



# Despite the relatively high incidence of Down syndrome, there is no cohesive program in Ontario to support children with this condition and their families.

Three-year-old Elena is described by her mother as a real character who loves Dora the explorer, reading books, and playing with her dolls.



Many children born with Down syndrome will face health problems, including one or more of the following medical conditions:

- heart defects (40% of cases)
- intestinal abnormalities (2% to 10% of cases)
- eye problems
- hearing problems
- recurrent ear infections
- sleep apnea
- underactive thyroid gland (hypothyroidism)
- leukemia (10% of cases)
- increased susceptibility to infections, including pneumonia

Even when children with Down syndrome are relatively healthy they still need regular checkups and special help to advance their learning and development, including speech, physical or occupational therapy.

To address a critical gap in care, SickKids is working with partners to establish the first Down Syndrome Clinic focused on providing children under three and their families with a single point of access for addressing all of their many medical and developmental needs.

## The Need

The rate of Down syndrome (DS) worldwide remains stable at 1:800 live births. Advances in medical technologies and approaches to care have dramatically improved the life expectancy for people with DS from 25 years of age in 1983 to 60 today. As a result, growing numbers of these children live with this complex multi-system genetic disorder.

While the degree of severity of medical illness and developmental delay in children with DS varies, the vast majority of these children require support from numerous health-care providers and specialists. Coordination of care between providers, children and their families is extremely challenging and if not done well can result in long wait times, fragmented communication, inadequate planning and poor health and quality of life outcomes.

For example, a healthy child with Down syndrome may require approximately 10 medical and therapeutic appointments a month at different locations on different days, while a child with significant health challenges may require 25 appointments or more. Such a demanding schedule makes it difficult for parents to support their child with DS while holding down a job, caring for other family members and maintaining a good quality of

life. Resolving health issues through supportive, *coordinated* care is therefore critical to enabling families to lead rich, meaningful lives while allowing children with DS to reach their full potential.

## Why SickKids

SickKids recognizes the need for greater coordination of care for children with DS. As the referral centre and key care provider for children with complex medical conditions, SickKids has the broad clinical expertise to lead the implementation of a dedicated Down Syndrome Clinic that will address the current gap in care. SickKids also has the research expertise to ensure the care we provide continues to meet the highest standards, drawing on best practices pioneered or perfected in our own hospital as well as leading centres around the world.

## Vision

Through the establishment of an interdisciplinary clinical program, in partnership with Surrey Place, SickKids will direct efforts and resources towards filling the current gap in care for children with Down syndrome. Working together with community partners, parents of children with Down syndrome and Circle 21, we

will realize our vision of excellence in coordination of care for children with Down syndrome facing complex, chronic medical and developmental needs.

Patient referrals to the Down Syndrome Clinic will be made through a Nurse Coordinator who will determine patient eligibility based on established admission criteria for Phase 1 of the initiative, which include:

- all children with Down syndrome under 3 years of age
- living within the Greater Toronto Area (GTA)
- not otherwise followed by the SickKids Complex Care Program
- readiness of the family to participate in the program

These criteria may be refined as the clinic becomes more established, for example to include older children or children living outside of the GTA.

Once the referral is accepted, an intake questionnaire will be sent out to families. A condensed summary of critical information including highlights of the child's past medical history and treatment recommendations will be prepared for review by the paediatrician and other members of the team. This summary will remain part of the health record at SickKids and will be made available to other hospitals through the

electronic Child Health Network should the child and family require care elsewhere.

A clinic appointment will then be booked at which time the team will meet the child and family to review the summary information, conduct a baseline physical examination and a developmental assessment as well as discuss a plan of care and coordination of needs.

Allied health care specialists—including social workers, dietitians, physiotherapists, occupational therapists, audiologists, speech therapists, psychologists and child life specialists—will be consulted as needed and access to their advice will be provided to patients and families through the Nurse Coordinator. This approach will allow issues that arise to be addressed promptly, avoiding delays in diagnosing problems and reducing emergency room visits.

Dedicated clinic space will be provided within current facilities at SickKids and Surrey Place. The Nurse Coordinator for the program will be responsible for triaging patients and ensuring appointments are scheduled at convenient times for the family, properly sequenced with recommended tests, and coordinated with other visits whenever possible. The nurse will also serve as a resource for families and community services requiring education and support around Down syndrome.

The clinic will be rolled out over a two-year period. In phase 1, the clinic will be run one half day per week.

Ensuring that the ongoing needs of children with Down syndrome are met and that the necessary supports are in place along a seamless continuum of care requires a significant amount of coordination, communication and collaborative decision making that is often lacking in our current fragmented health-care system. Adding to the challenges are time consuming and outdated methods of maintaining the large amount of health information generated by a child with Down syndrome. Sharing this information across sectors is extremely difficult and typically family members must tell their child's story repeatedly to different health-care providers.