

Cerebral Palsy Foundation Impact Report 2020/21



**CEREBRAL
PALSY
FOUNDATION**

DISCOVERY FOR DISABILITY

IMPACT REPORT

2020/21

OUR MISSION IS TO BE A
CATALYST FOR CREATING
POSITIVE CHANGE FOR PEOPLE
WITH CEREBRAL PALSY.

Introduction

For over 70 years, the Cerebral Palsy Foundation (CPF) has provided answers for individuals with cerebral palsy and their families through leadership in advocacy, science, research and medicine. The use of best evidence to make change is at the forefront of everything we do. Our commitment to accessibility, representation, inclusion and our passionate belief in the abilities of all people drive us to accept nothing less than continued growth, innovation and success.

CPF is committed to developing a diverse and inclusive workplace across all levels of the Foundation including our staff, consultants, scientific advisory council, board, volunteers and partner institutions. We strongly believe there is a critical difference between obtaining community feedback and giving our community the real power needed to affect our programs and resulting outcomes.

In the last 12 months we have delivered on our promise of expanding and ensuring the success of our key initiatives across Health, Education, Advocacy and Design & Technology. Today our Early Detection and Intervention initiative is making people aware of not only why it is critical to identify, fund and provide early diagnosis and interventions but importantly how to do it. This work is now scaling to High Risk Follow Up programs across the US and the world. Key to this expansion is our education and training packages and partnership with UNICEF and the World Health Organization.

Just as important is our work across the lifespan. Our digital platforms provide a one stop shop for individuals and families to gain the best and latest information about CP. While at times challenging due to the current environment, we have continued to grow our partnerships to implement “Just Say Hi” inclusion curriculum in schools across the country. T

As people experience and understand the impact of our work, we are seeing a significant growth in our impact.

Rachel Byrne

Executive Director



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Karolinska Institutet

PROGRESS OF CPF PRIORITIES

FOCUS AREA

01 DEVELOP OPERATIONALLY CAPABLE ORGANIZATION
Strengthen & enhance Foundation infrastructure; improve process across all foundation functions

02 DEVELOP DIVERSE & INCLUSIVE WORKPLACE ACROSS ALL LEVELS OF THE FOUNDATION
Foster spirited, engaged and opportunistic team

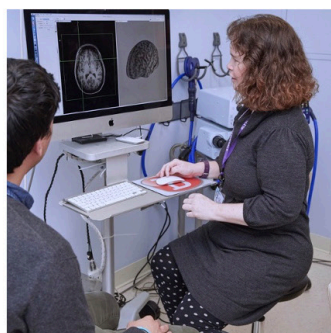
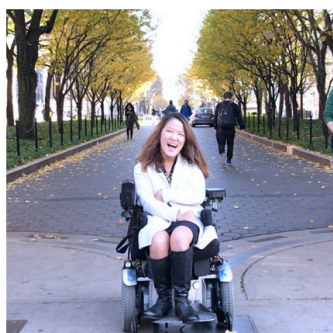
03 REFOCUS/STRENGTHEN FOUNDATION POSITIONING AND PROGRAM GOALS
Utilize leadership’s teams collective experience to increase output across all program areas

04 EXPAND NATIONAL AND INTERNATIONAL REACH
Identify key markets for growth and expand the Foundation’s signature initiatives.

05 STRENGTHEN CORPORATE PARTNERSHIPS
Continue to strengthen the Foundation’s position as a thought leader in disability, innovation and collaboration.

06 EXPAND GRANT PORTFOLIO & REVENUE OPPORTUNITIES
Continue to identify key grant opportunities that fulfil our mission

07 BROADEN DIGITAL REACH
Optimize digital channels to increase the number of people that the Foundation’s work reaches



PROGRAM AREAS

We enable real world impact through influential researchers, thinkers, and organizations around the world to drive significant change.

- ✓ HEALTH
- ✓ EDUCATION & EMPLOYMENT
- ✓ AWARENESS & ADVOCACY
- ✓ DESIGN & TECHNOLOGY

NETWORKS OF CHANGE & CPF IMPLEMENTATION MODEL

DESIGNED TO IDENTIFY A BIG PROBLEM AND COMMITTED TO CONNECTING INDUSTRY PARTNERS, RESEARCHERS, PRACTITIONERS AND ADMINISTRATORS WITH INDIVIDUALS WITH CEREBRAL PALSY AND THEIR FAMILIES TO DRIVE BEST POSSIBLE OUTCOMES.

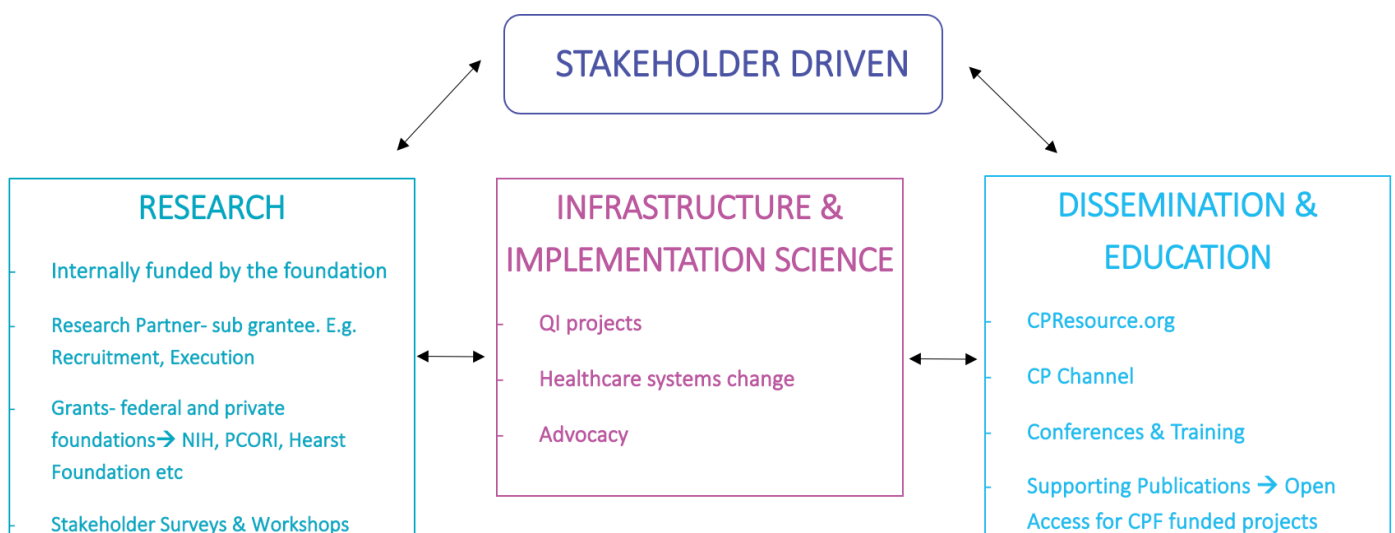
Goal to work closely with leaders, to develop, share, invest and provide infrastructure to otherwise underfunded areas.

Use proven models of implementation and developed research agendas.

Led by individuals and organizations deeply rooted in the contexts and systems they seek to transform.

The model is designed to support deep systems change, with a particular emphasis on inclusion of individuals with CP and their families across all aspects of the collaborative's work.

PROGRAM STRUCTURE



ABOUT CPF

Cerebral Palsy Foundation is a catalyst for creating positive change for people with cerebral palsy.

We enable real world impact through influential researchers, thinkers, and organizations around the world to drive significant change in healthcare, education, technology, public awareness and policy.

CP is caused by an injury to the developing brain that interferes with movement and coordination.

CEREBRAL PALSY IS THE MOST COMMON MOTOR DISABILITY IN CHILDREN AND ALSO AFFECTS A LARGE ADULT POPULATION. OVER 17 MILLION WORLDWIDE

In the majority of CP cases, the cause is still unknown and has not been well researched.

IMPROVING HEALTHCARE

• We are committed to improving the health of individuals with cerebral palsy across the lifespan. We strive to impact health on multiple fronts: research, diagnosis and intervention, access to healthcare, changing the way healthcare is provided. We have identified key areas of need and have developed initiatives to improve each.

1. Early Detection & Intervention
2. Women with Disabilities
3. Pain & Mental Health
4. Sports, Recreation and Fitness
5. Research

CREATING INCLUSIVE EDUCATION & COMMUNITIES

• The Cerebral Palsy Foundation is committed to creating meaningful, inclusive opportunities for individuals with disabilities across the lifespan...in the schools, in the workplace, in the community. To us, inclusion goes beyond ensuring the person is present or "has a seat at the table," inclusion is meaningful and authentic participation in the activities and environment to which the individual pursues or belongs.

1. Just Say Hi in Schools
2. Inclusive Employment

ADVOCACY & AWARENESS

At the Cerebral Palsy Foundation we aim to increase global awareness and focus for cerebral palsy research and funding in order to improve health outcomes for people with cerebral palsy. We not only lead the way in advocating for US federal funding and national cerebral palsy initiatives, but we also partner with global entities including the World Health Organization, UNICEF and the United Nations to improve lives around the world. Awareness and Advocacy go hand in hand to create positive change.

1. National Cerebral Palsy Awareness Day
2. US Federal Advocacy: Centers for Disease Control / National Institutes of Health Appropriations

ACCESSIBLE DESIGN & TECHNOLOGY

Aim to improve access and participation of people with cerebral palsy where they live, work, and play. We have prioritized initiatives that focus on environmental, technological, and wearable advancements which can provide the necessary supports to improve how a person interacts with and thrives in their chosen environment. Through innovative design, new opportunities are created and we change the way individuals with disability are perceived.

1. Design 4 Disability
2. Lexus Adaptive Vehicle
3. Accessibility is Beautiful - Universal Design

SIGNATURE PROJECTS

EARLY DETECTION & INTERVENTION

WE ARE IMPLEMENTING WAYS TO RECOGNIZE CP AND PROVIDE INTERVENTIONS EARLIER

Impacting health begins with early detection and early intervention of cerebral palsy. Through our research and professional training, we are reducing the time it takes for an infant to be diagnosed with cerebral palsy to less than one year of age, down from an average of 24 months to 9 months, thus allowing infants to get the intervention services they need even earlier which can reduce the lifelong impact of impairment.

A total of 6 sites are currently included in the CPF Early Detection Network (Nationwide Children's Hospital, Kennedy Krieger Institute, UCLA Medical Center, Children's Hospital of Philadelphia, University of Utah and Lurie Children's Hospital). We will be expanding to Emory University in Atlanta and Columbia University in New York in 2021.

The purpose of this project is to create a scalable approach to system wide practice change resulting in earlier diagnosis and treatment of cerebral palsy.

Goals for 2021 include

1. Start of a five year study for early intervention supported by a NIH RO1 grant.
2. Testing of automated technology for assessment of General Movement Assessments in the NICU. We aim to validate the sensitivity and specificity of the GMat compared to a group of advanced GMA trained examiners through a multisite study (throughout the network).
3. Standardize telehealth visits and neurodevelopmental consults for high risk or CP under 2 years old.
4. Expand Electronic Medical Record project: implement modules through EPIC and SQL forms for common elements of early CP detection.
5. Continue development of the 3 for the under 3: Expand and refine the intervention for infants with high-risk for motor delays. We will provide web-based modules with support groups and online discussions.

PUBLICATIONS

Maitre et al. Standardized neurodevelopmental surveillance of high-risk infants using telehealth: implementation study during COVID-19. *Pediatr Qual Safety*. 2021

Duncan AF, Maitre NL. Sleep, cognition and executive functioning in young children with cerebral palsy. *Adv Child Dev Behav*. 2021;60:285-31, DOI: 10.1016/bs.acdb.2020.11.002

Letzkus et al. A systematic review of assessments and interventions for chronic pain in young children with or high risk for cerebral palsy. *J Child Neurol*. 2021

Ayala et al. Assessments and interventions for spasticity in infants with or at high risk for cerebral palsy: A systematic review. *Pediatr Neurol* (2020), doi: <https://doi.org/10.1016/j.pediatrneurol.2020.10.014>

Tanner et al. Assessments and interventions for sleep disorders in infants with or at high risk for cerebral palsy: A systematic review. *Pediatr Neurol* (2020), doi: <https://doi.org/10.1016/j.pediatrneurol.2020.10.015>

Maitre et al. Network Implementation of Guideline for Early Detection Decreases Age at Cerebral Palsy Diagnosis. *Pediatrics* May 2020, 145 (5) e20192126;

Byrne et al. 2019 Comparing parent and provider priorities in discussions of early detection and intervention for infants with and at risk of cerebral palsy

Byrne R, Noritz G & Maitre N. 2017 Implementation of Early Diagnosis and Intervention Guidelines for Cerebral Palsy in a High-Risk Infant Follow-Up Clinic

PRESENTATIONS

Our network has presented this work over 50 times at international conferences, ground rounds and workshops.

EDUCATION AND TRAINING

1. Implementation of Early Detection and Intervention Conference
2. HINE training

INTERNATIONAL COLLABORATION

Partnering with UNICEF and World Health Organization to pilot study in Peru, Uganda and Bulgaria with the plan to create a model that can be developed by countries from around the world. Two part study- with Part 1 completed and plan to start Part 2 May 2021

INCLUSIVE SCHOOL COMMUNITIES

CPF IMPROVES INCLUSION OF STUDENTS WITH DISABILITIES

We believe that inclusion begins in the schools by ensuring that not only are children with disabilities receiving the very best possible education to meet their individual needs but also creating communities where children of all abilities learn, play, and grow together. The Just Say Hi in the Schools Curriculum is a national program with digital materials available that teaches children, and supports teachers, to break down stereotypes, start respectful conversations, and create meaningful relationships with those who may be different from themselves. Our Just Say Hi program results in acceptance and understanding of each other's needs and differences within the educational setting, ultimately creating a more successful, inclusive school community.

Just Say Hi in Schools 2021 Priorities

1. Complete online student portal for NYC DOE.
Justsayhinschools.org

This was completed in February. Support for the portal completion was made possible by funding provided by the NYC DOE. The portal contains over 100 lesson plans, video resources, professional learning resources, and family engagement materials.

2. Create stakeholder working group to revise Just Say Hi materials and webinar series.

Stakeholder group, made up of 5 individuals with disabilities, convened to focus on targeted updates to the webinar series. Revisions for webinar series are in process and will be completed by the summer.

3. Develop a strategy for national JSH expansion.

CPF seeks to scale JSH nationally to increase impact beyond current rates of growth in NYC. Informed by pilot learnings, CPF initially planned to scale to specific geographies that have strong local funding potential as well as grassroots support of principals and parents toward disability inclusion. Based on preliminary research, CPF has prioritized six cities (Atlanta, Boston, Chicago, Columbus, Los Angeles, and San Diego). In light of COVID-19 and racial justice uprisings in the US, CPF is seeing an increased demand from schools for academic remediation work as well as social-emotional learning and diversity, equity, and inclusion (DEI) programming, presenting new opportunities for how CPF packages JSH to schools

4. Partner with NYU to create a research agenda for JSH.

Develop a research agenda to empirically evaluate the impact of Just Say Hi and propose a longitudinal plan of study with variations in effort across activities. Partner with NYU and Dr. Mary Aciri, a senior evaluator and health and mental health disparities services researcher with a background in clinical social work.

PRESENTATIONS

This preliminary work has been presented at AACPDM inclusion workshops.

EDUCATION AND TRAINING

Development of webinar series for teachers.

COLLABORATION

Partnering with Morgan Stanley to develop an implementation strategy for growth.



DIGITAL RESOURCES

CEREBRAL PALSY RESOURCE

Being exposed to a whole new world of cerebral palsy medical terminology, interventions and information can be confusing and overwhelming. The Cerebral Palsy Resource, CPResource.org features reliable information and resources, from expert videos, podcasts, books, or research studies to great toys, parenting tips, accessibility resources, and travel blogs all designed to help our community navigate their journey more easily.

NEW TOPICS INCLUDE

Research & Clinical Trials

Self Advocacy

Gait Development & Mobility

From feedback from our community updated navigation will also allow the user to search by Ages & Stages, Functional Level and Type of CP.

<https://cpresource.org/>

CP CHANNEL

All things cerebral palsy, all on one free mobile APP, providing exclusive content and resources when you need it, where you need it. Get the facts from the worlds leading experts and get inspired by our celebrity cerebral palsy advocates.

<https://www.yourcpf.org/cpproduct/cp-channel>



HOME > ABOUT CP RESOURCE > TOPICS > VIDEOS & PODCASTS >

How Does Cerebral Palsy Affect The Body?



"How we talk or think about cerebral palsy can make a big difference in how other people think and talk about cerebral palsy."

[Watch the Expert Video](#)

EVOLVE 21

Evolve 21 is the first inclusive exercise app for people of all abilities. Evolve21's trainers represent individuals with different physical abilities. Originally designed as a fundraising APP the foundation will now work with Dr. Byron Lai and NCHPAD to develop this into an exercise app for people with disabilities.



ADVOCACY & AWARENESS

OVERVIEW

We aim to increase global awareness and focus for cerebral palsy research and funding in order to improve health outcomes for people with cerebral palsy. We not only lead the way in advocating for US federal funding and national cerebral palsy initiatives, but we also partner with global entities including the World Health Organization, UNICEF and the United Nations to improve lives around the world. Awareness and Advocacy go hand in hand to create positive change. Our awareness initiatives highlight the achievements, talents, and diversity of those living with cerebral palsy, clinicians and researchers, as well as highlighting the critical public health need that there is much more to be done to improve long term outcomes, increase community programs and support services so that those with cerebral palsy can lead their very best lives.

OUR IMPACT

National Cerebral Palsy Awareness Day – Since 2006, March 25th is designated National Cerebral Palsy Awareness Day. Cynthia Frisina, VP of Partnerships at the Cerebral Palsy Foundation, and past Reaching for the Stars. A Foundation of Hope for Children with

Cerebral Palsy (RFTS) Co-Founder and Executive Director, created this national awareness day to focus on the lack of research and progress in the treatment of Cerebral Palsy despite CP being the most common lifelong motor disability. Through the merger of CPF and RFTS in 2019 we have strengthened our ability to bring cerebral palsy awareness to the forefront.

US Federal Advocacy: Centers for Disease Control / National Institutes of Health Appropriations – Our Advocacy efforts currently focus on increasing the focus and federal funding of cerebral palsy research in the United States. the annual federal Appropriations budget. If we took everyone in America who has cerebral palsy, we would be the 12th largest city in the country! Yet, Cerebral Palsy is vastly underfunded at the US federal level despite impacting more than 1,000,000 Americans and more than 17,000,000 people worldwide. We work with key lawmakers and policy makers with the goal of ensuring cerebral palsy research initiatives are considered and funded.

CDC Funded Disorders	U.S. Population	2020 CDC Budget
Fetal Alcohol Syndrome	0.2 – 1.5 per 1,000 children	\$11,000,000
Spina Bifida	1 in 2,758	\$6,000,000
Autism/ASD	1 in 88 children	\$23,100,000
Thalassemia	Fewer than 1,000 cases in U.S.	\$2,100,000
Fragile X	1 in 11,000 females	\$2,000,000
Hemophilia	1 in 5,000 males	\$8,600,000
Cerebral Palsy	1 in 345 children	\$0

EDUCATIONAL & TRAINING EVENTS

EARLY DETECTION & INTERVENTION CONFERENCE

The 2021 E-Health Summit shared new pathways for translating knowledge into practice for the Implementation of early detection and intervention of cerebral palsy from the best researchers and clinicians in the field. Attendees included over 400 physicians, therapists and administrators from around the world. We were also excited to offer limited selections of in-person HINE, HNNE, and GMA training at Emory University in Atlanta, GA. Our virtual format provided access to more than 40 interactive workshops with continued access over the next 3 months. This year also featured an optional pre-conference Basic Core Early Detection E-Course for those who had not attended a past conference. This course provides attendees with a structured outline of basic information for translating knowledge into practice for early detection of cerebral palsy at their local sites.

- Live Keynote Lectures
- Moderated Expert Panels
- Over 30 Interactive Workshops led by World-Renowned Clinicians and Researchers
- On Demand workshops available for 3 months
- Free Digital Poster Presentations
- Implementation Skill-Based Courses
- Exhibitor Hall and Networking Opportunities
- NEW - Pre-Conference Basic Core E-Course will be made available as a pre and post conference registration
- NEW - Poster Symposia Workshop: Top poster abstracts to be presented in a panel.



 **CEREBRAL
PALSY
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2021 | Aug 13-14
Early Cerebral Palsy
e-health summit

DETECTION INTERVENTION IMPLEMENTATION

SAVE THE DATE

VIRTUAL TOWNHALLS

In 2021 we expanded our educational offering to people with cerebral palsy and their families with a 5 part "Virtual Town Hall- New Horizons Webinar Series." This series with top clinicians took an in-depth look at treatment options for symptoms of cerebral palsy, medical conditions that may accompany cerebral palsy, as well as providing advice on managing care, and helpful tips to improve participation and inclusion of those with cerebral palsy.

We conducted 5 Townhalls with Columbia University in New York, Shirley Ryan Ability Lab in Chicago, Rady Children's Hospital in San Diego, Scottish Rite Children's Hospital in Texas and Nationwide Children's Hospital in Ohio. We had over 610 registered attendees who participated in the Townhalls and over 10,000 views of the recording on our social media channels.

Excitingly this series will continue in the Fall of 2021 with two more townhalls being conducted focused on Adult Healthcare and Sports & Physical Activity.

VIRTUAL TOWN HALL SERIES



NEW HORIZONS
CEREBRAL PALSY UPDATE FOR FAMILIES

Join leading experts from:

NEW YORK - Thursday November 5th, 6:30pm ET

SAN DIEGO - Monday November 16th, 5pm PT

CHICAGO - Thursday December 3rd, 7pm CT

 **CEREBRAL PALSY FOUNDATION**

 **COLUMBIA**
WEINBERG FAMILY
CEREBRAL PALSY CENTER

 **Rady Children's Hospital**

 **Southern Family Center
for Cerebral Palsy**

 **Shirley Ryan
AbilityLab**

 **UC San Diego**
SCHOOL OF MEDICINE

 **Northwestern
University**

