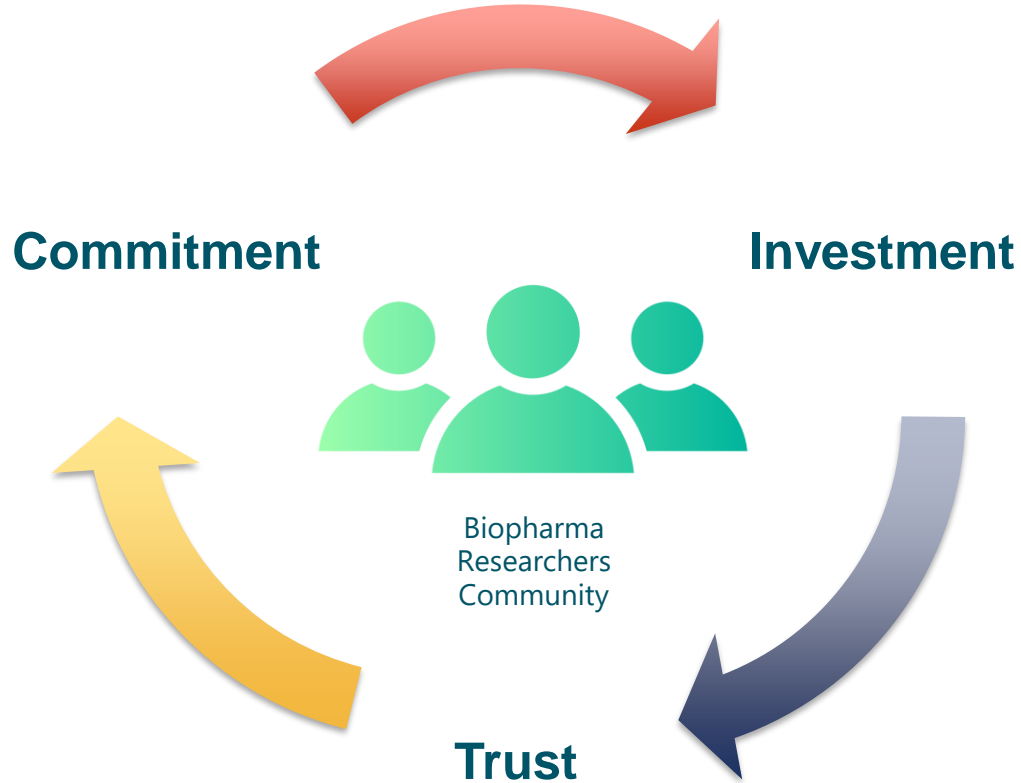




Navigating Foundation Dynamics

12 November 2024

Creating a Virtuous Cycle with Stakeholders Propels Strategic Goals



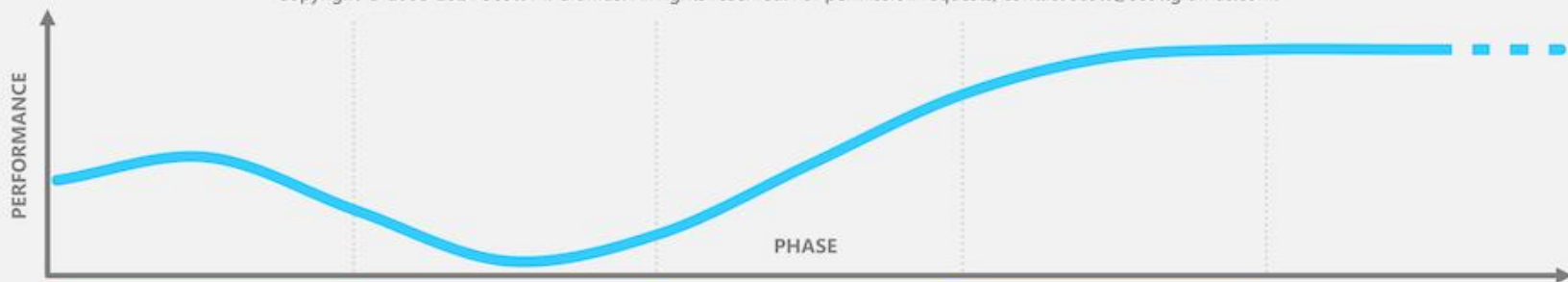
Characteristics of Successful Entrepreneurs

10 Characteristics of Successful Entrepreneurs

-  Curiosity
-  Risk Tolerance
-  Willingness to Experiment
-  Comfort with Failure
-  Adaptability
-  Persistence
-  Decisiveness
-  Innovative Thinking
-  Self-Awareness
-  Long-Term Focus

Phases of Team Development

Forming, Storming, Norming, Performing, and Adjourning — based on group development model by Bruce Tuckman
 All phases are necessary and inevitable for a team to grow, tackle problems, find solutions, plan work, and deliver results.
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	FORMING	STORMING	NORMING	PERFORMING	ADJOURNING
CHARACTERISTICS	<ul style="list-style-type: none"> • Displaying eagerness • Socializing • Generally polite tone • Sticking to safe topics • Unclear about how one fits in • Some anxiety & questioning 	<ul style="list-style-type: none"> • Some resistance • Lack of participation • Conflict based on differences of feelings & opinions • Competition • High emotions • Starting to move towards group norms 	<ul style="list-style-type: none"> • Purpose & goals are well-understood • More confident • Improved commitment • Members are engaged and supportive • Relief, lowered anxiety • Developing cohesion 	<ul style="list-style-type: none"> • High motivation, trust & empathy • Individuals defer to team needs • Effectively producing deliverables • Consistent performance • Demonstrations of interdependence & self-management 	<ul style="list-style-type: none"> • (Also referred to as the Transitioning or Mourning phase) • Shift to process orientation • Sadness • Recognition of team & individual efforts • Disbanding
STRATEGIES	<ul style="list-style-type: none"> • Taking the 'lead' • Being highly visible • Facilitating introductions • Providing the 'big picture' • Establishing clear expectations • Communicating success criteria • Ensuring response times are quick 	<ul style="list-style-type: none"> • Requesting & encouraging feedback • Identifying issues & facilitating their resolution • Normalizing matters • Building trust by honoring commitments 	<ul style="list-style-type: none"> • Recognizing individual & team efforts • Providing learning opportunities & feedback • Monitoring the 'energy' of the team 	<ul style="list-style-type: none"> • 'Guiding from the side' (minimal intervention) • Celebrating successes • Encouraging collective decision-making & problem-solving 	<ul style="list-style-type: none"> • Recognizing change • Providing an opportunity for summative team evaluations ('lessons learned') • Providing an opportunity for individual acknowledgments • Celebrating the team's accomplishments (an 'after-party')

Models of Engagement - External

- Join a consortium
- Partner on 1 project
- Invite them to your conference
- Compare missions and roadmaps, divide and conquer on gaps
- Bring them into board
- Merge

Examples

STXBP1 Global Connect

www.stxbp1globalconnect.org

Global collaboration and partnership

11 Associations and growing!

Quarterly Calls including 19 countries

Census Project

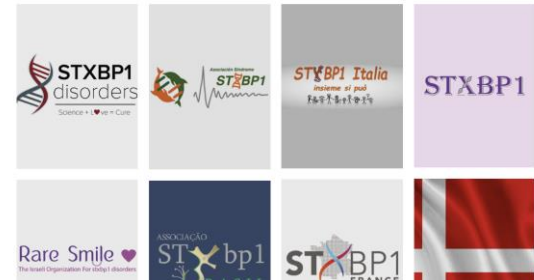


STXBP1 Global Connect

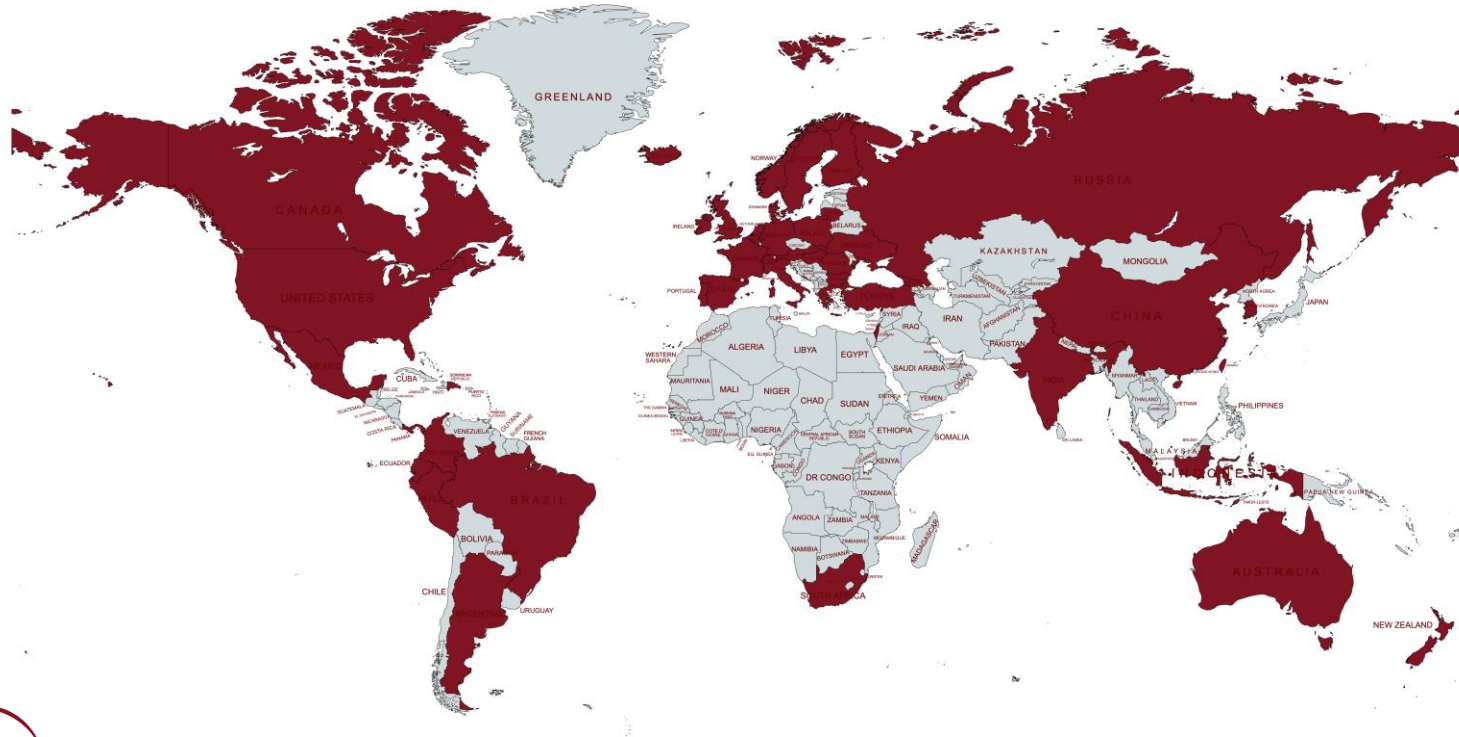
STXBP1 Global Connect

STXBP1 Global Connect is an affiliation of groups from around the world all chartered with improving the lives of patients affected with STXBP1 disorders. Our communities of parents, scientists, and medical professionals are connected across the globe with the common purpose of ultimately finding a cure for this rare genetic disease. STXBP1 Global Connect is the central online location that lists all related STXBP1 organizations whether they are websites, social media groups, or simply an email list. There are new groups forming every month and we are glad to welcome everyone who will join us in whatever manner they are able.

Together we are stronger. Together we will find a cure.



STXBP1 Sept '24 Census: 1157 Patients in 52 Countries



Resources

- Think Like a Start-Up: Grow your Patient Advocacy Group session from Global Genes' Week in Rare 2024: currently accessible through conference app, will soon be posted on globalgenes.org
- Working Nicely in the Same Sandbox session from Global Genes' RARE Advocacy Summit 2023: <https://globalgenes.org/video/working-nicely-in-the-same-sandbox-2023-rare-advocacy-summit/>
- Global Advocacy Alliance: <https://globalgenes.org/about-us/global-advocacy-alliance/>
- Mental Health resources: <https://globalgenes.org/mental-health-and-well-being/>