

AN EXCEPTIONAL DONATION FROM THE MARCELLE AND JEAN COUTU FOUNDATION TO SUPPORT AUTISM RESEARCH

Q1K: A collaborative undertaking involving 1,000 families to transform autism care

Montreal, November 12, 2019 — The CHU Sainte-Justine Foundation, the Douglas Mental Health University Institute Foundation, the Fondation les petits trésors and The Neuro (Montreal Neurological Institute-Hospital) today announced a major donation of nearly \$10 million from the Marcelle and Jean Coutu Foundation. This significant contribution will enable the partner institutions of the Transforming Autism Care Consortium (TACC) to establish **Quebec 1,000 (Q1K)**: an innovative, multidisciplinary and collaborative initiative aimed at having an unprecedented impact on autism research.

The purpose of the leading-edge Q1K project is to accelerate the pace of discovery and integrate research outcomes into healthcare practices for autism. As the flagship project of the TACC, the initiative is spearheaded by some of the top scientific leaders in the autism field at the CHU Sainte-Justine, the Hôpital en santé mentale Rivière-des-Prairies – CIUSSS du Nord-de-l'Île-de-Montréal (CIUSSS NIM), The Neuro – McGill University and McGill University Health Centre (MUHC), the Douglas Mental Health University Institute and the Montreal West Island Integrated University Health and Social Services Centre (CIUSSS-ODIM). This ambitious scientific undertaking will comprise a cohort of 1,000 families – the most substantial and diverse group of its kind in the world – and leverage a unique, centralized source of information to galvanize genetic, cellular, brain and behavioural research. In so doing, Q1K will put Quebec front and centre of new discoveries and therapeutic approaches that will transform the care and services provided to people with autism spectrum disorders (ASDs), both here at home and around the world.

“The collective scientific power of the Q1K project and its objective to advance our understanding of autism and the quality of care provided were what persuaded us at the Marcelle and Jean Coutu Foundation to support this forward-looking initiative,” said Marie-Josée Coutu, President of the Marcelle and Jean Coutu Foundation. “Knowing that this dedicated community of researchers will be working with 1,000 families and that it will have a decisive impact on the generations to come fills us with hope.”

A UNIQUE ENDEAVOUR

This multidisciplinary project will bring together clinicians and researchers with recognized and complementary high-level expertise to maximize the impact of every aspect of autism research. Research outcomes will be measurable in terms of the advancement of knowledge, diagnostic accuracy and recommended treatments and ongoing care.

“The Q1K project will be unique in that it will provide a comprehensive analysis of patients,” Dr. Sébastien Jacquemont of the CHU Sainte-Justine proudly asserted. “We have been working for quite some time with some of the largest research cohorts out there. We know them very well, but they have limits that we are forced to contend with on a routine basis. Q1K is our chance to develop a study that takes the multiple factors associated with ASD into account.”

One of the unique features of Q1K will be the sharing of data acquired in accordance with the principles of open science. As a result, researchers in Quebec, the rest of Canada and beyond will be able to benefit from the information generated by this project. In addition, the project will inform evidence-based practices and healthcare policies. “This will make it possible to guide autism care more effectively and give us a better idea of patients’ trajectories and outcomes,” said Dr. Carl Ernst of the Douglas Mental Health University Institute. “With time, the approaches used will improve and be better suited to the needs of both patients and their families.”

PUTTING FAMILIES AT THE HEART OF RESEARCH

Families will be at the heart of the project. In addition to basic and translation research, teams of specialists will be breaking new ground by actively considering the consequences of research efforts on the daily lives of the members of this extensive cohort. Current research has not measured the quality of life of people with autism and their families. Q1K will therefore help make a real difference in their lives.

“Q1K will focus on the experiences and concerns of families, as well as those of autistic children as soon as they can express them,” said Dr. Laurent Mottron of the Hôpital en santé mentale Rivière-des-Prairies – CIUSSS NIM, associated with the Université de Montréal. “It is our aim to use the knowledge gleaned from this cohort to profoundly transform the way families understand their child’s autism, as well as how autistic children perceive their own condition.”

AN ALTERNATIVE MODEL

With TACC and Q1K, Quebec is taking the lead internationally as a driver of innovation through a collaborative, cooperative approach that is bringing together universities and hospitals in Montreal – and elsewhere in the province – in order to unify and complement their respective expertise, and utilize the professional and scientific strengths of each partner.

“Our innovative work model takes collaboration one step further, drawing inspiration from our philanthropic community, especially the Marcelle and Jean Coutu Foundation,” said Dr. Guy Rouleau, Director of The Neuro. “What we have been entrusted to do is clear: join forces and work together to provide a better future to people with autism and their families.”

AUTISM

Children, youth and adults on the autism spectrum exhibit a broad range of symptoms and varying levels of functioning, autonomy and verbal communication. This inherent heterogeneity must be taken into consideration so that any research outcomes have direct benefits for people and families living with autism.

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Information and media enquiries

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