

Adults with TSC Newsletter



February 2021

Issue 47

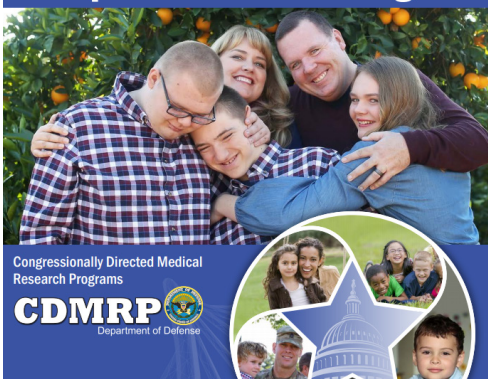
The Tuberous Sclerosis Complex Research Program

By Rob Grandia, Adult Regional Coordinator (Regions 1 & 2)

What is the Tuberous Sclerosis Complex Research Program (TSCRP) and why is it so important to the TSC community? The TSCRP began in 2002 when a group of TSC advocates reached out to their representatives and were able to get \$1 million in research funding through the Congressionally Directed Medical Research Programs (CDMRP) funded by the Department of Defense. Since then, \$97 million has been appropriated to the program, including \$8 million this past year. Over the years the TSCRP has funded research projects which have resulted in “accelerating high-impact research, exploring new concepts, encouraging innovation, and bringing new investigators into the TSC field.”

Currently the strategic

Tuberous Sclerosis Complex Research Program



focuses of the TSCRP are Tumor Eradication (get rid of tumors), Epilepsy (seizures), and Neurodevelopmental Features (emotions, learning gaps, behavior issues, and self-control). There is a two-tier review process created by the CDMRP to award funds to researchers who submit proposals. This process includes specialty doctors, scientists and those living with TSC or is a family member of

Continued on Page 2

Adult Resources

Upcoming Adult Open Forums:

Join us for our upcoming free Open Forum hosted by our Adult Regional Coordinators! These Open Forums will be hosted quarterly in January, April, August and December. You can join using your computer or dialing in on the phone.

Register for the next TSC Adult Open Forums now by clicking the register link below! If you have questions before the call, contact Julie Scroggins at jscroggins@tsalliance.org or (800) 225-6872.

Wednesday, April 21, 2021
8 PM Eastern | 7 PM Central | 6 PM Mountain | 5 PM Pacific
[REGISTER](#)

You MUST register in advance to participate in a call.

You can find all of our Adult Resources, including a list of our Adult Regional Coordinators, at tsalliance.org/adults.



TSC Now is the TS Alliance’s podcast series!
[Check out the last episode!](#)

Additional Resources



The TS Alliance will host 28 e-webinars throughout 2021!
[Learn More](#)



TSC Matters is a bimonthly e-newsletter from the TS Alliance!
[Subscribe Today](#)

Continued from Page 1

an individual with TSC. Those living with TSC or have a family member with TSC play an important role in evaluating the impact of the research and helping to determine where the funds should go to best support the TSC community. “Working together, TSC researchers, clinicians, and consumers ensure that the TSCRP funds the most relevant, groundbreaking, innovative, and high-risk/high-reward projects to end TSC.”

To get the continued funding for the TSCRP, TSC advocates from across the country converge on Washington, D.C. the first week of March to meet with their representatives in the Senate and the House of Representatives to ask them to sign a letter of bipartisan support (known as a Dear Colleague Letter). In these meetings representatives are looking for personal stories and letters of support from constituents within their district. This is where the TSC community can make a huge impact by simply sharing their journey or getting loved ones to write letters asking for support. Covid-19 has forced advocating for the TSCRP to look vastly different this year.

Instead of meeting in person, advocates will be scheduling virtual appointments and these stories and letters are needed more than ever before. Often it just takes one constituent to be the deciding factor on whether the representative will sign on to support the continued funding or not and the lifetime of experience within the adult community paints a vivid picture for representatives as to why the research is so vital.

Time is limited, appointments are being made and meetings will be held the first week of March. Adult Regional Coordinators (ARC) and Community Alliance Chairs are collecting these important stories and letters now to share with representatives during the meetings. If you are not sure who your representative is, or you are not sure where to begin in writing a letter your ARC or Community Alliance Chair can help. Simply by sharing your journey or having loved ones write letters you become an important part of the TSCRP and the life-altering research for the TSC community.

Learn more by checking out the [TSCRP Program Booklet](#).

In Their Own Words: Why We Participate in the March on Capitol Hill

“March on the Hill is important to because I am actively a part of the changes we all want in our collective TS community. Our finish line is obtaining Representative signatures, & confirmed support for our TRSP request. It takes each one of us to make a change in our community. March on the Hill is starting line for me.”

- Danielle Clark, Adult Regional Coordinator (Region 3)

“March on the Hill makes a difference in families that struggle with TSC being able to advocate. It also raises awareness for the TSCRP and funding for research.”

- Emilie Peters, Auxiliary Adult Regional Coordinator (Region 4)

“The aides, congress people and senators have been very gracious with their time and I could see a genuine empathy. It is a kind of a double-edged sword for us that TSC is so complex when we live it but the fact that research can help so many disorders has always got their attention.”

- Kathy Henkel, Adult Regional Coordinator (Region 8)

Upcoming Events



Join Our Future Leaders for an Upcoming Webinar and Open Forum!
[Learn more](#)



Interested in participating in the March on the Hill? Email grc@tsalliance.org to learn more!



Registration is now open for our 2021 Virtual Global Walk-Run-Ride!
[Register](#)