

# 2021 IMPACT REPORT

#### **WHO WE ARE**

Cerebral Palsy Alliance Research Foundation (CPARF) supports cerebral palsy research from every angle. We find, fund, and support the brightest US researchers to reshape the scientific landscape and change what's possible for cerebral palsy.

CP is a diverse disability that demands a diverse research portfolio, and we steadfastly support research that serves the whole community. We start at Day One with the earliest interventions to potentially lessen CP's severity or prevent the injury that causes it. We keep going with science that will make it more comfortable for children to get the therapies they need. We continue with research that will uncover new chronic pain treatments for adults. We proudly champion research for every age and every stage.

Driven by grants from organizations and donations from more than 8,100 individuals, we collectively raised \$2.7 million for CP research in 2021. The proceeds enabled CPARF to fund new projects and continue funding ongoing research that will help 18 million people with CP worldwide.

## CPARF is currently funding several research projects. Select work focuses on:

- Identifying the **people with CP most likely to experience pain** and correlating pain symptoms with sensation and specific bio markers. This research could be life-changing for the 13.5 million people with CP who live with chronic pain. *Conducted by scientists at Kennedy Krieger Institute/Johns Hopkins University.*
- 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*.
- Uncovering the **true prevalence and lifetime cost of CP**. 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.
- 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.

- 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. This work could help the 1 in 323 babies diagnosed with CP in the US. Conducted by scientists at University of California San Francisco.
- Studying a cutting-edge, non-invasive way to monitor blood-oxygen 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 cerebral palsy** in children. The earlier a child is accurately diagnosed with CP, the sooner they can begin treatment. *Conducted by scientists at Northwestern University*.

### **MOVING FORWARD IN A NEW WAY**

Starting in 2022, CPARF is expanding our focus to bring science to life and make an impact that one million people with CP in the US — and 18 million people worldwide — can feel much sooner. By funding the implementation of scientific research, we will bring scientific discoveries from the pages of prestigious publications to the people with CP who need help right now.

We are also launching the US branch of the successful Australian disability technology start-up accelerator Remarkable, supporting three initial start-ups committed to enhancing the lives of people with cerebral palsy and other disabilities through innovation.

CPARF is doing this crucial work to build and grow the cerebral palsy ecosystem in the US and to fund projects that will address the problems and frustrations that affect most of the CP community.

We are doing this because it is what people with cerebral palsy need. And, just as importantly, it's what people with cerebral palsy deserve.

It's an exciting time. And we can only advance research at all of its stages and innovation in all of its forms **because of you.** 

### Thank you.