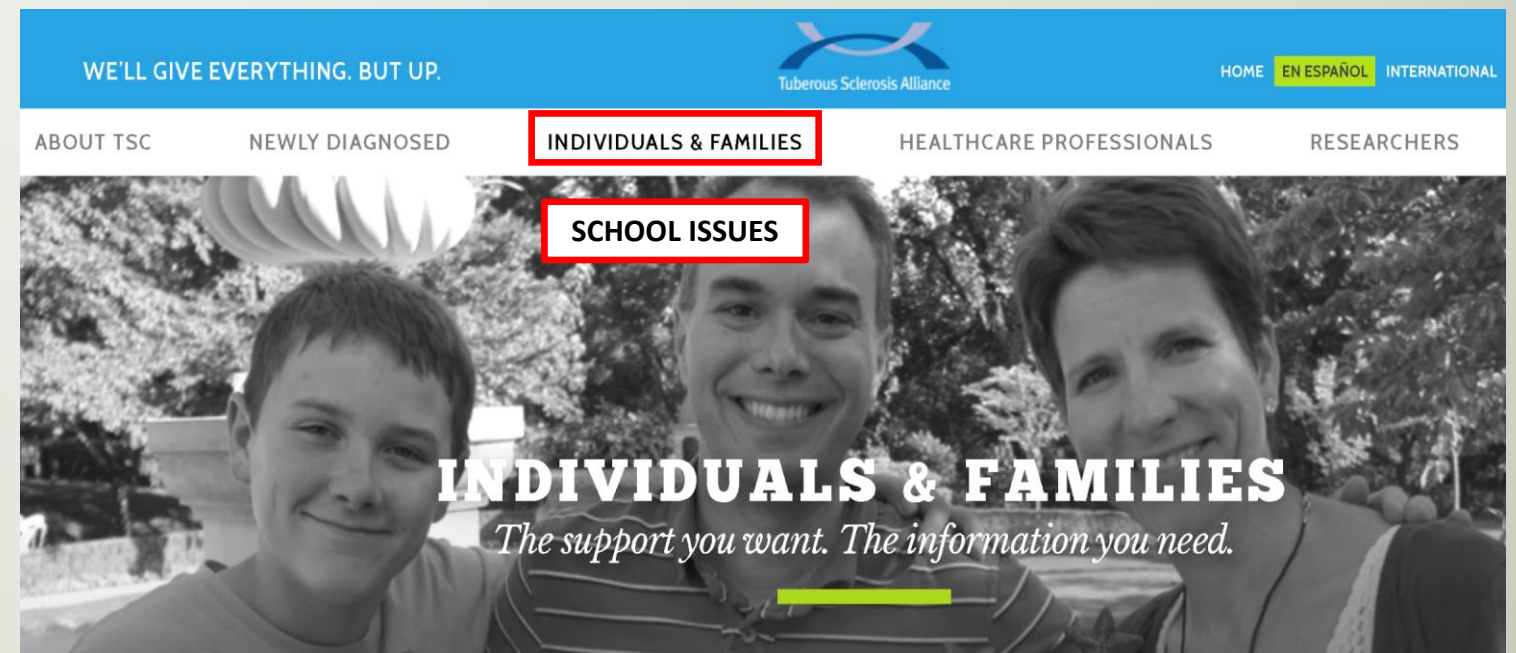
- Understanding IDEA: Your Rights as a Parent
- School Resources
- TSC 101 (Education Parent Mentors)
- Teacher's Guide: Educating a Child with TSC
- TSC-Associated Neuropsychiatric Disorders (TAND) and Education

Support for Anything!

- Contact me at dhook@tsalliance.org



www.tsalliance.org/individuals-families/school-issues



Join the Movement!



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