

# Monthly Newsletter

September 1st, 2025

CTNNB1 FOUNDATION

Issue #5

## Dear CTNNB1 community,

As summer comes to a close, we hope you've had time to rest, recharge, and enjoy moments with your loved ones. Many of our CTNNB1 children are also heading back to school, and we wish them lots of success, growth, and - most importantly - fun in the year ahead. 📖 🍀

With renewed energy, our team is also stepping into the new season ready to take on the challenges and opportunities ahead.

This month, we're excited to share important updates, from our presence at international conferences and progress in research, to the latest developments in our Dragonfly study. Together, these milestones bring us one step closer to our shared mission: advancing treatments and improving lives for everyone affected by CTNNB1 syndrome. 💙

Best,  
*The CTNNB1 Team*

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## Community News



### CTNNB1 Foundation at SPARK: Advancing CTNNB1 and Autism Research 🧪

Our president, Špela, recently attended the **SPARK conference** in San Francisco, USA (SPARK NS course "*Positioning Autism Discoveries for Successful Drug Development*"). The event brought together world-leading researchers and experts in autism, offering the latest insights and best practices in the field.

Špela participated not only to learn from these advances but also to raise awareness about **CTNNB1 syndrome**, which often presents with autism-like symptoms and characteristics. She had the opportunity to connect directly with leading experts, helping to strengthen dialogue on the overlap between autism

and CTNNB1, and contributing to the expansion of knowledge and research in both areas.

We are also proud to share that the CTNNB1 Foundation has advanced as a **finalist in the SPARK NS 2026 Translational Research Program**. Our proposal, *“URBAGEN: A first-in-class gene therapy targeting CTNNB1-linked autism and neurodevelopmental delay,”* puts forward an innovative and robust approach to address urgent unmet needs.

We now eagerly await the program’s final results, expected by the end of September. 🙌

## Other exciting news 👁️👁️

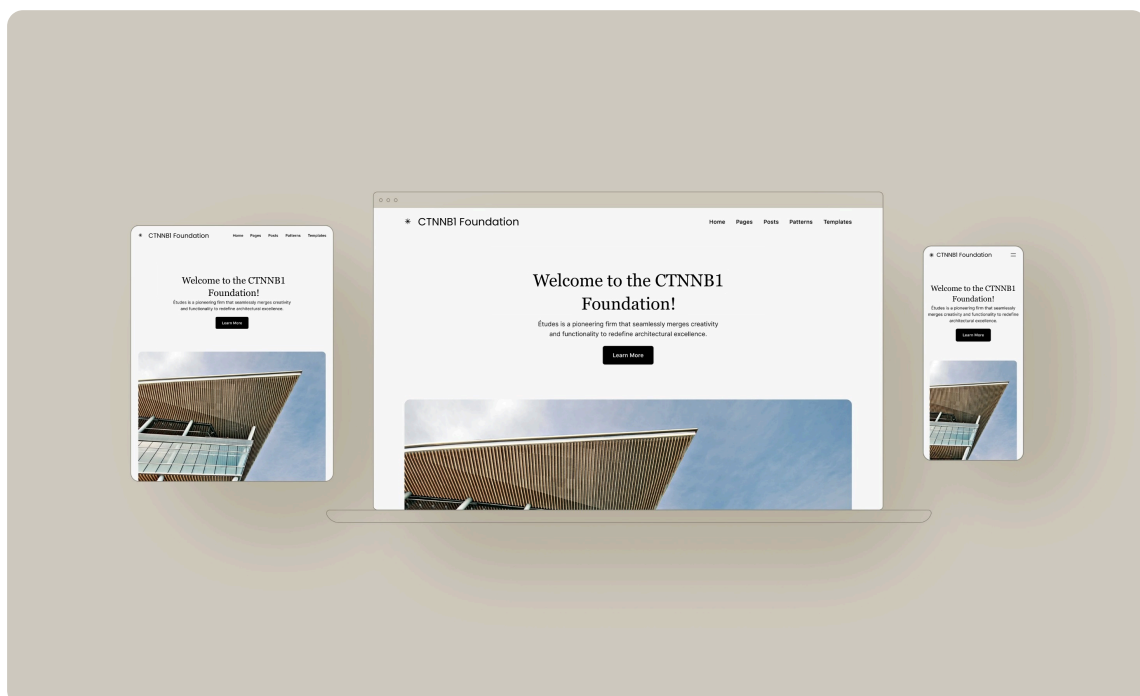
We’re thrilled to share that we’re actively working on something else – **our brand-new website!** 🎉

We’re giving the entire site a fresh makeover, making it easier to explore and more useful for our community. You’ll find updated content, more opportunities to get involved in research and activities, and redesigned sections such as *“Signs and Symptoms”* and *“Research Activities.”* These pages will reflect the latest scientific insights and will be designed to guide families toward accurate diagnosis and a deeper understanding of CTNNB1 syndrome.

We will also add a section dedicated only to our **Dragonfly Natural History Study**, where you’ll find all the key information, whether you’re considering participation or are already part of the study.

The new website will be launching in October – stay tuned!

Here’s a little sneak peek:



## 🦋 Dragonfly study update

Our team is steadily organizing the data collected from clinical examinations. 🩺

We plan to begin data analysis this autumn and are eager to uncover the trends and insights that have emerged over the course of the past two years of this ongoing study. 📈

We look forward to sharing some preliminary results with you in the near future!



## 📄 New research article published

*'An evolutionarily conserved role for CTNNB1/ $\beta$ -CATENIN in regulating the development of the corpus callosum'*

This research advances the understanding of CTNNB1 syndrome, showing that mutations in the CTNNB1 gene cause defects in the corpus callosum (CC) – the structure connecting the two brain hemispheres. Consistent with findings in mouse models, it was found that CTNNB1 gain- or loss-of-function during early brain development disrupts midline cells that guide neurons across the CC, leading to faulty connections. These findings help explain why children with CTNNB1 syndrome often experience differences in brain wiring and development.

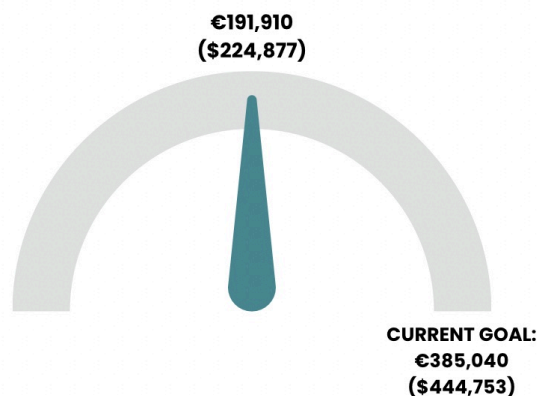
🔗 Read more [here](#).

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## Fundraising Updates

### 🧬 The Final Push for CTNNB1 Gene Therapy

Donations are adding up fast - since the last update, we've raised an additional **€13,973 (\$16,331)**. We're already halfway there! ❤️



A heartfelt thank you to our entire community for your dedication, generosity, and support, you're the driving force behind this journey.

Each day matters. Let's keep pushing forward so children can receive this treatment as soon as possible.

### **Workplace donation guide**

Did you know many companies match donations their employees make to nonprofits? This means **your donation for our gene therapy program could go 2x, 3x, or even 4x further, at no extra cost to you!**

What is corporate matching?

Corporate matching is when your employer matches your charitable donation, often at a 1:1 ratio (dollar-for-dollar) or even higher. Some companies also run employee giving programs through platforms like Benevity.

How to check if your workplace offers matching:

1. Check Your Workplace Giving Portal: Log into your company's employee giving or HR portal and search for Benevity, workplace giving, or corporate matching.
2. Ask HR Directly: Email or ask your Human Resources team: "Does our company support charitable giving through Benevity or offer donation matching?"
3. Check which companies offer corporate matching: You can search for various lists of companies who do corporate matching on the internet and which platforms they use.

If your company uses [Benevity](#), search for:

**CTNNB1 Foundation** or ID: **5617602575719\_1cf2**

If you're in the USA and your company uses another matching platform, nominate us with:

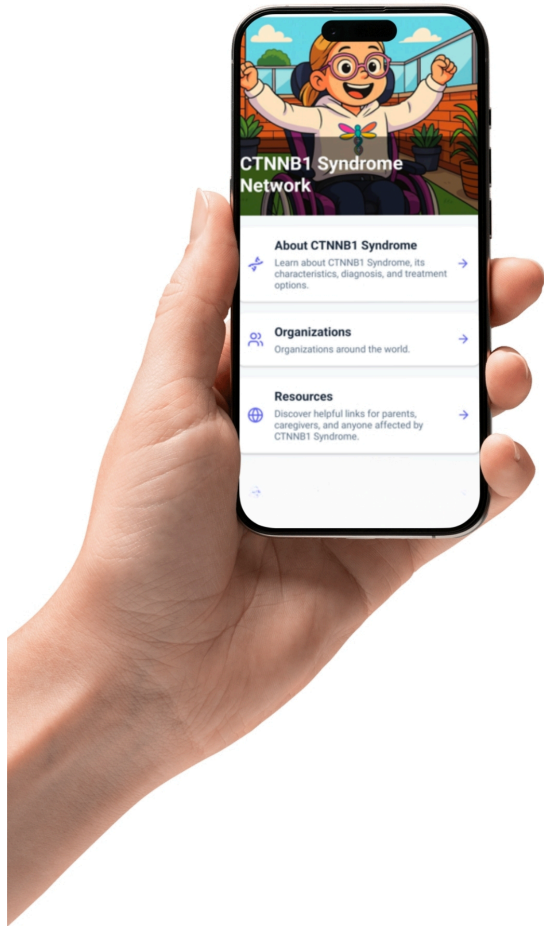
**CTNNB1 Gene Therapy Foundation**

EIN: **99-3901640**

Contact: **Deepti Agarwal, [deeptiagarwal74@gmail.com](mailto:deeptiagarwal74@gmail.com)**

Keep supporting us on Givebutter

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## Don't forget to download the CTNNB1 app!

This app is your central hub for **connection, support, and information-sharing** within the CTNNB1 community.

Available in **English, Deutsch, Español, Français, Italiano, Português, Slovenščina, and Polski.**

Through the app, you can:

- Stay up to date with the latest news and research
- Discover community events and meetups
- Join support group discussions
- Access educational resources
- Connect with experts through live chat assistance

Download for  
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