**CHILD-BRIGHT NETWORK**

#### 2021-2022 Report to Community. Building on our momentum.

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# LANDING PAGE

**Welcome Letters**

Annette Majnemer, Frank Gavin, and Logan Wong welcome you to our Report to Community with their personal highlights for 2021-2022, and thoughts on our network’s mission going forward.

[BUTTON: Learn more]

**About CHILD-BRIGHT**

Our innovative pan-Canadian network endeavours to improve life outcomes for children and youth with brain-based developmental disabilities and their families.

[BUTTON: Learn more]

**Program Updates**

Read about the work of our research, training, knowledge translation, and citizen engagement teams, as well as our data coordinating centre and health economics platform.

[BUTTON: Learn more]

**PROJECT UPDATES**

Learn more about the progress of our 13 research projects across Canada in the last fiscal year.

[BUTTON: View projects]

**Our Youth**

Our National Youth Advisory Panel continued to make their mark in patient-oriented research.

[BUTTON: Learn more]

**Preparing for Phase 2**

Our network strives to grow from Network to Movement. Our transition from Phase 1 to Phase 2 will help us achieve this goal.

[BUTTON: Learn more]

**Network Outputs**

It has been a busy year for all our members. Discover how researchers, patient-partners, families, and staff made their mark in patient-oriented research through various outputs.

[BUTTON: Learn more]

**CONTACT US**

Interested in the CHILD-BRIGHT Network’s work? Reach out to learn how you can get involved, to share your story, or to ask a question.

[BUTTON: Get in touch]

Follow CHILD-BRIGHT online

# LETTERS

**Welcome to our Report to Community!**

We hope that you enjoy scrolling through this issue and reading about our project and program teams’ many accomplishments in the last year. In addition to sharing about our progress, we are excited to share insights into our upcoming work as part of CHILD-BRIGHT Phase 2. During Phase 2, we plan to build on our achievements for greater health impact for children and youth with brain-based disabilities and their families.

Read our welcome messages to learn more, and thank you for being part of the CHILD-BRIGHT community!

## A letter from Annette Majnemer

CHILD-BRIGHT Nominated Principal Investigator and Scientific Co-Director

To our CHILD-BRIGHT community,

It’s hard to believe I am penning these words for our sixth annual Report to Community! When we launched this network in 2016, we set an ambitious goal: pioneering patient-oriented research to meaningfully improve the lives of children and youth with brain-based disabilities and their families.

We had high hopes, but the network’s advances since then have exceeded all of our wildest expectations. I’m so proud to see the strides we’ve collectively taken in meeting this goal. As Phase 1 of our network winds down, we are turning our attention to the question of how we can continue building on this momentum to accomplish our mission in Phase 2. At this turning point, I am moved to look back not only at the accomplishments of the 2021-22 year but from the entire span of this first phase of our work.

Allow me to share just a few highlights of the past six years with you here:

**RESEARCH**

Our 13 patient-oriented research projects have progressed by leaps and bounds since the beginnings of the network. In some ways, we were starting from scratch in developing research processes in partnership with patients and health/community partners. Our research project teams have been at the forefront of innovation in patient-oriented research. Guided by our Research Program team, each project has spearheaded novel interventions to improve the health outcomes of children with brain-based developmental disabilities using child and family-focused approaches.

We’ve also learned how to leverage our network structure to best effect. Our Research Program has facilitated connections across the 13 project teams through quarterly meetings throughout Phase 1. These meetings have led to program-wide initiatives and allowed for new collaborations across project teams to flourish.

None of these research activities would be possible without the engagement of our patient-partners, including 41 parents, 18 youth with brain-based developmental disabilities, and 13 partnering First Nations communities —as always, I am grateful to our partners for the trust they continue to place in CHILD-BRIGHT and what we are building together.

[BUTTON: READ OUR RESEARCH PROGRAM UPDATE]

[BUTTON: READ OUR 2021-22 PROJECT UPDATES]

**CITIZEN ENGAGEMENT**

Throughout Phase 1, our Citizen Engagement Program has worked to create meaningful connections with our patient- and community partners. Building strong relationships takes time, but we have seen it pay off in how responsive our research activities have been to the needs of children and youth with brain-based disabilities and their families. These authentic collaborations have ensured that our research is relevant and meaningful to families, and likely to have a greater impact on the health care of children with developmental disabilities and their families.

The two committees at the core of this program, the Citizen Engagement Council (CEC) and the National Youth Advisory Panel (NYAP), have overseen the engagement of our patient- and community partners. The CEC established and revised compensation guidelines to support our patient-partners’ contributions as members of CHILD-BRIGHT. The program also pioneered a Parent Liaison role, created to help onboard new parents to the network and provide ongoing support. Meanwhile, the NYAP has been hard at work establishing its own set of tips for researchers looking to engage youth and setting up its consultation service.

[BUTTON: READ OUR CITIZEN ENGAGEMENT PROGRAM UPDATE]

[BUTTON: READ OUR YOUTH MEMBERS’ UPDATE]

**KNOWLEDGE TRANSLATION**

Right from the start, our Knowledge Translation (KT) Program opted to spearhead an integrated KT approach, which engages potential knowledge users (families, people with disabilities, other scientists, clinicians, government agencies and funding partners) as partners in the research process.

This approach has yielded significant results, as we have disseminated knowledge throughout the research process. Over 900 participants have attended the series of webinars our KT team has conducted in collaboration with Children’s Healthcare Canada and CHILD-BRIGHT research projects.

We’ve also fostered innovation in KT thanks to two funding competitions. Seven projects received funding from our KT Innovation Incubator, while the KT outputs of eight CHILD-BRIGHT research teams were supported through our ConneKT grant.

[BUTTON: READ OUR KNOWLEDGE TRANSLATION PROGRAM UPDATE]

**TRAINING**

Our Training Program had a crucial role right in Phase 1: introducing our members to the core elements of patient-oriented research through workshops and webinars exploring the general application of patient-oriented research principles within research projects. Building on this baseline knowledge, over the years our Learning Series and Patient-oriented Discussion sessions explored more challenging topics as teams worked to navigate the intricacies of effective partnership.

As the network’s collective capacity developed, the Training Program team turned its attention to the next generation of patient-oriented research researchers through the Summer Studentship and Graduate Fellowship, Training Innovation Fund and Collaborative Mentorship Grant.

The Training Program also built relationships with other SPOR entities across Canada throughout Phase 1, which led to the creation of the SPOR National Training Entity which will not only streamline patient-oriented research training activities across Canada, but design novel ways of delivering training and mentorship opportunities.

[BUTTON: LINK TO TRAINING PROGRAM UPDATE]

**SUPPORT SERVICES**

Undergirding all our Phase 1 research activities was i) our Data Coordinating Centre team, which set up research project databases and supported the data quality management and analytics needs of each study, and ii) our Health Economics team, which provided ongoing support for the development and implementation of economic evaluations for our research projects.

[BUTTON: READ OUR DATA COORDINATING CENTRE UPDATE]

[BUTTON: READ OUR HEALTH ECONOMICS UPDATE]

Throughout, our central office team has ably shepherded our many activities and shared the results with the community.

Thank you to the Canadian Institutes of Health Research (CIHR) under Canada’s Strategy for Patient-Oriented Research (SPOR), our 28 Phase 1 funding partners, and our 15 Phase 2 funding partners for making our work possible, in the past, present, and future.

Our sights are now set on the future as we build on these many successes. We’ve set the stage; now it is time to move our patient-oriented research into action through insight and methods grounded in implementation science and knowledge mobilization that embed the principles of equity, diversity, inclusion, decolonization and Indigenization. From 2022 to 2026, with your support and that of all our members, we hope to go from Network to Movement.

[BUTTON: READ ABOUT PHASE 2]

It’s been an honour to grow with this network for the past six years. And I know the future is bright. Collectively, we have so much more to contribute to the evolving landscape of patient-oriented research. Will you join us in this next stage of our network?

With gratitude,

Annette Majnemer

## A letter from Sharon McCarry

CHILD-BRIGHT Director of Citizen Engagement

To all our members,

On a personal level, 2021-22 was a milestone: It marked my first year as CHILD-BRIGHT’s Director of Citizen Engagement (CE), as well as my fifth year with the network.

In fact, as a long-time advocate for families living with autism spectrum disorder and other neurodevelopmental disabilities as well as a CHILD-BRIGHT parent-partner prior to taking on this role, I have been fortunate to witness firsthand how the network and its approach to partner engagement has grown over the years.

In that time, I’ve sat in on and participated in an untold number of conversations about how to best engage (and retain!) our patient- and community partners.

Again and again, one of the themes that I’ve heard come up is that of *recognition*. How are we ensuring that the tireless efforts of our patient- and community partners are appropriately acknowledged?

With these past discussions in mind, I’d like to take this space to do just that.

I’ll start off by thanking the 72 patient-partners—of whom 41 are parents, 16 are youth, and two are former pediatric patients—and 13 community partners who are currently engaged at CHILD-BRIGHT. We continuously engaged patient-partners on all projects and in every program committee in Phase 1 and are happy to notice the continued steady increase in our number of partnerships over the years, which I believe to be a testament to the strength and durability of the connections we have fostered over time.

I’d also like to recognize members, past and present, of our program’s two committees, the Citizen Engagement Council (CEC) and National Youth Advisory Panel (NYAP), for their devoted efforts. These parents, patients and youth have been the backbone of this program, as they’ve offered guidance in ways to initiate, improve, and sustain engagement within the network. Working alongside these motivated members continues to be a pleasure.

In particular, I’d like to highlight the work of our youth members in taking the initiative to set up and launch their consultation service for Canadian researchers seeking input on their childhood disability studies. Seeing them make their voices heard in research really hammers home a familiar (but no less true) adage: Nothing about us without us.

[BUTTON: Read our NYAP Chair’s Letter]

[BUTTON: Read updates from our youth]

A crucial component of patient recognition is also equitable remuneration. From the very beginning, CHILD-BRIGHT has striven to be a leader in fair compensation for our partners involved in research, governance, and network activities. The network established a set of compensation guidelines early on in Phase 1. We’re also working to develop and deepen relationships with people from underrepresented groups and have updated our compensation guidelines to ensure that these are appropriate and equitable for these new partnerships.

[BUTTON: Read our compensation guidelines]

Speaking of leadership…After six years of the network’s existence, there are many true leaders in patient engagement who have emerged. My mind goes first to my predecessor Frank Gavin, who expertly led CHILD-BRIGHT’s citizen engagement efforts between 2017 and 2021. This past year, we launched the Frank Gavin Patient Engagement Leadership Award in his honour. Donna Thomson, our inaugural recipient, has been a fearless advocate and beacon of excellence both within CHILD-BRIGHT and in the wider research community.

As we grow together in Phase 2 of the network, many things will continue to evolve and shift—as they should! Thanks to our engagement measurement strategy, a collaboration with the Knowledge Translation program team, we have collected solid information about how to optimize our engagement in the years to come.

[BUTTON: Read our Citizen Engagement Program update]

At the same time, I know one thing will not change: the quality of the people around me. You all continue to inspire with your brilliance and dedication to improving the lives of infants, children, and youth with brain-based developmental disabilities and their families and are doing so in true partnership with us.

Hand in hand, let’s move forward with confidence on the road ahead.

Sharon McCarry

## A letter from Logan Wong

CHILD-BRIGHT National Youth Advisory Panel Chair

Dear CHILD-BRIGHT members,

When I joined CHILD-BRIGHT’s National Youth Advisory Panel (NYAP) in 2018, I did so with one primary goal: I wanted to help bring youth voices to research.

Involving youth with brain-based developmental disabilities as partners has not historically been the norm in research, so it’s been great to witness how things have changed even in the past few years. It’s also been exciting to take part in the great works that the NYAP has made towards this goal.

Since 2018, the other NYAP members and I have shared our lived experience as Canadian youth with brain-based developmental disabilities—as well as our knowledge of patient-oriented research—to help shape research, first within CHILD-BRIGHT and then with Canadian researchers working on childhood disability projects. We’ve noticed that researchers are responsive to our suggestions and ideas, so we feel we are having an impact.

In 2021-22, my second year as chairperson, I was pleased to represent the NYAP in many ways, including on CHILD-BRIGHT’s Network Steering Committee and as part of a collaboration with Autism Canada. The NYAP also contributed to two panel sessions on policy and care with the Royal Society of Canada and Children’s Healthcare Canada. I’m proud that we were included in these spaces.

The NYAP also continues to offer our consultation service to Canadian researchers looking to integrate youth perspectives into their research projects about childhood disability. NYAP members completed three external consultations in 2021-22!

We’ve consistently received positive feedback about the value of our input from the project teams who have consulted with us. I see this as a sign that researchers are acknowledging the importance of engaging youth in their work.

We’ve also reached a point as a team where we can share what we’ve learned in our time as Phase 1 members, for example, we participated in a CHILD-BRIGHT Learning Series webinar in 2021 where multiple NYAP members, including myself, spoke about diversity, accessibility, and accommodation considerations when engaging youth in patient-oriented research. We were also invited to contribute to a training session led by the Kids Brain Health Network Policy Advocacy Research Training (PART) Committee on youth engagement in research.

[BUTTON: READ MORE ABOUT THE NYAP’S ACTIVITIES IN 2021-22]

I can’t wait to see how the NYAP continues to grow in Phase 2 and to welcome new youth members from across the country. I’m also excited to be joined by fellow long-time NYAP member Hans Dupuis as co-chair for the 2022-2024 term.

We’ll keep working together to make space for youth with brain-based developmental disabilities to be heard in research!

Logan Wong

# ABOUT

The CHILD-BRIGHT Network is a pan-Canadian patient-oriented research network based at the Research Institute of the McGill University Health Centre. Created in 2016, it works to create brighter futures for children and youth with brain-based developmental disabilities and their families. It is funded by the Canadian Institutes of Health Research (CIHR) under Canada’s Strategy for Patient-Oriented Research (SPOR) in partnership with 28 funding partners from across the country in Phase 1 and 15 funding partners in Phase 2. Our national network includes 350 researchers, clinicians, decision-makers, youth, and parents.

CHILD-BRIGHT’s extensive research program was developed based on research priorities identified by youth, parents, and other knowledge users such as frontline clinicians and health care administrators. From 2016 to 2022, CHILD-BRIGHT carried out 13 multi-centre projects focusing on three themes: early intervention to promote brain and child development; strategies to support the mental health of children and families; and service delivery redesign to address gaps in service. From 2022 to 2026, CHILD-BRIGHT will move its patient-oriented research into action through insight and methods grounded in implementation science and knowledge mobilization, and by embedding the principles of equity, diversity, inclusion, decolonization and Indigenization.

**Our Mission**

Our mission is to foster a movement for change: moving patients into research teams, moving research into improved practice and policy, and moving children and families forward towards brighter futures.

**Our Population**

The CHILD-BRIGHT Network works to make the present and the future brighter for infants, children, and youth with lifelong brain-based developmental disabilities and their families, including individuals with diagnoses of brain-based disorders (e.g. autism spectrum disorder, attention deficit hyperactivity disorder, fetal alcohol spectrum disorder, cerebral palsy, intellectual or learning disabilities), and individuals at high risk for a brain-based disability (e.g. preterm birth, congenital heart disease, genetic anomaly).

**Our Reach**

We aim for our work to reach and involve families across the country, and the world! Consult our map to see the geographic reach of our membership, activities, and impact.

[BUTTON: Download the map]

**Our Membership**

To successfully accomplish our mandate under Canada's Strategy for Patient-Oriented Research (SPOR), we work in active partnership with a wide range of people including patients, parents, youth, researchers, health professionals and decision-makers in research so as to build a sustainable and accessible health care system that optimizes the health of children with brain-based developmental disabilities, and their families.

[BUTTON: View our membership]

**Our Funding Partners**

CHILD-BRIGHT is made possible thanks to grant by the Canadian Institutes of Health Research (CIHR) under Canada’s Strategy for Patient-Oriented Research (SPOR), and generous funding partners from public and private sectors across Canada.

[BUTTON: View our Phase 1 partners]

[BUTTON: View our Phase 2 partners]

**OUR RESPECT OF THE LAND ON WHICH WE WORK**We recognize that CHILD-BRIGHT's work takes place on many traditional Indigenous territories across Canada. Our head office is located on the traditional unceded territory of the Kanien’kehà:ka Peoples, a place which has long served as a site of meeting and exchange among First Nations.

The legacy of our colonial history continues to have ramifications on the health and wellbeing of children across the country. We are committed to doing our part in rooting out colonialism and systemic racism in our pediatric health systems. We understand that there is much for us to do in order to make strides towards this goal and the acknowledgement of the traditional on which our work takes place is only the first step in a much larger process. We recognize the importance of doing our part to address these harms so we can ensure that all children with brain-based developmental disabilities, including First Nations, Métis, and Inuit children, receive the care and supports they need to live rich and full lives.

# PROGRAMS & SERVICES

The CHILD-BRIGHT Network is composed of four programs and two service teams that work to create a brighter future for children and youth with brain-based developmental disabilities and their families across their lifespan. Read more about their activities below.

**Research Program**

The Research Program is studying new therapies, service models, diagnostic tests and technologies to improve the physical and mental health of children with brain-based developmental disabilities and their families.

[BUTTON: Read our update]

**Citizen Engagement Program**

The Citizen Engagement Program aims to meaningfully and effectively engage as many people touched by brain-based developmental disabilities as possible to guide the network.

[BUTTON: Read our update]

**Knowledge Translation Program**

The Knowledge Translation Program develops and implements strategies to effectively translate the results of our research findings to families, health care professionals and society at large.

[BUTTON: Read our update]

**Training Program**

The Training Program develops training and mentoring opportunities to help foster a culture of patient-oriented research that will positively impact health research in Canada and improve outcomes for patients and their families.

[BUTTON: Read our update]

**Health Economics**

The Health Economics team evaluates the resource and service use, costs, and cost-effectiveness of emerging technologies, interventions, treatments, and services for a wide range of childhood brain-based developmental disabilities. We also evaluate the health-related quality of life of children and their caregivers.

[BUTTON: Read our update]

**Data Coordinating Centre**

The Data Coordinating Centre helps CHILD-BRIGHT research project teams develop secure, reliable, and rigorous systems for the collection, analysis, and reporting of study data.

[BUTTON: Read our update]

We are deeply committed to the goals of equity, diversity, inclusion, decolonization, and Indigenization and are building a program to centre these concepts in our work.

[BUTTON: Read more]

## CITIZEN ENGAGEMENT PROGRAM

THE CITIZEN ENGAGEMENT PROGRAM AIMS TO MEANINGFULLY AND EFFECTIVELY ENGAGE AS MANY PEOPLE TOUCHED BY BRAIN-BASED DEVELOPMENTAL DISABILITIES AS POSSIBLE TO GUIDE THE NETWORK.

This year saw the culmination of many years of building relationships and fostering connections bear fruit for the Citizen Engagement (CE) Program. In 2021-22, the CE team:

**Shared our findings on CHILD-BRIGHT partner engagement**

After many years developing and refining our engagement strategies, we asked for feedback on these from our network members via surveys and interviews. We published the results in a three-part blog series, “Stakeholder Engagement in the CHILD-BRIGHT Network, 2018-2020.” The series was prepared by our Measuring Patient Engagement working group, composed of CE and Knowledge Translation Program members, in collaboration with our Communications team.

Working with our patient-partners, we developed tip sheets for researchers and patient-partners involved in POR based on the survey responses from the open-ended questions on the Public and Patient Engagement Evaluation Tool (PPEET), part of the Stakeholder Engagement series.

[BUTTON: LEARN ABOUT STAKEHOLDER ENGAGEMENT IN THE CHILD-BRIGHT NETWORK]

[BUTTON: READ TIPS FOR RESEARCHERS WORKING WITH PATIENT-PARTNERS]

[BUTTON: READ TIPS FOR PATIENT-PARTNERS ENGAGED IN PATIENT-ORIENTED RESEARCH]

Patient-partners were involved at every step of this process. They were part of the working group; contributed to the series by responding to the surveys and participating in the interviews; provided commentary on the survey results; gave recommendations for the network on how to improve and sustain engagement and created resources for teams to do so, and a parent-partner conducted half of the interviews.

**Recognized leaders in patient engagement**

Over the past six years, we’ve been proud and grateful to note the emergence of many leaders in patient engagement within our network and across Canada. In 2021, we launched the Frank Gavin Patient Engagement Leadership Award to honour Frank Gavin (former Director of Citizen Engagement) and to recognize other leaders in patient engagement in research related to children with brain-based developmental disabilities and their families.

Our first recipient, Donna Thomson, received the award for her exemplary leadership skills, active partnership in research, advocacy work, and contributions to CHILD-BRIGHT as well as to other organizations. Our patient-partners (parents and youth) sat on the panel and contributed to the selection process and gave helpful feedback for the next iteration.

[BUTTON: MEET DONNA THOMSON, THE FIRST RECIPIENT OF THE FRANK GAVIN PATIENT ENGAGEMENT LEADERSHIP AWARD]

**Furthered our commitment to EDI**

We hired a student through the Canada Summer Jobs program to help further CHILD-BRIGHT’s commitment to advancing equity, diversity, and inclusion (EDI). The student analyzed our current membership demographics, gathered information regarding EDI best practices in patient-oriented research (POR), compiled and presented this information to help inform our strategy.

**Prepared for CHILD-BRIGHT’s Phase 2**

We developed five main objectives for Phase 2:

* Creating a toolkit on best practices in patient-engagement and POR based on learnings from Phase 1 for teams to incorporate at the start of their implementation science (IS) research projects
* Recruiting from underrepresented groups to the Citizen Engagement Council and National Youth Advisory Panel to ensure that more voices are heard
* Updating our patient-partner compensation guidelines based on gaps identified by our patient-partners
* Supporting all IS projects and knowledge mobilization (KM) outputs to engage patient-partners during Phase 2, from protocol development through to final reports
* Continuing to develop our engagement measurement strategy to optimize patient-partner engagement for Phase 2.

[LINK: LEARN MORE ABOUT CITIZEN ENGAGEMENT IN PHASE 2]

[PHOTO CAPTION: CHILD-BRIGHT Patient-Partner and inaugural Frank Gavin Patient Engagement Leadership Award recipient Donna Thomson

*Alt text: Headshot of Donna Thomson*]

## KNOWLEDGE TRANSLATION PROGRAM

THE KNOWLEDGE TRANSLATION (KT) PROGRAM DEVELOPS AND IMPLEMENTS STRATEGIES TO EFFECTIVELY TRANSLATE THE RESULTS OF OUR RESEARCH FINDINGS TO FAMILIES, HEALTH CARE PROFESSIONALS AND SOCIETY AT LARGE.

In 2021-22, we:

**Developed KT tools**

Over the course of the year, we conducted four webinars in collaboration with our research projects and Children’s Healthcare Canada.

[VIDEOS]

We also developed the KT Bulletin, a newsletter that provides targeted KT content to network research projects.

We were also proud to launch the KT Library in March 2022. The library houses network publications as well as lay summaries created by youths with disabilities who were mentored by our team.

**Fostered KT innovation and research**

We continued to fund innovative KT projects via our KT Innovation Incubator (KTII) grant competition. In the past year, two new projects were funded. The innovative selection process for projects continued to include parents, youth with disabilities, clinicians, and other community partners in the grant peer review process.

The first project, Let’s go to the Library, is creating a digital library of brief storybooks on different topics covering sexuality for pre-teens to read alone or with their parents.

The second project, CommuniKIDS, is developing a freely accessible bilingual trial results communication tool in collaboration with youth and families impacted by different forms of childhood disability.

[BUTTON: Learn more about the 2021 KTII winners]

Through the ConneKT Fund, we awarded funds to two CHILD-BRIGHT research projects this year to develop knowledge translation events or products.

The PIUO project team will use the funds to expand the collection of articles of their newsletter, *Trends in Pediatric Palliative Care*, to include articles relevant to families of children living with serious illness.

And the BRIGHT Coachingteam is designing a ConneKT event on telerehabilitation for families of children with developmental disabilities.

In addition to these funding opportunities, the KT Program conducted KT research projects looking at network community engagement and KT innovation. We are also conducting a process evaluation of the KT Program. The evaluation aims to explore the process of the implementation of the KT Program activities.

In 2021-22, the CHILD-BRIGHT Policy Hubworked closely with various groups to organize three Policy Dialogues:

* February 1, 2022: Transitions Process In Canada
* February 17, 2022 (Side event - Global Disability Summit): [A](https://www.youtube.com/watch?v=twmG_CHgFjE)pplying the UN CRPD During COVID-19 Pandemic and in the Recovery Process
* March 28, 2022: Inclusive Play in Canada Through a Mobile Health App: Research, Community and Policy

In Phase 2, the Knowledge Mobilization (KM) Program will build on our KT Program’s achievements to facilitate the movement of network-driven evidence for rapid uptake. The program will do so by expanding Phase 1’s Policy Hub and by establishing new clinical, family, and community Hubs. These hubs will support collaborative and multidirectional exchange of knowledge within and across these knowledge user groups.

[BUTTON: Learn more about the KM Program’s Phase 2 plans]

## RESEARCH PROGRAM

THE RESEARCH PROGRAM IS STUDYING NEW THERAPIES, SERVICE MODELS, DIAGNOSTIC TESTS AND TECHNOLOGIES TO IMPROVE THE PHYSICAL AND MENTAL HEALTH OF CHILDREN WITH BRAIN-BASED DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES.

In Phase 1, our research project teams conducted research to generate evidence for novel interventions aimed at improving outcomes for children and youth with brain-based developmental disabilities. Many years of hard work are now bearing fruit for our teams. In 2021-22, we:

**Moved our Phase 1 projects towards completion**

As of March 31, 2022, nine of our 13 projects had completed recruitment, which is a major accomplishment. Most teams are currently collecting and analyzing data. We are excited to learn about and disseminate the findings from each project.

[BUTTON: READ THE UPDATES FROM OUR PROJECT TEAMS]

“The evidence generated by the 13 research teams in Phase 1 is leading to new discoveries and treatments and moving our field further ahead. I’m looking forward to Phase 2, where we will bring evidence-based interventions one step closer to changing the lives of children with brain-based developmental disabilities and their families.” – Steven Miller, CHILD-BRIGHT Scientific Co-Director and Research Program Co-Lead

[BUTTON: View our research project update infographic]

**Studied our membership demographics**

The Research Program and Citizen Engagement Program co-supervised a summer student, Garima Saini, who conducted research related to equity, diversity, inclusion, decolonization and Indigenization (EDI-DI) in our network. Garima's work served as useful background material for our new EDI-DI Program and CHILD-BRIGHT’s grant application to the SPOR Networks – Knowledge Mobilization and Implementation Science competition in December 2021.

**Fleshed out the Phase 2 Implementation Science Research Program**

Implementation science (IS) is a field of research that studies how evidence-based interventions will interact with “real-world” settings with the ultimate outcome of understanding what needs to be in place for the intervention to succeed in practice and at scale. For Phase 2, our primary goal is conducting IS research to promote the uptake of evidence generated from Phase 1, as well as evidence-based tools that were used in Phase 1, to improve health processes and outcomes for children with brain-based developmental disabilities and their families.

We recognize that there are too few IS researchers who focus on implementing evidence to improve outcomes for children with brain-based developmental disabilities and their families. By conducting our Phase 2 projects, we will build capacity at the intersection of these two fields in collaboration with the Training & Capacity Building Program.

To prepare for this next phase of our network, our teams began brainstorming the design of their new research projects in August 2021. This evolved into larger, collaborative group discussions at our quarterly theme-wide meeting. Recognizing that CHILD-BRIGHT required more expertise in knowledge mobilization (KM) and IS to develop these projects, we recruited Janet Curran as our new IS Research Program Co-Lead. By the time we submitted our grant application to CIHR in December, we had developed 10 IS and one KM projects.

In addition to these 11 projects, we are very grateful to be collaborating with the Maternal Infant Child and Youth Research Network (MICYRN[)](https://www.micyrn.ca/) to evaluate the implementation of patient-oriented research. We expect that findings from this work will inform child health research infrastructure needs across Canada.

[PHOTO CAPTION: Phase 2 IS Research Program Co-Lead Janet Curran]

[BUTTON: Learn more about our plans for Phase 2]

## TRAINING PROGRAM

OUR PROGRAM DEVELOPS TRAINING AND MENTORING OPPORTUNITIES TO HELP FOSTER A CULTURE OF PATIENT-ORIENTED RESEARCH THAT WILL POSITIVELY IMPACT HEALTH RESEARCH IN CANADA AND IMPROVE OUTCOMES FOR PATIENTS AND THEIR FAMILIES.

In 2021-22, our Training Program continued developing capacity in patient-oriented research (POR) throughout the network. We focused on enhancing the training experience of students and trainees while providing research teams with training opportunities on advanced POR topics. In 2021-22:

**We enhanced POR capacity by offering a suite of training events**

We developed and launched our new virtual bi-monthly **Patient-Oriented research Discussions (PODs),**in partnership with our Graduate Fellowship recipients. The PODs are an open forum designed to facilitate the exchange of ideas and explore topics, questions, or resources that enhance patient engagement in research. In the 2021, we hosted four sessions:

[Recordings]

"One of the Training team's proudest achievements in Phase 1 has been our ability to adapt to the pandemic, like with our diverse Patient-Oriented research Discussions (PODs) series.”- Kent Cadogan Loftsgard, CHILD-BRIGHT Patient-Partner & Training Committee member

Through our ongoing annual **Learning Series** webinars, we also continued to explore practical considerations in relation to POR. CHILD-BRIGHT’s National Youth Advisory Panel members as well as members from our broader network facilitated this year’s series:

[Recordings]

CHILD-BRIGHT’s Training Innovation Fund funded the development of a suite of simulation-based learning vignettes and associated facilitation guides. Hosted at Holland Bloorview**,** the Client and Family Engagement in Research Simulations are designed for research teams and patients/families to co-learn and address complex challenges experienced by patients and scientists when partnering in family-centered research in childhood disability.

We also hosted our second **Virtual Symposium** and improved it based on feedback from the previous year. For instance, we expanded the schedule to provide more opportunities for projects focused on childhood brain-based developmental disabilities to provide updates and address questions from the community.

[BUTTON: View the recording]

**We developed capacity for the next generation of patient-oriented researchers with two opportunities**

We offered the **Graduate Student Fellowship in Patient-Oriented Research** for a second timeto enhance the training experience of graduate students and postdoctoral fellows engaged with POR projects related to childhood brain-based developmental disabilities. In 2021-22, we supported six candidates across Canada with over $55,000 in funding.

[BUTTON: LEARN MORE ABOUT THE GRADUATE STUDENT FELLOWSHIP]

We also awarded $40,000 in financial support to 14 students via our fifth annual **Summer Studentship Program**. This supported theirsummerwork with eight of our CHILD-BRIGHT research project teams.

[BUTTON: LEARN MORE ABOUT THE SUMMER STUDENTSHIP PROGRAM]

In anticipation of CHILD-BRIGHT’s **Phase 2** launch, we welcomed Celia Laur as co-lead of our Phase 2 program, which will be renamed the **Training & Capacity Building Program.** Celia’s expertise in Implementation Science and education will inform our training activities over the next four years. We also strengthened our partnerships with key representatives from CHILD-BRIGHT’s new Implementation Science (IS), Knowledge Mobilization (KM), and Equity, Diversity, Inclusion, Decolonization and Indigenization (EDI-DI) Programs to highlight training needs and areas for collaboration. We are focusing our efforts on introducing these new topic areas, while identifying the specific learning needs of our network members and project teams so we can better deliver targeted training activities.

[BUTTON: Learn more about the Training Program’s Phase 2 plans]

[PHOTO CAPTION: Celia Laur is the new Phase 2 co-lead of the Training & Capacity Building Program]

[PHOTO CAPTION: Kent Cadogan Loftsgard is a long-time CHILD-BRIGHT Patient-Partner and Training Committee member]

## HEALTH ECONOMICS

The Health Economics team evaluates the resource and service use, costs, and cost-effectiveness of emerging technologies, interventions, treatments, and services for a wide range of childhood brain-based developmental disabilities. We also evaluate the health-related quality of life of children and their caregivers.

Our team provides ongoing support for the development and implementation of economic evaluations for CHILD-BRIGHT research projects by:

* Designing and adapting tools for measuring the resources used by families for the care of children with neurodevelopmental disorders. These tools are based on the Resource Use Questionnaire, a validated health economic tool.
* Supporting the incorporation of tools for measuring the health-related quality of life for children and caregivers, such as the Health Utilities Index.
* Engaging undergraduate and graduate trainees as part of the Health Economics core team.
* Retrieving and assigning costs to all resources reported using provincial sources.
* Working with members across CHILD-BRIGHT to facilitate cooperation between platforms and users, including the Data Coordinating Centre.
* Developing and conducting network-wide webinars on heath economics.
* Examining key emerging issues and challenges for economic evaluation in the field of childhood disability.

*“It is very powerful to see the common quality of life and socioeconomic information provided by youth and families across Canadian provinces who are participating in different CHILD-BRIGHT projects. In addition to providing information about the cost-effectiveness of CHILD-BRIGHT interventions, this information can provide better context around out-of-pocket cost and caregiving time.”*

*– Jennifer Zwicker, Health Economics Co-Lead*

In 2021-22:

* We began to transfer data from completed network studies to start analyzing economic data. We will continue our cost-effectiveness analysis as data and resources become available.
* Our team helped four CHILD-BRIGHT research projects collect common quality-of-life outcome measures for children and caregivers.
* We assisted five projects in collecting common resource utilization and cost data.
* We helped five projects collect health economic data.
* We engaged five trainees as part of the Health Economics team.
* Health Economics Co-Lead Jennifer Zwicker led a working group advising the CHILD-BRIGHT executive team on policy-related considerations for the network.

*“Despite the many challenges posed by the COVID-19 pandemic, project teams were able to generate and share vital health economic data which is currently under analysis for multiple studies. These analyses will constitute vital evidence to inform the funding and delivery of services and programs for children with a brain disorder.”*

*– Wendy Ungar, Health Economics Lead*

[BUTTON: Learn more about CHILD-BRIGHT Phase 2]

## DATA COORDINATING CENTRE

WE HELP CHILD-BRIGHT RESEARCH PROJECT TEAMS DEVELOP SECURE, RELIABLE, AND RIGOROUS SYSTEMS FOR THE COLLECTION, ANALYSIS, AND REPORTING OF STUDY DATA.

In 2021-22, we:

* Worked closely with seven CHILD-BRIGHT research teams to support their data management needs in relation to their studies. Three of their studies require oversight from the CHILD-BRIGHT Data Safety Monitoring Board (DSMB). The DSMB meets twice a year to review the safety and effectiveness of trials. For example, the DSMB can ensure the safety of participants in a trial by monitoring whether there are any side effects caused by the treatments being tested.
* Continued our work with the Health Economics service team [LINK to HE page] to support their collection of high-quality data that can be analyzed, disseminated, and implemented into policy and practice.
* Supported the CHILD-BRIGHT Central Office team with their data management needs related to surveys, annual reporting, and network membership.

Throughout Phase 1 of CHILD-BRIGHT, we supported the network in setting up research project databases and supported the data quality management and analytics needs of each study. As research projects complete enrollment for their studies, we will be supporting them by providing statistical analysis and helping with manuscript preparation. Our team will work with project teams to finalize their respective study data sets, which will be retained by each lead study site. We will also work with the studies to explore if and how study data can be made available for future potential reuse by making high-level information about the study data available through Borealis: The Canadian Dataverse Repository.

[BUTTON: Learn more about CHILD-BRIGHT Phase 2]

# PROJECTS

CHILD-BRIGHT’s 13 patient-oriented research examine new diagnostic tests, therapies, service models, and technologies that could improve the physical and mental well-being of children with brain-based developmental disabilities. Discover how each research project progressed in 2021-2022 below.

**BRIGHT Beginnings**

Projects to optimize brain and developmental outcomes

**BRIGHT Supports**

Projects to integrate mental health support into care

**BRIGHT Futures**

Projects to redesign health care services to be more responsive to family needs

View the progress of our 13 research teams

[BUTTON: Consult the infographic]

## MATCH

OUR PRELIMINARY FINDINGS SUGGEST THAT GIVING MOTHERS SUPPLEMENTAL OXYGEN IN THE THIRD TRIMESTER OF PREGNANCY REDUCED RATES OF BRAIN INJURY FOR THEIR BABIES WITH HEART DISEASE.

***Principal Investigators:*** *Mike Seed (SickKids) and Steven Miller (BC Children’s Hospital)*

**Looking back: our work in Phase 1**

In CHILD-BRIGHT’s Phase 1, the MATCH project team tested whether giving mothers supplemental oxygen in the third trimester improved the brain development of their infant with congenital heart disease (CHD). For the chronic hyperoxygenation arm of our study, in which we provide moms with supplemental oxygen throughout the third trimester, our preliminary analysis of 20 participants (of a planned total sample size of 30) has yielded promising results. We are excited to report that the newborns have lower rates of brain injury compared to a control group of newborns with heart disease who were not supplemented with oxygen during pregnancy. In fact, only one of the babies in our study had a mild brain injury, while in the control group, brain injury was present in around 28% of newborns. Our mothers found the oxygen tolerable, and the treatment was not associated with any serious adverse events. We have observed a modest reduction in birthweight in our babies, on average 260 g, which could be an unwanted effect of the treatment.

In the acute hyperoxygenation arm of our study, we provide pregnant moms with supplemental oxygen while doing medical imaging. This allows us to better understand the impact of the oxygen on blood flow around the fetus and how much oxygen reaches the fetus’ brain. For this arm, recruitment is ongoing to reach our target of 150 participants.

Overall, we are learning important information about the effect of supplemental oxygen, which is of interest to those considering this as a strategy to protect the brain in the setting of congenital heart disease. Some of the feedback we have received from mothers participating in the study includes: “It has been a truly rewarding and positive experience to participate in the MATCH research study. My son Henry has greatly benefited from this early intervention. […] Thank you for your passion and dedication to research, and for serving and caring for children like our sweet Henry.” – Jamie, mom of Henry (age 2.5 years old). We’ve worked hard to disseminate these exciting early findings. Our team has published six peer reviewed articles and one book chapter, while our trainees have presented our work at four scientific conferences. Our patient-partners continue to offer invaluable support to the mothers who enrol in the study.

**An eye to the future: what Phase 2 has in store for us**

In the process of undertaking the MATCH study, we have noted rather low rates of neurodevelopmental follow-up in children with CHD. This is in keeping with other recent research, indicating that the neurodevelopmental needs of children with heart disease are underserved. In line with CHILD-BRIGHT’s priorities for Phase 2, we are now planning to explore implementation science practices that might be employed to improve neurodevelopment follow-up practices of babies with CHD in Canada. Babies with significant heart disease require periodic neurodevelopmental assessments to identify developmental delays and treatments in a timely fashion. In Phase 2, we will study how to improve health services such that the patients with CHD who require neurodevelopmental assessments receive them.

We’re excited to tackle this next phase and continue helping babies with CHD and their families. To quote the words of Jamie, one of the mothers in our study, “Put your sunglasses on, because the future is bright!”

[PHOTO CAPTION: Mom Jamie is pictured here with Henry and Meredith.]

[BUTTON:Visit the MATCH project page]

[BUTTON:Read our publication: “Impact of fetal haemodynamics on surgical and neurodevelopmental outcomes in patients with Ebstein anomaly and tricuspid valve dysplasia”]

[BUTTON:Read our publication: “Neurodevelopment and Cognition Across the Lifespan in Patients With Single-Ventricle Physiology: Abnormal Brain Maturation and Accumulation of Brain Injuries”]

[BUTTON: Video to watch: A Strong Heart for a Brain's Healthy Start (SickKids)]

## Parent-EPIQ

WE ARE WORKING WITH PARENTS AND FAMILIES TO CHANGE HOW INFORMATION IS COLLECTED ABOUT CHILDREN BORN PREMATURE, AND TO PUT IN PLACE PRACTICES TO IMPROVE THEIR DEVELOPMENT.

***Principal Investigators:*** *Anne Synnes (BC Women’s Hospital) and Prakeshkumar Shah (Mount Sinai Hospital)*

**Looking back: our work in Phase 1**

Children born very preterm (or “preemies”) and their families may face numerous challenges. In Phase 1, the Parent-EPIQ project worked with parents to improve how we communicate with families about brain-based developmental disabilities, implement practices to improve the development of preemies, and track their health and development.

Our research has revealed a need to change the information that is collected about preemies and how health care providers describe the lives of these children. We’ve identified outcomes and themes that are important to parents, such as motor and language skills, socio-emotional health and behaviour, and quality of life. We are now putting these findings to use by developing recommendations for health care providers and parents.

“As a physician in the neonatal intensive care unit, I was trained to help children who were born preterm reach their ‘best’ potential. However, what is considered the ‘best’? Do we, health care providers, define ‘good’ or ‘bad’ outcomes? We have ignored a big part of the picture: parents and families. While most of the research used deficit-based outcomes, parents and families’ opinions should be acknowledged. This is the way to translate research and knowledge to practice. The importance of patient and family priorities, as well as their research involvements, should be recognized.” -- Mei Mei Lam, neonatologist and CHILD-BRIGHT Summer Student

In the past six years, we have been pleased to note an increasing awareness of the importance of patient-oriented research and outcomes identified by key stakeholders. Importantly, supports for parents of infants born premature have gotten better in Canada, especially with respect to peer support and advocacy.

As we share our team’s work in various venues, we have noticed that the outcomes that matter are shifting and go beyond outcomes that are neurodevelopmental in nature. This shift is an exciting indication of the reach and impact of our study. We look forward to continuing this work in Phase 2 as we engage parents to improve important outcomes of preterm birth.

**An eye to the future: what Phase 2 has in store for us**

Phase 1 was critical to establishing knowledge and understanding what outcomes are most important to parents of preterm children. Our Phase 2 goals include knowledge mobilization (which refers to the co-creation of knowledge by researchers and knowledge users and the use of research results and other knowledge to improve the health care system and its practices to enhance health outcomes) and implementation of our Phase 1 findings (or bringing them into our health care and community systems).

As part of our knowledge mobilization plan, we aim to target three groups: parents; perinatal health care providers such as obstetricians and neonatologists; and the neonatal follow-up community (health care professionals who follows the children in the first few years of life). From the very beginning, we have engaged parents as partners in this work, along with health care teams. This engagement will continue into Phase 2 to ensure our knowledge mobilization will be successful due to our established relationships – especially with patient-partners.

[BUTTON: Visit the Parent-EPIQ project page]

[BUTTON: Read the first Parent Voices blog post]

[BUTTON: Read our publication: “Parental voice - what outcomes of preterm birth matter most to families?”]

[BUTTON: Read the CNFUN 2021 annual report]

## Metformin in CP

WE ARE EVALUATING WHETHER METFORMIN ENHANCES MOTOR AND COGNITIVE SKILLS IN CHILDREN WITH CEREBRAL PALSY.

***Principal Investigators:*** *Darcy Fehlings (Holland Bloorview Kids Rehabilitation Hospital) and Donald Mabbott (SickKids)*

**Looking back: our work in Phase 1**

Our team continues to study whether metformin, a drug commonly used to treat diabetes, can be used to enhance motor and cognitive skills in children with cerebral palsy (CP).

Over the course of our study, we recruited three participants and formed a Stakeholder Engagement Committee (SEC) consisting of five parent-partners and individuals with lived experience with CP. The SEC has been instrumental in ensuring our project is patient oriented by helping us communicate research terms and procedures in lay language, communicating with families, and helping us modify our study methods and procedures to make them less burdensome and more meaningful to families.

However, our progress in determining the effectiveness of using metformin as an intervention for children with CP, and our progress in determining if it is feasible to do the study has been hampered by slow recruitment, despite many families’ interest in participating. We were proactive in finding potential solutions to this ongoing challenge: we changed the criteria and made some of our research activities virtual to help minimize burden on families. Despite these changes, recruitment continued to be unsuccessful. In October 2021, we presented an update to CHILD-BRIGHT’s Data Safety Monitoring Board (DSMB), a group of researchers and clinicians that reviews the safety, data integrity, progress, and efficacy of our trial. The DSMB concluded that we would not be able to recruit enough participants before the end of Phase 1, and recommended the trial be stopped or significantly redesigned.

We then began working with our SEC to redesign our study. Our goal was to design a study with broader inclusion criteria and other changes that would facilitate recruitment, but still yield preliminary clues about whether metformin can enhance motor and cognitive skills in children with CP.

In February 2022, our redesigned study was approved by our SEC, CHILD-BRIGHT leadership, and the DSMB. Our modified protocol has also been approved by Health Canada and the REB at Holland Bloorview and is almost approved by the REB at SickKids. We will soon begin recruiting using our modified protocol.

**An eye to the future: what Phase 2 has in store for us**

Should our study redesign be approved by the research ethics boards, we hope to have 10 participants between the ages of 5 and 18 complete the trial. Once data collection is complete, we will conduct data analysis to answer our study questions about the feasibility, safety, and effectiveness of metformin in improving motor functioning in children and adolescents with CP. We hope to continue to work with our SEC to ensure that our trial is patient oriented in nature, to also help us conduct knowledge translation in a way that is meaningful, relatable and understandable by the CP community and the community at large.

[BUTTON: Visit the Metformin in CP project page]

## SPORT

WE ARE WELL ON OUR WAY TO COMPLETING OUR CLINICAL TRIAL TESTING WHETHER NON-INVASIVE BRAIN STIMULATION IMPROVES FUNCTION IN CHILDREN WITH CEREBRAL PALSY (CP).

***Principal Investigator:*** *Adam Kirton (University of Calgary)*

**Looking back: our work in Phase 1**

We are close to successfully completing our pediatric neurostimulation trial: by the end of the 2021-22 fiscal year, 59 children and families had participated in our camp-based therapy programs and achieved many of their personal goals, with another 27 children committed to participating in our 2022 summer camps in Calgary, Edmonton, and Toronto. Participants completed advanced brain imaging and mapping studies before and after the camps, which will help us understand how their brains develop and respond to therapy.

Thanks to these participants, we are on track to determining whether non-invasive brain stimulation in combination with intensive physiotherapy can enhance motor function in children with weakness due to perinatal stroke. We will collect more data from camp participants in February 2023, after which point we will be ready to move ahead with data analysis.

Importantly, connecting kids and families with similar challenges and goals through the summer camps has yielded social and psychological benefits for the participants. **“**I had a beyond amazing two weeks participating in the [SPORT summer camp] at Holland Bloorview Hospital,” shared camp participant Simone. “Meeting other kids with the same condition as myself, cerebral palsy, some of whom also have faced similar challenges as me, was an eye-opening experience.”

Overall, the SPORT project has created new opportunities for the integration of research and modern clinical care since its inception over five years ago. In that time, brain stimulation has become a popular treatment. Our findings will offer important information to children and families about this popular treatment, including clear estimates of the relative benefits and risks of non-invasive brain stimulation for children with CP.

Our project is also a good example of some of the challenges of institutional, group-based intensive therapy, as the global pandemic delayed the trial by two years.

We were thrilled to see so many kids and families participate across the country and achieve their goals this year and look forward to continuing this work in Phase 2.

**An eye to the future: what Phase 2 has in store for us**

We’re currently in the planning stage for the next phase of the SPORT project. We have already identified promising avenues for knowledge mobilization (which refers to the co-creation of knowledge by researchers and knowledge users and the use of research results and other knowledge to improve the health care system and its practices to enhance health outcomes) and implementation science (bringing our evidence-based interventions into our health care and community systems) that are directly informed by our Phase 1 study.

Our work in Phase 2 will hinge upon collaboration; we have already engaged with CHILD-BRIGHT leadership, multiple partners from Phase 1, and experts in implementation science as we plan our next steps. We have also already begun recruiting patient- and parent-partners to inform the earliest stages the project.

(PHOTO CAPTION: SPORT Principal Investigator Adam Kirton is chased by four summer camp participants during a water gun fight.]

[PHOTO CAPTION: A group of 2022 SPORT summer camp participants.]

[PHOTO CAPTION: Ben, aged 10, rides his bike without training wheels after participating in a 2022 summer camp.]

[BUTTON:Visit the SPORT project page]

[BUTTON: Read our publication: “Exploring Clinical and Neurophysiological Factors Associated with Response to Constraint Therapy and Brain Stimulation in Children with Hemiparetic Cerebral Palsy”]

[BUTTON: Read our publication: "Feasibility of High Repetition Upper Extremity Rehabilitation for Children with Unilateral Cerebral Palsy"]

## IMAGINE

WE’VE USED ADVANCED GENOMICS AND METABOLOMICS TO PROVIDE A DEFINITIVE DIAGNOSIS TO 50% OF CHILDREN WITH ATYPICAL CEREBRAL PALSY.

***Principal Investigators:*** *Jan Friedman**(University of British Columbia) and Clara Van Karnebeek**(University of British Columbia)*

**Looking back: our work in Phase 1**

Our team’s Phase 1 goals were to provide insight into the possible genetic or genomic causes underlying atypical cerebral palsy (CP) in children and to identify the best ways to communicate and support families before, during, and after testing. Atypical CP is an umbrella term for some types of neuro-muscular coordination problems where the cause appears likely to be genetic.

We are happy to announce that we completed the whole genome sequence analysis for all of our 100 study participants and notified them of their results. We were able to provide a definitive, clinically confirmed diagnosis to half of these families. Approximately two-thirds of the metabolomic analysis is complete with the remainder to be completed within the 2022-23 fiscal year.

Our team, including trainees, developed novel bioinformatic tools to look for some specific types of genomic variants that may be responsible for the neurodevelopmental problems seen in some families. Bioinformatic tools are the computational methods used to make sense of the billions of pieces of DNA that we are looking at. This year was spent refining these tools and beginning to re-analyze the genomic data for patients where no cause was found for their atypical CP in our initial analysis.

Throughout Phase 1, we have kept families at the heart of our work. We have explored the needs of families, responded to their suggestions and requests, co-developed several tools to support families throughout their testing journey, and gathered information on how to optimally communicate testing information to families. Our team includes three active parent-partners who helped inform this important work.

Our family-oriented work has already had a demonstrable impact; researchers and clinicians in our field now realize that genetic counselling work does not end at the time of diagnosis but that post-test counselling is as important as pre-test counselling.

**An eye to the future: what Phase 2 has in store for us**

Over the next four years, as we continue to explore possible diagnoses for many of the families without a definitive diagnosis, we hope to build on our research findings from Phase 1. We aim to design, implement, and assess the effectiveness of a comprehensive clinical genomic service for children with severe brain-based developmental disabilities.

Parent involvement is key to achieving this goal. We will identify factors that will help optimize families’ genomic testing experience. We will also consult with parent-partners in other regions of Canada, as well as those involved in other CHILD-BRIGHT Phase 2 projects, to understand how to optimize local implementation of such a clinical service elsewhere in the country.

[BUTTON: Visit the IMAGINE project page]

[BUTTON: Read our paper about the development and early use of the Genomic Results Booklet in *Patient Education and Counselling*]

[BUTTON: Read our publication: "After genomic testing results: Parents’ long-term views"]

[BUTTON: Read our publication: “Genetic counseling considerations in cerebral palsy.”]

## POE-NAS

WE ARE WORKING WITH 13 FIRST NATIONS TO BETTER UNDERSTAND THE IMPACT OF PRENATAL OPIOID EXPOSURE ON CHILDREN, FAMILIES, CAREGIVERS, AND COMMUNITIES.

***Principal Investigators:*** *Jennifer Walker (ICES, McMaster University), Astrid Guttmann**(ICES, The Hospital for Sick Children, University of Toronto) and Serene Kerpan**(Ontario Tech University, Vancouver Island University, ICES)*

**Looking back: our work in Phase 1**

Our project team is working with 13 First Nations to answer community-driven questions about prenatal opioid exposure. This year, we have focused on completing quantitative and qualitative data analyses and preparing to report our findings. For the quantitative arm of our research project, we determined the rates and trends over time of prenatal opioid exposure and neonatal abstinence syndrome for each participating First Nation, as well as the aggregated rates and trends for all 13 communities. We also looked at characteristics of mothers and babies.

We have finalized the data analysis for the qualitative arm. Data was generated from focus groups and interviews with community members such as parents, grandparents, caregivers, leaders, health and social service providers, educators, and Elders. After completing the initial analysis, we worked with our community partners and research participants to ensure the findings reflected what people shared.

In all our work this past year and throughout Phase 1, we have grounded ourselves in Indigenous understandings of wellness and a strengths-based approach to research to support First Nations in their efforts to shift from patterns of intergenerational trauma to intergenerational healing.

**An eye to the future: what Phase 2 has in store for us**

Community partner involvement and engagement will continue to be at the centre of our Phase 2 work. Participating First Nations have already expressed great interest in Phase 2 based on preliminary discussions. As we move into the action component of the community-engaged participatory action research cycle, we will work with participating First Nations to determine how they want to use their Phase 1 findings to address prenatal opioid exposure in their communities.

In this phase, we are prioritizing an approach to research funding autonomy that is increasingly becoming an important feature of community-engaged research. Participating First Nations will each be given funds to support the development and implementation of community-specific knowledge mobilization plans. This approach to fiscal relationships with Indigenous communities aligns with Indigenous communities’ rights to self-determination and Indigenous-led knowledge mobilization.

The effects of the opioid epidemic, especially during the COVID-19 pandemic, continue to make themselves felt; there is growing concern in Canada regarding opioid-related harm and deaths among Indigenous peoples, seniors, pregnant women, and youth. It is important to understand the impacts of prenatal opioid exposure in the context of an Indigenous determinants of health framework, which acknowledges that this disruption of Indigenous knowledges, governance systems, identities, family structures, and lands have contributed to intergenerational trauma and disrupted individual and community wellness. The recent discovery of unmarked graves at former residential school sites may also negatively impact the health and well-being of First Nations people in Canada.

There is still so much to learn about prenatal opioid exposure and its impacts, and research on emerging topics does not always include First Nations people. By sharing insights into the impacts of prenatal opioid exposure in First Nations in Ontario and strategies to better support children and families, we hope our work will fill an important gap in the literature and benefit communities across Canada and globally.

[BUTTON: Link to project page]

## PIUO

WE’RE TESTING A SYSTEMATIC APPROACH TO MANAGING UNEXPLAINED PAIN IN NON-VERBAL CHILDREN WITH SEVERE BRAIN-BASED DEVELOPMENTAL DISABILITIES.

***Principal Investigators:*** *Hal Siden**(BC Children’s Hospital & University of British Columbia) and Tim Oberlander**(BC Children’s Hospital & University of British Columbia)*

**Looking back: our work in Phase 1**

We’re pleased to report that as of March 31, 2022, 73 children had completed the Pain and Irritability of Unknown Origin (PIUO) Pathway, which is the systematic approach we developed to help manage their pain. Even as we finalize our Phase 1 results, our research has already shone a light on the importance of individualized attention to complex medical needs and solutions. For families who are used to seeing multiple specialists, going through the pathway may turn the tide in their day-to-day experience of managing a distressing feature of their child’s condition.

*"We did this study for my son two years ago. The nurse was amazing to work with. The doctor as well. We were able to manage the unknown pain effectively, and honestly, our lives have become better because of it. I knew when we started that a positive outcome wasn't guaranteed, but we were fortunate!" ­— Parent of a PIUO study participant*

This year, our efforts to build capacity for patient-oriented research initiatives resulted in multiple research projects coming to fruition. We hosted a journal club for parents of children with complex medical needs, with a second session scheduled for spring 2022. The journal club provided a space for parents to have a rich discussion about a curated list of academic literature related to their family experiences and led to the creation of a special edition newsletter. Because of the overwhelming positive feedback, we are now making the journal club a standing feature of our research activities.

We also launched two other projects investigating the research process as it relates to the experiences of self-identified “medical families”. One project is led by our Family Liaison Laesa Kim and looks at parents’ motivations for participating in research related to their children’s special medical needs. Another project, led by the local team at one of our study sites, is an investigation of the recruitment challenges faced by our broader team during the COVID-19 pandemic.

**An eye to the future: what Phase 2 has in store for us**

Team members with lived experience that parallels that of our target population are an integral part of every stage of our research process. We are listening closely to patient-partner voices as we move towards translating the results of our Phase 1 research into a readily available tool for community practitioners. We believe the PIUO Pathway can help clinicians who see kids with complex medical needs to systematically assess the potential root causes of their pain and irritability. In Phase 2, our cross-disciplinary team, including patient-partners, will flesh out what this tool looks like and how to implement the pathway in a community setting.

[BUTTON: Visit the PIUO project page]

## STRONGEST FAMILIES™ NEURODEVELOPMENTAL PROGRAM

WE HAVE DEVELOPED TWO PROGRAMS TO HELP PARENTS OF NEURODIVERSE CHILDREN MANAGE CHALLENGING BEHAVIOURS AND PARENTAL POSTTRAUMATIC STRESS.

***Principal Investigators:*** *Patrick McGrath**(IWK Health Centre and Dalhousie University) and Lucyna Lach**(McGill University Health Centre)*

**Looking back: our work in Phase 1**

We’ve come a long way with our two research projects, the Strongest Families Neurodevelopmental Program and Life Beyond Trauma. These e-health programs are designed to support parents of neurodiverse children; one is aimed at enhancing parenting skills and the other at understanding posttraumatic stress and offering one-on-one intervention for parents experiencing posttraumatic stress. Both projects achieved major milestones this year, reaching their combined enrollment target of almost 500 Canadian families. These families have completed the programs, and our team continues to collect follow-up data to assess the impacts of the programs on parents and families over time.

This year, we focused on sharing our discoveries with a broad range of audiences. In addition to several papers published in scientific journals, our researchers, parent-partners, and trainees hosted webinars, created an infographic, filmed an educational video, and gave several conference presentations. By diversifying the resources and the methods we use to share research findings, we are advancing understanding of how to help neurodiverse children and their parents thrive.

As this phase winds down, we are working together to analyze, interpret, and report results from both studies. We will continue to conduct further research on the effects of the Life Beyond Trauma Program, to improve outcomes for families impacted by trauma. We will also continue other research on posttraumatic stress, such as studying the impact of racial trauma.

**An eye to the future: what’s in store for our team**

In Phase 2, we aim to implement the results from the Strongest Families Neurodevelopmental Program into real life practice and make the intervention available across Canada.

Parents are at the heart of our research; it remains critical that they be included as partners at every stage. This next phase has the potential to be an even stronger demonstration of the power of parent partnership in research as we are building on relationships that have evolved and been sustained since the beginning of the network. Parents’ involvement and contributions can create meaningful action to make changes in the lives of Canadian families.

“This project has been thrilling and unprecedented in my experience as a parent-partner. We started by investigating an intervention to help families parent children who are neurodiverse and have behaviour challenges. That inquiry naturally evolved into testing an intervention to treat posttraumatic stress disorder in parents of children with complex needs. The next phase of our activities will see parents in Canada being able to access support that is proven to be helpful. This work is possible because the researchers listened closely to parents like me at every stage of the project.” – Donna Thomson, Parent-Partner

[BUTTON:Visit the Strongest Families project page]

[BUTTON:Read about our publication: “Content analysis of parenting interventions for children with neurodevelopment problems and mental health problems: A scoping review.”: <https://doi.org/10.1080/09638288.2021.2017493>]

[BUTTON: Read our full publication: “The influence of social support on posttraumatic stress symptoms among children and adolescents: a scoping review and meta-analysis.” <https://doi.org/10.1080/20008198.2021.1991650>]

[PHOTO CAPTION: This family took part in the Strongest Families Neurodevelopmental study. Mom Danielle completed the self-managed version of the Parents Empowering Neurodiverse Kids online parenting program and was one of several parents who took part in a video describing the impact the program has had on their family. From left to right: Lily, Kevin, and Danielle.]

## Jooay

OUR JOOAY APPLICATION PROVIDES FAMILIES WITH EASY ACCESS TO INFORMATION ABOUT APPROPRIATE LEISURE ACTIVITIES IN COMMUNITIES ACROSS CANADA.

***Principal Investigator:*** *Keiko Shikako**(McGill University)*

**Looking back: our work in Phase 1**

The Jooay App is a free mobile and web app that helps children with disabilities and their families locate accessible leisure opportunities that are close to where they are, suit their needs and abilities, match their preferences, and can help them develop and participate in society.

Since 2016, Jooay has also become a community, helping parents, rehabilitation professionals, educators, and communities to connect, exchange, and learn from each other. In that time, we have increased our repertoire of activities to close to 3,000 activities across Canada, including over 400 online activities in response to the COVID-19 pandemic.

“[During the pandemic] there was a need to listen to the community and see if any needs or supports could be tangibly filled. One need that arose was play: what was available in my area, what was offered online and where could I access it. That need is still present.” - Rachel Martens, Parent-Partner

Collaboration and partnership have been cornerstones of our project from the start. Parents and community organization representatives are members of our research teams and provided input at every stage of our project.

Thanks to this momentum, 2021-22 was a banner year for our engagement with community, policy makers, and other interested parties. In March 2022, we hosted a dialogue on the subject of "Inclusive play in Canada through a mobile health app: research, community, and policy.” We also partnered with the Earth Rangers organization to launch the national *Project 2050: Climate-friendly habits to change the world* movement. Working with AIDE Canada, we also put together a toolkit to help children with autism and/or intellectual disabilities be active and play.

**An eye to the future: what Phase 2 has in store for us**

Building on the success of these past years, we have ambitious goals for Phase 2. We want to increase the number of app users from 4,000 to 40,000 across Canada; we want to identify more play opportunities for children with disabilities; and we want to automatize the database. We will also strengthen our communities of practice across provinces by recruiting local champions who can help identify more inclusive activities in their geographic areas and promote the participation of children with disabilities in leisure in their communities. Using gamification (creating interactive activities that increase motivation and engagement through game-based features and on-screen notifications), we will also build community with children with disabilities, parents, educators, and organizations to enable the exchange of ideas about inclusive play. Finally, we will identify opportunities to build inclusive and healthy communities where all children, with and without disabilities, can play, learn, and develop together.

[BUTTON: Visit Jooay.com]

[BUTTON: Visit the Jooay project page]

[BUTTON: Consult our toolkit with Aide Canada]

[BUTTON: Read our publication: “Changes in Use of a Leisure Activity Mobile App for Children With Disabilities During the COVID-19 Pandemic: Retrospective Study”]

[PHOTO CAPTION: Rachel Martens, Parent-Partner]

## Mega Team

WE’RE WORKING TO IMPROVE MEMORY AND EXECUTIVE FUNCTIONING SKILLS IN CHILDREN WITH BRAIN-BASED DEVELOPMENTAL DISABILITIES THROUGH COGNITIVE-BASED VIDEO GAME TRAINING.

***Principal Investigator:*** *Jennifer Crosbie (SickKids)*

**Looking back: our work in Phase 1**

Mega Team is a convenient and fun at-home video game created to help children and youth with attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), and congenital heart disease (CHD) improve their working memory and behavioural control.

This year, we recruited 66 new study participants to test the video game, for a total of 228 participants. This was in no small part thanks to new recruitment strategies that compensated for pandemic-related challenges, including the use of parent Facebook groups and the Holland Bloorview Kids Rehabilitation Hospital connect2research database, a large database of eligible candidates at that institution. Once we complete our recruitment phase, we will move ahead with data analysis, with the goal of completing our clinical trial by fall 2022.

“We worked really hard to incorporate creative recruitment strategies and it’s been paying off!” – Taha Arshad, Mega Team Clinical Research Project Coordinator

In the past year, we successfully onboarded several new co-op students, who were responsible for a variety of tasks, including running our many participant visits and working extensively with data management.

“Flexible scheduling has really helped accommodate and support a wider breadth of families so they could participate in our study.” – Navi Dhaliwal, Clinical Research Project Assistant

**An eye to the future: what Phase 2 has in store for us**

As we complete the clinical trial and Phase 1 results become available, we will be able to focus on knowledge mobilization, dissemination, and implementation (taking significant findings and moving them into wider use in routine practice).

Youth and patient-partner involvement will be key as we shift into this next stage. We will work closely with our patient-partners to ensure our knowledge mobilization plan is accessible to children and youth with ADHD, ASD, and CHD and their families, since they will be the video game training’s end users.

Phase 2 represents an exciting opportunity for our team, as we believe the potential benefits of our research to be significant. In the six years since Mega Team’s inception, the use of technology in clinical practice has increased. The COVID-19 pandemic led to a greater appreciation and acceptance of, and desire for, virtual assessment and intervention tools. Many supports were lost for individuals with brain-based developmental disabilities. Meanwhile, stress related to the pandemic increased mental health concerns for all children and youth, but particularly for those with pre-existing conditions such as ADHD and ASD. As such, the validation of a novel virtual tool such as ours aimed at improving attention and self-regulation is of even greater importance now.

[BUTTON: Visit our project page]

[PHOTO CAPTION: Summer student Vaishnavi Bhamidi and Mega Team Clinical Research Project Coordinator Taha Arshad analyze a participant’s assessment data sheet.]

[PHOTO CAPTION: Navi Dhaliwal, Clinical Research Project Assistant]

[PHOTO CAPTION: Taha Arshad, Mega Team’s Clinical Research Project Coordinator]

## CCENT

WE’VE PIONEERED NEW WAYS TO SUPPORT PARENTS AS THEIR NEWBORN TRANSITIONS FROM THE NICU TO HOME.

***Principal Investigators:*** *Julia Orkin**(SickKids), Eyal Cohen**(SickKids), Nathalie Major (CHEO), and Paige Church (Sunnybrook Health Sciences Centre)*

**Looking back: our work in Phase 1**

Since 2016, we have been supporting and empowering families as they and their baby transition from the neonatal intensive care unit (NICU) to their homes. To do so, we’ve pioneered the role of the nurse navigator. CCENT nurse navigators support NICU families in three ways: 1) parental coaching and psychosocial support, 2) care coordination, and 3) education about caring for an infant with medical complexities.

We reached our recruitment target of 275 participants and all participants have completed the study. We have already begun preparing our data for analysis. Our next steps will be to analyze our data, summarize our findings, draw conclusions about the effectiveness of the nurse navigator intervention, and disseminate our findings to knowledge users across the pediatric academic community.

“Being part of the CCENT study was very meaningful to me. The interactions I had with families changed the way that I practiced nursing. It was a privilege to be so intimately involved in their journey. My hope is that families found the support of the Nurse Navigator important, and that this role can continue at SickKids in the future.” - Kimberly Colapinto, Nurse Navigator

**An eye to the future: what Phase 2 has in store for us**

This data will inform the development of our Phase 2 project. In the next stage, we will study how to incorporate the effective components of the nurse navigator intervention across Canada. We will hold focus groups with study participant families, nurse navigators, NICU staff, neonatal follow-up teams, and implementation scientists to refine the project and prepare it for implementation in other institutions.

Our preparations for Phase 2 are well underway. We’ve created guides for focus groups, come up with questions to ask interested parties in order to refine the Phase 2 study protocol, and discussed our goals with the core team of investigators and patient-partners. Patient-partner involvement will be crucial to the success of Phase 2; we will focus on the elements of the intervention that patient-partners tell us are useful and important to them.

[BUTTON:Visit the CCENT project page]

[BUTTON: Read our study protocol]

[BUTTON: Read about using Acceptance and Commitment Therapy in the NICU]

[BUTTON: Listen to a podcast about the CCENT study]

## BRIGHT Coaching

WE ARE EVALUATING WHETHER OUR VIRTUAL COACHING PROGRAM HELPS SUPPORT PARENTS OF PRESCHOOL CHILDREN WITH EMERGING DEVELOPMENTAL DELAYS AS THEY TRANSITION TO SCHOOL ENTRY.

***Principal Investigators:*** *Annette Majnemer**(McGill University Health Centre) and Maureen O’Donnell**(University of British Columbia)*

**Looking back: our work in Phase 1**

In 2021-2022, our team worked to collect the last of our data about the individualized coaching resource and online education tools we developed to help parents of preschool children with emerging developmental delays as they wait for a diagnosis and/or therapeutic interventions. We successfully completed recruitment, with a total of 306 participants enrolled. By the end of this fiscal year, all but 10 participants had completed our program.

In addition to data collection, we consulted with our coaches and parent advisors to prepare for Phase 1 data analysis and implementation in Phase 2. We held a focus group with our coaching team about their experiences delivering our program. Our coaches told us what was successful as well as what could be modified. This insight will help us implement our program in the health care system in Phase 2. We then conducted focus groups and interviews with our parent advisory group to understand what parents hoped to learn from our data analysis. We gained invaluable patient-oriented information from these discussions that will guide our analytic approach.

We also focused on knowledge translation and dissemination this year. Prior to completing her postdoctoral training with our team, Tatiana Ogourtsova presented the results of our patient engagement survey at the 76th Annual Meeting of the American Academy of Cerebral Palsy and Developmental Medicine. In collaboration with our co-principal investigators, Annette Majnemer and Maureen O’Donnell, Tatiana also conducted a series of webinars for provincial and national health organizations. These webinars focused on the scientific evidence supporting telerehabilitation treatments and assessments for children and youth with brain-based developmental disabilities and their families.

We look forward to collecting the remaining data, completing our data analysis, and sharing our Phase 1 results widely.

**An eye to the future: what Phase 2 has in store for us**

Evidence continues to mount on the effectiveness of online coaching interventions and telehealth more generally. The COVID-19 pandemic demonstrated that a service like BRIGHT Coaching can have an important place in the health care system. We’re therefore excited for the opportunity to prepare the coaching program we developed for use in diverse communities across four provinces: British Columbia, Manitoba, Quebec, and Nova Scotia.

***“I would have had great difficulty getting through the experience without [the coach’s] encouragement and support […] participating in [BRIGHT Coaching] has changed my life and that of my family.” – BRIGHT Coaching parent participant, on their experience after receiving a troubling diagnosis for their child.***

In Phase 2, our team will focus on identifying and working with knowledge users, including frontline health care providers, decision makers, policy makers, and caregivers, to ensure that BRIGHT Coaching is ready for this expansion. To do so, we will collaborate and consult with community partners to address gaps from an inclusive and equitable lens. We will also work with health care facilities and networks as well as governmental authorities to integrate this online service as part of the public health care delivery system. CHILD-BRIGHT’s experts in implementation science and policy development will help us accelerate uptake and impact.

[BUTTON: Visit the BRIGHT Coaching project page]

[BUTTON: Read our publication: “Fathers Matter: Enhancing healthcare experiences among fathers of children with developmental disabilities.”]

[BUTTON: View the BRIGHT Coaching Report to Community]

[PHOTO CAPTION: Parent Advisory Group member Natalina Pace]

[PHOTO CAPTION: Parent Advisory Group member Faizan Khan with son]

### READYorNot™

WE DEVELOPED AND ARE NOW EVALUATING AN E-HEALTH APPLICATION DESIGNED TO HELP PATIENTS AND FAMILIES TRANSITION FROM THE PEDIATRIC TO THE ADULT HEALTH CARE SYSTEM.

***Principal Investigators:*** *Ariane Marelli (McGill University Health Centre) and Jan Willem Gorter (McMaster University)*

**Looking back: our work in CHILD-BRIGHT Phase 1**

To help youth with brain-based disabilities (BBD) such as autism spectrum disorder, cerebral palsy, epilepsy, fetal alcohol spectrum disorder and spina bifida, prepare for the transition from pediatric to adult health care, our team co-created the MyREADY TransitionTM BBD App with patients, families, health care partners, and industry partners.

In 2021-22, we completed recruitment of 46 participants in Alberta, Ontario, and the Maritimes for our randomized controlled trial (RCT). We actively worked with sites in Quebec to facilitate recruitment start-up in that province. We worked with QUOI Media, recruitment sites, and our Patient and Family Advisory Council (PFAC) to recruit participants and leveraged relationships with other organizations (like CanChild and the Children’s Healthcare Canada Transition Hub), front line service providers, colleagues, and personal networks to promote the study.

Even as we continue to collect data, we are proud of all we have accomplished to date. Our study has responded to the needs of families as well as the need for systematically well-designed research approaches to co-create evidence-based eHealth transition tools. Despite the many ways the pandemic impacted our project, our research team maintained strong connections and continued our commitment to true collaboration with our patient and family partners.

Together with our partners, we co-presented experiences preparing and conducting the RCT by publishing our research protocol and by giving presentations, presenting posters, and delivering webinars about our collaboration. Our team also co-developed print, electronic, and video resources to improve the overall experiences of participants, to offer support and guidance for using the App, and to prepare research staff for conducting study visits.

**An eye to the future: what Phase 2 has in store for us**

We continue to move our CHILD-BRIGHT Phase 1 project forward and expect to have results analyzed late in 2022. Collaborative interpretation discussions involving our PFAC, RCT and Core teams are also planned for early 2023, at which point we will make decisions about the next steps for our project. We are also excited to share our App IT and content development processes; we have several articles in development on these topics. Our CHILD-BRIGHT Phase 1 results will focus on sharing our learning related to setting up a multi-site patient-oriented research trial, co-creating an App with patients and families, the feasibility of recruiting and conducting a trial virtually, as well as some information about experiences and benefits of using the App.

Health care systems across the globe quickly pivoted to offering virtual care when in-person clinical appointments were restricted. Since we began in 2016, global awareness of the significant role for eHealth has grown exponentially, such that the need for eHealth interventions in health care transition remains prevalent across Canada. We are learning from trial participants about how the App content can best serve families as a resource in the future. National Transition Guidelines were created in 2017 but have not been widely implemented. Our work can help particularly with the recommendation for assessment of transition readiness and tailored interventions to foster skills and knowledge.

[BUTTON: Visit the READYor Not Project page]

[BUTTON: Visit the Canadian transition hub]

[BUTTON: Read the 2017 CAPHC National Transition Guidelines]

[BUTTON: Read the Canadian Paediatric Society (CPS) call for action]

[PHOTO CAPTION: “I’ve personally felt a great sense of satisfaction from being an integral member of the team. The experience gave me the impetus to continue to collaborate [and] continue to pursue patient partnership. As a result, I'm currently working on a few very interesting projects.” - JoAnne Mosel, READYorNotTM Parent-Partner]

[PHOTO CAPTION: Caption: Sonya Strohm, READYorNotTM Research Coordinator]

[PHOTO CAPTION: A subgroup of the Patient and Family Advisory Council (PFAC), spearheaded by PFAC member and 2021 CHILD-BRIGHT Summer Student Claire Dawe-McCord, held a Stakeholder Dialogue event in February 2022 to discuss current age of transfer practices across Canada. The subgroup continues to work in collaboration with the CHILD-BRIGHT Policy Hub.]

# OUR YOUTH

THE NATIONAL YOUTH ADVISORY PANEL ADVISES RESEARCH PROJECTS ON HOW TO OPTIMIZE YOUTH ENGAGEMENT ACTIVITIES.

In 2021-22, we continued to grow in number and reach. We:

**WELCOMED A NEW MEMBER**

We were pleased to announce the addition of Neela Spurway to the NYAP! Based in Nova Scotia, Neela was a Grade 12 student upon joining the NYAP in 2021, with plans to go to Nova Scotia Community College to study Applied Media and Communication Arts.

[BUTTON: MEET NEELA]

**PROVIDED CONSULTATIONS TO THREE RESEARCH PROJECTS EXTERNAL TO CHILD-BRIGHT**

As part of our fee-based youth consultation service, the NYAP works with Canadian researchers working on childhood disability projects who need input from youth with brain-based developmental disabilities to shape their studies.

NYAP member Gillian Backlin accepted the first consultation mandate external to CHILD-BRIGHT in June 2021, for the Partnering for Pain and iOuch research teams. She participated in virtual sessions and consulted on an infographic/paper about engaging youth in a dialogue around access to virtual care during the COVID-19 pandemic. Learn more.

Several NYAP members, including Gillian, chairperson Logan Wong, Claire Dawe-McCord, and Hans Dupuis, then consulted with the “Nothing Without Us” study team. Gillian joined the study’s patient advisory council, while Logan, Claire, and Hans all provided feedback on a survey for youth on the impacts of the COVID-19 pandemic on young people’s mental health. Learn more.

Finally, Gillian provided a review of the *Project 2050: Climate-friendly habits to change the world!* website, a joint effort from the Jooay App and Earth Rangers teams. Gillian helped ensure the website was accessible to, and inclusive of, children with disabilities. Learn more.

**LED A 2021 LEARNING SERIES WEBINAR**

Multiple NYAP members led a webinar as part of the CHILD-BRIGHT 2021 Learning Series. Logan, Shafniya Kanagaratnam, and Gilian, along with Citizen Engagement Program Coordinator/Project Manager Corinne Lalonde and Administrative Assistant Julia Tesolin, spoke to diversity, accessibility, and accommodation considerations when engaging youth in patient-oriented research.

[BUTTON: WATCH THE WEBINAR RECORDING]

**CONTINUED TO LEARN**

As a group, the NYAP is also committed to engaging in a continual learning process, including about colonialism and systemic racism in pediatric health care. In December 2021, we were grateful to welcome Citizen Engagement Council member and Wisdom Translator Symbia Barnaby to our NYAP meeting, where she gave a presentation on the importance of Indigenous land acknowledgements.

[BUTTON: Read more about the presentation]

**PLANNED FOR PHASE 2**

A priority for NYAP in CHILD-BRIGHT’s Phase 2 is recruiting members to ensure more voices are heard. We received much interest from youth with brain-based developmental disabilities across Canada. You can visit CHILD-BRIGHT’s website to meet our newest members as they are announced!

 “Before joining the NYAP, I had no previous exposure to patient-oriented research. Being part of consultation projects allowed me to think critically about the challenges individuals with brain-based disabilities and researchers face. The opportunity to share my lived experience is rewarding. It showed me that it is valuable and credible in many ways and the NYAP has provided a platform to express myself […] I look forward to the opportunities Phase 2 will bring us.” - Shafniya Kanagaratnam, NYAP member

[BUTTON: Learn more about the NYAP Consultation Process]

# PHASES 1 & 2

**Phase 1**

During CHILD-BRIGHT Phase 1, from 2016 to 2021, we developed novel interventions to improve the health outcomes of children with brain-based developmental disabilities using child and family-focused approaches. We did this to optimize their development, as well as to identify ways to deliver more responsive and supportive services to them and their families. Thanks to our patient-oriented research approach, we made great strides and created positive change for these children and their families in Canada!

**Phase 2**

In CHILD-BRIGHT Phase 2, from 2022 to 2026, we will grow from *Network to Movement* and realize our mission: moving our patient-oriented research into action through insight and methods grounded in implementation science and knowledge mobilization that embed the principles of equity, diversity, inclusion, decolonization and Indigenization.

**Phase 2 focus**

In Phase 2, we intend to augment our emphasis on equity, diversity, inclusion, decolonization and Indigenization (EDI-DI), and further shape our patient-oriented research, implementation science agenda, and knowledge mobilization efforts. We will do so by meaningfully engaging key people, paying careful attention to those who may experience differing health care needs due to socio-demographic factors, or whose voices have been historically excluded.

**Phase 2 - Objective 1**

Using our Phase 2 funding, we will accomplish 5 objectives:

Firstly, we will study how to bring novel, evidence-informed interventions to the health care and community systems. For this, we will select Phase 1 interventions that can be incorporated into health systems to serve the needs of children, youth, and families.

**Objective 2**

Secondly, we will co-build the infrastructure to spread relevant knowledge to knowledge users, such as children, youth and families, Indigenous and other equity-deserving communities, health professionals, and decision-makers in a targeted fashion, using tools such as podcasts, videos, policy briefings, dialogues, and champions.

**Objective 3**

Thirdly, we will train patient-oriented research teams to plan for equitable and sustainable health intervention implementation, spread, and scale.

**Objective 4**

Fourthly, we will support ongoing patient engagement in research and governance, and amplify patient voices in decision-making.

**Objective 5**

Finally, we will build relationships with individuals and communities, and ensure that diverse and culturally appropriate strategies are embedded across the network.

**Meet our Phase 2 team leads**

Meet our Phase 2 program leads, and learn about their vision and plans going forward:

* Implementation Science Program
* Knowledge Mobilization Program
* Citizen Engagement Program
* Training & Capacity Building Program
* EDI-DI Program

# OUTPUTS

View our CHILD-BRIGHT KT Library, to consult the wide range of products created by our network since its inception in 2016, including scientific and plain language publications, books & book chapters, reports, education material, infographics, webinars, and more.

[BUTTON: Consult our CHILD-BRIGHT KT Library]