



Adults with TSC Newsletter



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My Experience at the St. Louis Regional Conference as an Adult Regional Coordinator

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The Arch... The Night Lights... The magic in the air from the Stanley Cup Parade it all was incredible, but what I loved most was the tuberous sclerosis complex (TSC) bond we all shared while at the St. Louis Regional TSC and LAM Conference in June! Meeting all the incredible physicians, doctors, educators, experts, nurse practitioners and families was beyond what you could ever imagine!

When a new family walked in the room it was lit up with hope, familiarity, love, understanding, encouragement, trust and dignity! We all were there to lend an ear and to share a voice as one! We were all united and spoke volumes as we shared our past, present and future, as well as how we have, are and plan to fight for a cure, while paving the way for new families to come.

Research is opening new doors for more opportunities and new medicines on the horizon, Less invasive surgeries, and top of the line care from all TSC clinics! I know for a fact we all fight hard. For some of us this road hasn't been easy and for the ones that fight for us daily in the background: we see you, we hear you loud and clear, we appreciate you, and we admire your strength to walk alongside us as we give everything, but up!

Adult Resources

Upcoming Adult Topic Calls:

Thursday, September 6, 2019
"LAM and TSC" presented by Karen D. Agricola, APRN, FNP-BC, Cincinnati Children's Tuberous Sclerosis Clinic, at 8 pm Eastern, 7 pm Central, 6 pm Mountain, 5 pm Pacific.

Thursday, October 24, 2019
"Open Forum," presented by Adult Regional Coordinators, 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 or (800) 225-6872.

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](#).

Questions? Contact Dena Hook, Vice President, Support Services, at dhook@tsalliance.org.

Upcoming TS Alliance Events



Get your tickets now for our 45th Anniversary Gala on Thursday, October 3, 2019 at the Edison Ballroom in New York City! [Learn More](#)



There are two upcoming Regional TSC & LAM Conferences in Chicago (September 7) and Atlanta (September 21). To learn more about the Regional TSC & LAM Conference Series and to register [click here](#).



Upcoming Step Forward Walks:
[September 7 - Charlotte, NC Walk](#)
[September 14- Tulsa, OK Virtual Walk](#)
[September 14 - Long Island, NY Walk](#)
To find a walk near you [click here](#).