



# Adults with TSC Newsletter



April 2020

Issue 45

## COVID-19 Updates

The Tuberous Sclerosis Alliance is here for you during the COVID-19 pandemic. For ongoing updates about COVID-19 and other TS Alliance resources, please visit [www.tsalliance.org/COVID-19](http://www.tsalliance.org/COVID-19).

## Upcoming Adult Open Forum

Join us next Wednesday, April 15 at 4 pm Eastern for a Virtual Open Forum for Adults with TSC. All adults with TSC are invited to this special open forum to discuss how you're coping with the pandemic and any other issues you'd like to address.

To register for the Open Forum go to: <https://bit.ly/3e9ml4c>

## Adult Resources

### Upcoming Adult Topic Calls:

#### Thursday, April 23, 2020:

"Anxiety in TSC" presented by Karen D. Agricola, APRN, FNP-BC, Cincinnati Children's Tuberous Sclerosis Clinic

#### Thursday, May 14, 2020:

"Environmental Health – Spring Cleaning of Your Mind" presented by Judith Shoulak, CEO of Relatively Speaking

#### Thursday, June 25, 2020:

"Open Forum" presented by Adult Regional Coordinators

All Adult Topic calls start at 8 pm Eastern, 7 pm Central, 6 pm Mountain, 5 pm Pacific.

To participate simply use the toll-free call-in number: 1-866-613-5223 then enter access code: 4334003#. If you have questions or would like to receive handouts (if available) before each call, contact Dena Hook at [dhook@tsalliance.org](mailto:dhook@tsalliance.org) or call (800) 225-6872.

## Behavior Intervention

By Rita Mason

Many of us in the TSC community have to live with behavior intervention every day. But what is it, how do we manage it, and what's the next step?

A recent Adult Topic Call led by Gregory Woznicki addressed this topic. Woznicki works with Community Options,

Inc., a national organization that develops housing and employment supports for persons with disabilities.

He deals with many individuals with a range of disabilities and conditions. All are handling some or all of the behavioral

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TSCNow

TSC Now is the TS Alliance's podcast series!

[Check out the last episode!](#)

## Additional Resources

TSC Talks, a podcast hosted by Jill Woodworth, explores tuberous sclerosis complex and other related issues. Each week Jill talks to parents/caregivers, adults affected by TSC, and other professionals about their experiences managing TSC, the challenges they've faced and where they find hope.

[Listen to the latest episode now](#)



TSCMatters

TSC Matters is a bimonthly e-newsletter from the TS Alliance!

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components that accompany these disabilities and conditions: anxiety, obsessive compulsive disorder, extreme anger, etc.

While he knows the issues are chronic, his advice is to make “the window smaller to manage the issues.” What does that mean? “What little piece can I work on today, that I can do, that’s a little better than yesterday?”

Goals are important, yes, but something that will take a year or more to accomplish will only lead to discouragement. Rather, if you make the end goal two or three weeks away, or two or three months, the satisfaction will be immediate and be a stepping stone to the larger goals. Also, don’t focus on the negative – instead, be honest with what works and what doesn’t and keep moving along.

Moving is stressed by Woznicki.

Throughout the call, he said the most important thing to handle these issues is going back to the basics. A simple walk around the neighborhood or park was top of his list. The stimuli gleaned from being outdoors is vital in maintaining mental health. Playing music; reaching out to your support system of family or that one friend; journaling – all contribute to overall well-being. By focusing on what you have before you, these concrete things, that can help defuse many situations. Eating well and taking care of your body are also important.

Woznicki was asked about how to manage anxiety during COVID-19. He said we can only control what we can control and reiterated the simple walks, the simple phone call, reaching out to your support group, etc.

Please click on the link to listen:

<http://www.tsalliance.org/wp-content/uploads/2020/03/Audio-on-Behavior-Intervention-COVID-19.mp3>

**For more adult resources including previous issues of the Adults with TSC Newsletter, information on reproductive health and contact information for your Adult Regional Coordinator, check out the Adult page on the TS Alliance website [here](#).**

## Upcoming TS Alliance Events

### SAVE THE DATE!

The TS Alliance will be hosting three Regional TSC & LAM Conferences in partnership with The LAM Foundation in 2020. Here are the dates and locations for these conferences (*tentative and subject to change*):

- Saturday, June 20, 2020 - Memphis, TN
- Saturday, October 17, 2020 - Gainesville, FL
- Saturday, October 24, 2020 - Denver, CO

More information, including a link to register, will be available later this year.



All Spring Step Forward to Cure TSC Walks have been postponed due to the ongoing COVID-19 pandemic. To see the new dates and find a walk near you, visit: [www.stepforwardtocurstsc.org](http://www.stepforwardtocurstsc.org)