

# DR. KAREN PAPE PROGRAM IN NEUROPLASTICITY



SickKids **VS** CerebralPalsy



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“My first instinct was to think of Daniel as an outlier, an exception who somehow defied the rules. The natural history of cerebral palsy has been studied and described over a period of decades, and Daniel’s ability to run so well didn’t fit the description. It was incomprehensible in terms of the accepted theory of permanent brain damage that my fellow physicians and I understood. Which is why I said, ‘You can’t do that!’ What he was doing was impossible.”

- DR. KAREN PAPE, THE BOY WHO COULD RUN BUT NOT WALK

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Cerebral palsy (CP) is the most common physical disability in children, affecting **1 in every 286 children.**

**Historically, the diagnosis of CP is made between one to two years of age** which delays intervention during a period when brain plasticity enables the best response to treatment.

**According to US data, CP occurs 3 times more frequently than brain cancer** but receives only 1/10th of the funding that is directed to brain cancer research.

# A LETTER FROM DR. PAPE'S CHILDREN

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Dear Friends, Colleagues and Supporters of our Mum,

In her lifetime, our mother started a revolution in the care of children with early brain injury. Your support of the Dr. Karen Pape Program in Neuroplasticity will ensure that the work she began will become widely accepted and available to children everywhere. The commitment SickKids has made to this Program is an endorsement of what our mother spent decades advocating for—clinical recognition that there is real hope for children with early brain injury. That they are capable of health and quality of life outcomes that were long thought impossible.

After decades spent trying to change the system from the bottom up by educating driven parents and innovative therapists, the enthusiastic reception she received at a 2014 American neonatal conference inspired her to consider how a project focused on the neonatal population might be a new avenue for driving systemic change. Our mother believed a reimagining of the mission of the Neonatal Follow-up Clinic she founded would be the fastest and most cost-effective way to transform the standard of care. Establishing this Program at an internationally respected hospital will serve as inspiration not only to other institutions, but to families everywhere dealing with the news that their child has suffered an early brain injury.

In the last two years of her life she reconnected with SickKids and began developing, with Drs. Estelle Gauda, Linh Ly, Steven Miller and Don Mabbott, what has become the Dr. Karen Pape Program in Neuroplasticity. While it is devastating that she did not live to see this day, her work lives on. The paradigm is shifting. A flag has been planted at SickKids and the Hospital is dedicated to carrying on the work our mother championed. We don't need to wonder what she would have done had she lived longer—we are investing in the Program she helped design. We are confident that the interdisciplinary team at SickKids is best positioned to translate evidence-based research about neuroplasticity into leading-edge clinical care.

System-wide change is needed to bring the standard of care for babies and children with early brain injury in line with what we now know about neuroplasticity. The Dr. Karen Pape Program in Neuroplasticity will accelerate this process by funding the education and research required to drive this systemic change. We hope you will join us in supporting this vital program.



Sarah Pape



Aaron Pape

# ABOUT KAREN PAPE, MD, FRCPC



**KAREN PAPE, MD, FRCPC**, was a neonatologist and clinical neuroscientist. Her ground-breaking work and approach to understanding brain recovery and neuroplasticity in the infant brain spans over thirty years of research and clinical work. She founded the Neonatal Follow-up Clinic and served as President of the Medical Staff at SickKids. She completed a research fellowship in Neonatal Pathology at Hammersmith Hospital in London, UK, where she was instrumental in the development of neonatal brain ultrasound, a technique now used in intensive care units around the world. She was the Founder and Director of The Magee Clinic in Toronto, where she developed a new personalized treatment approach, treating more than 5,000 children and adults with early onset brain injury. She published and lectured widely, conducting over 200 training workshops and conferences for parents, therapists, and physicians throughout North America and internationally in 12 countries.

As a medical innovator, she challenged the system to raise expectations for babies born with early brain injury. Karen's key discovery

**KAREN PAPE, MD, FRCPC**

was that the movement and speech patterns associated with cerebral palsy are not permanent injuries, but rather compensatory behaviours formed as the baby was learning to move while the brain had not yet recovered from the original injury. Full recovery from a first-time, mild stroke in adults is now an expected outcome, but parents of a newborn with a similar neonatal stroke are still told the baby will have cerebral palsy for life. The adult recovering from stroke has a complete repertoire of learned motor and cognitive skills. The child with a stroke must learn these skills with a damaged, developing brain, and with no prior knowledge of normal movement and speech. Their clinical needs are different, but their potential for recovery is just as real.

“Karen Pape, MD, was a pioneer, rightly demanding that colleagues integrate the new science of brain plasticity as it applies to these children, and this was her *cri de coeur*, recording not only the new breakthroughs, but effectively explaining why, tragically, so many families are still denied these important interventions.”

- **NORMAN DOIDGE, MD, RENOWNED EXPERT ON NEUROPLASTICITY**

The prevalence of children who could successfully perform higher order skills—children who can run normally while still limping when they walk, or who can sing more clearly than they can speak—led Karen to the discovery that learned behaviour hides recovery in children with an early brain injury. Karen captured this work in her book, *The Boy Who Could Run But Not Walk: Understanding Neuroplasticity in the Child’s Brain*.

On June 2, 2018 Karen died after an 18-month battle with cancer. To the end, Karen sought out ways to advocate for improving the treatments available to children with early brain injuries. She tasked her family with finding an ambitious and meaningful project through which to continue her work.

In 2013, **more than 29,000 babies were born pre-term in Canada**, putting them at high risk of developing conditions that impact the brain and nervous system, including motor and mental health disorders.

Neonatal conditions account for **202 million or 8% of all disability adjusted life years globally**, more than Alzheimer’s disease (3%), obesity (2.3%), diabetes (1.9%) and autism (0.3%) combined.

**Among children born very preterm, 5 to 10% have major motor deficits**, including cerebral palsy, and more than half have significant cognitive, behavioural, or sensory deficits, which makes prematurity a leading cause of neurodevelopmental disability in North America.

**There is no identifiable biomarker for CP** and a complete causal pathway has not been established. However, high risk indicators include: preterm birth, neonatal encephalopathy, genetic abnormalities, and atypical intrauterine growth restriction.

The most likely day for a person to have a stroke is **the day they are born.**

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**Our vision is to redefine what is possible for children with early brain injuries by initiating system-wide change in how we care for the developing brain.**

## **THE CHALLENGE**

Premature and critically ill babies are at high risk for conditions that can have a lifelong impact on the brain. Every year at SickKids approximately 350 to 400 patients are referred to our Neonatal Follow-up Clinic from our Neonatal Intensive Care Unit (NICU) and Critical Care Unit (CCU). These patients are at the highest risk of neurodevelopmental disabilities, including cerebral palsy (CP). At present, we are limited in our capacity to treat early brain injuries and enable healthy outcomes in these infants because of a lack of effective diagnostics and treatments that harness the brain's capacity to adapt and recover.

## **WHY SICKKIDS**

SickKids was Karen's professional home for many years. It's where she first began transforming the lives of patients and families through her insights about neuroplasticity. In the last two years of her life, Karen reconnected with SickKids because she wanted to drive systemic change for children with early brain injury and she believed SickKids was the place to start—we are the clinical home for infants with brain injury during a critical period of their brain development, we have a deep bench of interprofessional and neuroscience expertise, and we have an international reputation for excellence that inspires others to follow our lead. Most importantly, SickKids is fundamentally committed to leading the necessary system-wide change.

## **PROGRAM LEADERSHIP**

**DR. ESTELLE GAUDA**, Head, Division of Neonatology

**DR. LINH LY**, Director, Neonatal Follow-up Program

**DR. STEVEN MILLER**, Head, Division of Neurology and Centre for Brain & Mental Health

**DR. DONALD MABBOTT**, Head, Neurosciences & Mental Health Research Program

## PROGRAM STRUCTURE

Over a 10-year period, in Karen Pape's name, we will build a world-leading program in neuroplasticity focused on transforming outcomes for infants and children affected by early brain injury. The program will create synergy between clinical care, education, and research through investments in:

**NEONATAL FOLLOW-UP CLINICAL RESEARCH** Transforming our Neonatal Follow-up Clinic from one of assessment to one of intervention and rigorous research will create a living lab focused on infants, children and families affected by cerebral palsy. It will allow us to fill a current clinical gap, intervene earlier, apply promising new diagnostics and treatments sooner, support optimal parent mental health, and evaluate effectiveness. This will mean patients and their families receive the highest quality, evidence-based care in a critical period of neuroplasticity, and receive a tailored plan for how to support their child in reaching his/her full potential.

**NEUROPLASTICITY RESEARCH** While the reality of neuroplasticity has been known for some time, there is still so much we need to learn about the most effective ways to nurture it, particularly in the developing brain, from infants to young adults. By providing the resources to ensure we are constantly innovating and advancing our knowledge, we will be able to remain at the leading-edge of clinical practice.

**KNOWLEDGE AND CAPACITY BUILDING** The world needs more paediatric health-care professionals whose practice is informed by a rich understanding of neuroplasticity and how to nurture it to maximize patient outcomes. Towards this end, by investing in platforms to share new knowledge, provide training and education, and build the next generation of world-leading clinical professionals focused on neuroplasticity and brain repair in the neonatal period we will ensure our advances have an impact on as many children as possible.

**STATE-OF-THE-ART FACILITIES** World-leading care, research and education cannot take place in outdated facilities with outdated equipment. To unleash the full potential of the Dr. Karen Pape Program in Neuroplasticity, we need spaces and tools that reflect the very latest advances.

## IMPACT

With your support, the Dr. Karen Pape Program in Neuroplasticity will reimagine neonatal follow-up care at SickKids for infants with cerebral palsy, build evidence to support its broader adoption, and instill this new knowledge in the next generation of brain injury leaders. The key outcomes will be:

- Over a 10-year period, 450 patients at high risk of cerebral palsy enrolled in our clinical research program (approximately 50 new patients per year, beginning in year 2) and participating in clinical assessment and remote access intervention
- Implementation of personalized, all-encompassing treatment plans for each infant in the program, from time of enrollment to transition to outside agency
- Anticipated reductions in developmental disabilities and improved quality of life indicators among our patient population
- Evidence indicating the effectiveness of our care model with which we can apply to granting agencies and government for ongoing support
- Explore and bring to clinical trial innovative strategies for effectively preventing and treating early brain injuries
- Recruit talented clinicians with an interest in building research skills in the field of neuroplasticity to train with our experts, and then spread throughout the world to share their knowledge (3 fellows during the 10-year period alone)
- Ensure our clinical facilities enhance patient and family comfort, and promote bonding between parents and their baby—critical for the developing brain, particularly in premature infants.

# WAYS TO GIVE

**Your support for the Dr. Karen Pape Program in Neuroplasticity will deliver the change that infants, children, youth and families facing brain injuries need—change Karen spent decades working to ignite.**

**Karen and her family have invested more than \$2 million to launch the program and are seeking an additional \$4 million to achieve Karen's vision.**

**There are many ways to give, including direct donations, gifts of securities, U.S. and international donations that are receiptable.**

**For more information, please visit  
[www.sickkidsfoundation.com/drkarenpape](http://www.sickkidsfoundation.com/drkarenpape)  
or contact Angela Murphy, Vice-President, Campaign at 416-559-4711  
or [Angela.Murphy@sickkidsfoundation.com](mailto:Angela.Murphy@sickkidsfoundation.com).**

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