

BACKGROUND

GROUNDBREAKING PARTNERSHIP UNVEILED: CANADA'S LEADING PAEDIATRIC HOSPITALS AND THE AZRIELI FOUNDATION JOIN FORCES TO TRANSFORM CHILDREN'S HEALTHCARE IN CANADA

Context and Importance

- Rare diseases affect 1 in 12 people in Canada or approximately 3 million people and their families.
- Approximately two-thirds of Canadians with rare diseases are children.
- Fifty per cent of these children remain undiagnosed and 30 per cent will not live to see their 5th birthday.
- While tremendous strides have been made in treating children with cancer, 20 per cent will not survive their illness and 85 per cent of survivors live with lasting effects.
- Treatment for neurodevelopmental disorders is still limited to symptom control.
- Together, SickKids and CHU Sainte-Justine have unparalleled insight into children's health, serving 61 per cent of the paediatric population in Canada, making this partnership one of the most significant developments in paediatric medicine in Canadian history.

Precision Child Health

- Precision Child Health is a groundbreaking movement designed to improve current health outcomes by bringing together genomics, clinical research data and novel therapies.
- Precision Child Health uses information about a child's genes, biology, environment and social determinants to prevent, diagnose and treat disease in a more targeted way.
- Its tools and technologies offer opportunities for more rapid, accurate and cost-effective diagnostics, patient-tailored treatment, enhanced drug safety and universally accessible care.
- Precision Child Health will not only mean more lives saved, but also reduced morbidity and improved quality of life for children, youth, and their families.
- The ability to treat or reverse disease in childhood, sometimes before the very first symptoms appear, has the potential to reduce healthcare costs for all involved, for present and for future generations.
- Equally, advances and innovations in paediatric healthcare will have profound benefits that extend to adults.

The Partnership

- The Azrieli Foundation first invested \$2.6 million in seed funding two years ago to allow the partners to establish the required frameworks for governance, legal agreements, engagement of patient partners, and ethical considerations.
- With these frameworks now in place, the Foundation has now invested an additional \$50 million to accelerate this transformational vision for personalized child healthcare.
- The partnership between CHU Sainte-Justine, SickKids and the Azrieli Foundation is unprecedented and will establish for the first time a discovery and research pipeline between Canada's top paediatric hospitals, targeting better outcomes, improved quality of life, and tailored medical care for children across the country.
- While collaborations between clinical research organizations exist, this partnership is uniquely disease-agnostic and is designed to permanently transform paediatric care in Canada by putting in place shared core services, infrastructure, and expertise and growing cross-institutional knowledge and insight across a host of disease states and conditions.
- The partnership will see the capabilities and outputs of each institution far exceed what would be capable on their own.

About CHU Sainte-Justine and SickKids

- These are two of North America's largest child health research hospitals, serving 61 per cent of the paediatric population in Canada.
- They house the first integrated clinical genomics centres in Canada.
- Their combined average annual investment in genetic medicine is \$50 million.
- They are global leaders in genomics and innovative treatments such as immunotherapy.
- They have proven track records of research and care for children with cancer, neurodevelopmental conditions, rare diseases, and other complex illnesses.
- They offer leading expertise in big data, artificial intelligence/machine learning, genomics and advanced diagnostics, gene-editing, and cellular and gene-based therapies.

About the Azrieli Foundation

- The Azrieli Foundation is the largest public foundation in Canada, funding institutions and operating programs in Canada and Israel.
- The Foundation fosters excellence and innovation in scientific research, from fundamental to translational, and improves lives by supporting quality healthcare.
- The Foundation supports the work of brilliant scientists exploring novel ideas and making breakthroughs in their fields.

- The Foundation believes scientific research and patient care are inextricably linked and is proud of its partnership with CHU Sainte-Justine and SickKids.
- Other initiatives supported by the Foundation include:
- The Azrieli Accelerator at the University of Calgary, transforming neurodevelopment research across the lifespan
- Azrieli Centre for Autism Research at The Montreal Neurological Institute (the Neuro) at McGill University
- The Azrieli Adult Neurodevelopmental Centre at the Centre for Addiction and Mental Health (CAMH)
- Brain Canada's Future Leaders in Canadian Brain Research Program
- The Pediatric Learning Health System for Neurodevelopmental Disorders at McMaster University
- The Canadian Neurodevelopmental Research Training Platform (CanNRT)

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