

WHO WE ARE

Cerebral Palsy Alliance Research Foundation funds US-based research to change what's possible for people with cerebral palsy, implements proven science, and advances innovation to benefit all people with disabilities.

We envision a world where research and innovation reshape what it's like to have cerebral palsy and everyone with disabilities can access the affordable, assistive technology they need.

Connect With Us

142 West 57th Street Floor 11 New York, NY 10019 646.340.1208

www.cparf.org

Instagram
Facebook
Twitter
LinkedIn

2022 IMPACT REPORT

Driven by grants from organizations and nearly 15,500 donations from more than 11,500 individuals, we collectively raised **\$3 million for cerebral palsy (CP) research and disability innovation** in 2022. The proceeds enabled Cerebral Palsy Alliance Research Foundation (CPARF) to fund new research projects, continue funding ongoing research, and support technology that will help 18 million people with CP worldwide and people with disabilities everywhere.

CPARF currently funds several research projects. Select work focuses on:

The Whole CP Community

• Uncovering the **true lifetime cost** of CP in the US. Research relies on current data, and studies like this one are essential to advancing CP research — and ensuring that the voices of people with CP and their families are heard.

Technology

- Investigating noninvasive neuromodulation **technology to enable voluntary movement and control for children with CP** via an FDA-recognized breakthrough device. *Conducted by scientists at UCLA and the University of Southern California.*
- Examining whether **robotic exoskeleton training in nonambulatory children** with delayed motor skills makes exoskeleton therapy more effective than standard physical therapy. Approximately 5.9 million

people with CP of all ages can't walk, and it's crucial to build relative strength and work on range of motion early to give children the best possible start. *Conducted by scientists at University of California San Francisco.*

Early Detection and Early Intervention

- Studying a **cutting-edge**, **non-invasive way to monitor bloodoxygen levels in premature infants** to reduce death or severe brain injury. This research could reduce the occurrence of infant strokes and decrease the likelihood of a CP diagnosis. *Conducted by scientists at Washington University in St. Louis.*
- Determining the right time to use the general movements assessment to **improve the accuracy of early detection of CP in children**. The earlier a child is accurately diagnosed with CP, the sooner they can begin treatment. *Conducted by scientists at Northwestern University*.
- Researching whether improving the creation of myelin a vital brain component that ensures proper nerve signal transmission and brain development — can be used to treat CP. Conducted by scientists at University of California San Francisco.

Genomics

- Analyzing genetic information from CP families to **identify genetic risk factors** and perform functional studies to gain insight into identified genetic variations. This could help uncover novel genetic causes of CP where therapies could help, as well as increase precision in genetic counseling, assessing possible outcomes, and informing future clinical design. *Conducted by scientists at Washington University in St. Louis.*
- Finding and **creating a list of genes found in dystonic patients with CP** and adults with dystonia. This type of CP causes abnormal muscle contractions that force painful, unwanted movements and postures, and this research could lead to more treatment options. *Conducted by scientists at Phoenix Children's Hospital.*

Regenerative Medicine

• Investigating a **novel cell-selective treatment to reduce brain injury** and lessen the severity of CP and other stroke-related conditions. Around 5,000 babies have a stroke each year and this could help them in ways that 90% of current treatments can't. *Conducted by scientists at Children's Hospital of Philadelphia.*

2022 Highlights

<u>Scientific</u> <u>Advisory Board</u> <u>Established</u>

<u>Remarkable</u> Pilot Launches

Inaugural Tech Summit Featured in Forbes



ADVANCING INNOVATION

In 2022, we launched Remarkable US, a disability tech accelerator committed to developing startups that support affordable, life-changing assistive technology that covers the whole human experience. *Nothing about us without us* — a core disability rights and accessibility principle — is at the center of Remarkable US's mission. Our pilot program kicked off with three US companies: **Biomotum**, **Participant Assistive Products**, and **WearWorks**. Their diverse work addresses mobility, accessibility, and affordability — some of the most pressing and important challenges affecting the disability community.

A PARTNERSHIP TO MOVE SCIENCE AND INNOVATION FORWARD

The funds you helped CPARF raise in 2022 paved the way for our transformative partnership with the Cerebral Palsy Research Network, which will benefit all people with CP, parents, caregivers, and medical professionals by ensuring that proven science makes its way into practice throughout the country sooner. Through this partnership, scientists and innovators we fund will have access to more than 30 hospitals. This will mean more research, faster implementation, and additional technology options for everyone with CP and other disabilities.

2022 was just the beginning, and we can only keep advancing research at all of its stages and innovation in all of its forms **because of you.**

Thank you.

