



Advancing Collaboration with the TSC Alliance

Approach to Collaboration

The strides we have made for those living with tuberous sclerosis complex (TSC) couldn't have been achieved without a collaboration-first mindset. First and foremost, the TSC community and their needs guide everything we do, so we start our collaboration with them by listening to each of their unique journeys.

With the TSC community's guidance, we develop and nurture collaborative relationships with every other stakeholder we work with researchers, grant partners, donors, legislators, volunteers, industry, TSC clinics, physicians and other rare disease nonprofits. For example, because of our constant collaboration and the trust we work to establish and maintain, we have been able to coordinate and help fund research that resulted in two FDA-approved drugs for TSC. Working together to create progress like this will continue to lead to even more breakthroughs and enable more people with TSC to live their fullest lives.

We also seek out and form coalitions with other nonprofit partners. The TSC Alliance is a founding member of both the Infantile Spasms Action Network (ISAN) and the Seizure Action Plan Coalition (SAP Coalition). ISAN currently has more than 30 members from around the world, working together in concert to increase awareness of infantile spasms. TSC is the leading known genetic cause of infantile spasms. The SAP Coalition was formed in late 2020 to help educate people about the need to have seizure action plans in place. Eighty-five percent of individuals with TSC will develop epilepsy in their lifetime. These collaborations help individuals across disease states living with infantile spasms and epilepsy.

Application of the 9 Considerations for Collaboration

Build Trust

The best example of trust is the relationships we build with members of the TSC community. We remain laser-focused on making sure our support programs and research efforts constantly evolve to serve the needs they identify for us. This approach truly becomes the basis of all our collaboration.

Pursuing meaningful research is one way we can earn their trust as well as the trust of TSC researchers. We don't just approve their research projects, provide the funds, and leave them to their own devices. We support them at the early stages of preliminary data gathering that will help them earn additional funding from larger organizations and ensure TSC researchers have the data and connections they need to make progress.

Our Natural History Database – connected to our Biosample Repository with clinical information from TSC patients – provides a vast collection of data to help them answer questions and find patterns.

Our Preclinical Consortium embraces their dedication to our shared mission and de-risk the development they are pursuing to make sure they are well-equipped for their work.

And above all, we are completely transparent. All annual and financial reports, tax returns, community surveys, yearly State of the Community Reports, and annual updates on results to our strategic plan are posted on our website. We want anyone to be able to find information on how the TSC Alliance is making progress or if we are in a time of need.

Have a Vision

The TSC Alliance's Strategic Plan clearly lays out the roadmap to our future with specific goals, strategies, and measurements. It not only guides

our staff but also serves as a tool to share with all our collaborators to ensure everyone is on the same page.

We look first to our goals in our Strategic Plan to understand if a new collaboration is in alignment.

These goals include Accelerate Research, Improve Access and Quality Care, Support and Empower Constituents, Educate and Mobilize to Increase Investment, Build and Strengthen Organization. Collaboration is baked into our strategies as well. For example, under Support and Empower Constituents, one of our strategies is "Grow collaborations with other nonprofit organizations internationally, nationally and locally to ensure access to resources, support services, transition tools, and information." We have actively included collaboration as a key way to make certain we are able to deliver meaningful programs.

A member of the TSC community identified an issue that serves as a great example: those with rare diseases who were at high risk of COVID and their caregivers were not being prioritized when the vaccine rollout took place. Looking at our Strategic Plan, our goal is to Improve Access and Qualify of Care. We knew our constituents' voices would be amplified if we joined with others. The TSC Alliance created a sign-on letter, which was shared through some key email groups for other collaborations we participate in. The word spread and, in the end, we worked with 74 other rare disease organizations, biotech companies, and medical professionals. The letter was submitted to 10 individual states and the National Governor's Association; it was also highlighted in the press and through a proactive social media campaign.

Seek to Assure the Success of Your Collaborators

We're very fortunate to have a large community of people with TSC, parents and/or caregivers, researchers, academic institutions, and other



nonprofit partners who are all focused on improving outcomes for individuals and families living with TSC or connected rare diseases. With that in mind, we are very conscious of how we keep all interested parties connected and involved, both for the sake of efficiency and for the sake of constantly identifying new areas for opportunities and/or improvement.

One of our most frequent partners is The LAM Foundation. Lymphangioleiomyomatosis or LAM is caused by a mutation in one of the same genes as TSC. Together, we have held joint board meetings, three Virtual Town Halls during COVID-19, and 13 Regional TSC and LAM Conferences since 2016. We are currently in the process of planning our second International TSC and LAM Research Conference.

We start with a written plan to define the roles and responsibilities each organization will assume including sponsorships and how we will share the expenses and revenue. We schedule regular meetings and review each area of responsibility. We are honest when something wasn't completed or when we need a little extra help. Transparency has been key to building trust, and it starts at the CEO level.

Take Stock

Every five years as we prepare our Strategic Plan, we go through the SWOT exercise. We examine where we could strengthen our

organization through partnerships or where we may need to move on from partnerships if they are not in alignment with our Strategic Plan.

Additionally, our Strategic Plan includes milestone and time-based measurements, which allow us to constantly evaluate progress. Because we pay so much attention to it, its roadmap quickly reveals both our strengths and our weaknesses - not only internal ones but ones involving our outside stakeholders.

Finally, every other year, we implement an effectiveness assessment and make adjustments to the Strategic Plan where necessary. This also gives us the opportunity to evaluate key partnerships.

Start Small

One way we have been successful, for instance with the Infantile Spasms Action Network and SAP Coalition, is to start with a small number of collaborators to build trust the first year of the program (with a written plan, regular meetings, and designated areas of accountability). We have found first building a strong foundation then adding other partners is much easier, and the coalition is much more successful in the long run.

Our TSC community volunteer program includes very well-defined roles and responsibilities. We have an interview process for new volunteers, and we



offer a minimum of 1,200 hours of volunteer training to ensure they feel well supported. We invest our time to nurture their success. Because we are specific about the roles and responsibilities and we measure progress, it allows us to have conversations if goals are not being achieved and how we can work together to overcome any challenges.

Fail Fast, and Build Rigorous Feedback Loops

We like to start with written plans that assign specific areas of responsibility for our internal staff and outside stakeholders for any collaboration. These are reviewed in regularly set meetings so we can quickly assess if more assistance may be needed in a particular area. As part of our culture, the TSC Alliance staff meets monthly as a whole while departments often meet weekly, which allows for an internal process of evaluating what may be needed to meet our responsibilities.

Take a Portfolio Approach

Each department may work with several collaborations, whether we lead them or are a participant. Science and Medical have collaborations that they manage, evaluate and measure which is the same for our community programs as well as professional and public education programs. Each has a key outcome that ties directly to our Strategic Plan strategies and measurements.

Some collaborations may be time specific. For instance, I've been the Chair of the Public Advisory Round Table at the American Thoracic Society for the past two years, and I have two years left on my term limit. This has been an outstanding collaboration for providing the patient voice in a professional society.

Additionally, we are currently evaluating one collaboration about whether we are getting meaningful value out of it for our TSC community under the area of Improve Access and Quality of Care. Again, we use the Strategic Plan goals, strategies, and measurements as a roadmap.

Consider Non-Traditional Partners

We have had a partnership with Horizon Therapeutics over the past three years. Horizon does not have a current treatment in their portfolio for TSC, but they do have a RAREis program that raises awareness of rare diseases overall. We developed a three-way partnership with Horizon and another nonprofit called Sing Me a Story to create a public awareness campaign. Sing Me a Story works with children and a songwriter. The kids write a story, which is turned into a song that is performed by the songwriter, and the journey is chronicled by Horizon through videography. Proceeds from the song are split between the two nonprofits.



For our 45th Anniversary Gala, the family story video was shared, followed by a live performance of the song for the first time. The live performance became part of another awareness video, which was then shared via a social media campaign, at the Global Genes RARE Summit and at our additional fundraisers.

Keep Your Donors Apprised of Your Collaborations

Through our digital programs, such as podcasts, e-newsletters, and video announcements, we highlight the work of our collaborations.

We have also talked about collaborative research projects in one-on-one individual and corporate donor meetings to encourage support for building these resources to be made available for the entire TSC research community. These include our Clinical Research Consortium, Preclinical Consortium, and Natural History Database/Biosample Repository. Our collaborative research program is also highlighted during our Volunteer Leadership Summits, Regional and World TSC Conferences, and International TSC Research Conferences.

Future Collaborations

One collaboration we are trying to establish is taking a drug found to have good efficacy in our Preclinical Consortium and translating those results into a clinical trial. It takes the collaboration of our Preclinical Consortium members (researchers) working with our Clinical Research Consortium (clinicians), the company that owns the drug, and potential investors to move this new idea to market. Ideally, we will build the process for this type of collaboration to be a springboard for future drug development.



Kari Luther Rosbeck,
President & Chief
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About the Organization

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