



The European STXBP1 Consortium Newsletter

June 2025

Welcome

As summer begins to bloom across Europe, we welcome longer days, warmer weather, and the anticipation of holidays and time with loved ones. For many families, this season brings a welcome change of pace—but for those caring for a child with STXBP1-related disorders, it can also bring new challenges.

Whether it's navigating disrupted routines, planning travel with extra needs in mind, or simply managing daily care without the usual support systems, we know this time of year can be both joyful and demanding.

In this newsletter, we continue sharing the latest from across the European STXBP1 Consortium—from research updates to upcoming events and stories from our community. We hope these updates offer connection, inspiration, and a sense of solidarity as we move into the summer months together.

ESCO study update

Almost ready to begin!

In our last newsletter, we shared the exciting news that the STXBP1 Natural History Study was expected to begin in April. While the official start has taken a little longer than anticipated, we're thrilled to announce that **Belgium** will be the first site to launch the study, with more sites across Europe to follow.

Behind the scenes, a great deal of work has been happening every day—from finalizing ethical approvals to setting up systems and training—all to ensure that everything is in place to welcome participants safely and smoothly. We're incredibly grateful for the dedication of all the site teams and the ongoing support from families eagerly awaiting the opportunity to take part.

We'll continue to keep you updated as each site opens. Thank you for your patience and enthusiasm—we're getting closer!



ESCO's Scientific Advisory Board

We're proud to announce the formation of the **European STXBP1 Consortium Scientific Advisory Board (SAB)**. This board brings together expert researchers and clinicians from across Europe and beyond to help guide ESCO's scientific direction. The SAB will provide independent advice on study progress, research priorities, and emerging opportunities—ensuring that our work remains rigorous, collaborative, and focused on making meaningful impact for families living with STXBP1-related disorders.

You can always find the latest news from ESCO on our website.

[ESCO website](#)



European-wide relay for STXBP1 Awareness month

This September, in honor of STXBP1 Awareness Month, we're excited to launch the first-ever Europe-wide relay fundraiser—The European Move to Cure Relay! Inspired by Dutch families already leading the way, families and supporters across Europe are invited to organize local symbolic relays (“estafettes”) to raise awareness and support STXBP1 research.

Each group will create their own unique route—whether on foot, by bike, with strollers, scooters, or even on horseback—and film short clips of a symbolic “baton” being passed from one participant to the next. These videos will be combined into a powerful international relay film to be premiered at the STXBP1 Summit in Heidelberg this October.

If you or your family would like to participate, or if you'd like to help organize a local relay in your country, we warmly encourage you to reach out to your local family organization or contact us at esco@stxbp1eu.org.

You can also find donation pages and more information for each country at:

Move to Cure Europe 2025

For the latest updates on the relay and all things ESCO, follow us on social media:



Let's move together—across borders, communities, and hearts—to raise awareness and fuel progress for STXBP1.

Spotlight on Science

Gene Therapy Milestone: Capsida Launches First Clinical Trial for STXBP1

Capsida Biotherapeutics has received FDA approval to begin the first clinical trial of a gene therapy specifically targeting STXBP1-related disorders. The therapy, CAP-002, aims to restore STXBP1 protein function by delivering treatment to the brain through a specially engineered IV vector. This marks a groundbreaking step forward in treatment development—and offers renewed hope to the STXBP1 community worldwide.

While this is a significant milestone for the field, we want to clarify that the Capsida trial is an independent initiative and is not part of ESCO's Natural History Study or Registry. ESCO's research remains focused on understanding the progression of STXBP1-related disorders through long-term data collection, which continues to be a critical foundation for all future therapeutic development.

[Read the full update from Capsida](#)



Understanding Family Life with STXBP1-RD

A new study from Brainmodel offers vital insights into the daily realities of families

raising children with STXBP1-RD. Through interviews with 21 parents, the research captures the emotional, physical, and logistical challenges of caregiving—described using five powerful action verbs that reflect constant engagement, balancing responsibilities, and navigating emotional strain. The findings highlight the urgent need for holistic support that goes beyond medical treatment to include therapies, social resources, and post-diagnosis guidance

[Read the Brainmodel study](#)

Strides in STXBP1 – May Edition (STXBP1 Foundation)

Looking for a quick and easy way to stay up to date with the latest in STXBP1 research? The STXBP1 Foundation’s monthly *Strides in STXBP1* blog highlights new publications, discoveries, and scientific milestones—summarized in a clear and accessible way. Check out the May edition to see what progress was made this past month.

[Read Strides in STXBP1 - May](#)



The European STXBP1 Summit 2025 in Heidelberg, Germany

Plan Your Stay for the STXBP1 Summit in Heidelberg!

We are thrilled by the enthusiastic response to the 2nd European STXBP1 Summit and Family Day on Saturday, October 11, 2025! To help you plan your visit, we've reserved rooms at the **Heidelberg Marriott Hotel**, located near the Neckar River and close to the summit venue. The special group rate is:

- **€149.00 per night for a single room**, including breakfast.
- To book, please call **+49 6221 908650** and mention the code **STXBP12025**, or use this booking link to reserve online.

If you prefer to stay closer to Heidelberg's train station or city center, we recommend the following alternative hotels:

- **Leonardo Hotel Heidelberg City Center**
Bergheimer Str. 63, 69115 Heidelberg
- **NH Collection Heidelberg**
Bergheimer Str. 91, 69115 Heidelberg
- **BS Boutique Hotel Heidelberg**
Brückenstraße 14, 69120 Heidelberg
- **ATLANTIC Hotel Heidelberg**
Europaplatz 1, 69115 Heidelberg

We can't wait to welcome you in Heidelberg for a weekend of connection, learning, and community!

[Summit Website](#)

[Family Summit](#)



The European STXBP1 Consortium

De Boelelaan 1100, 1081HZ, Amsterdam

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