Ontario’s Newborn Screening Program Now to Include Screening for Severe Combined Immune Deficiencies (SCID)

In January, Newborn Screening Ontario (NSO) informed the provider community that the Ontario Government has accepted a recommendation from the Provincial Council for Maternal and Child Health to add Severe Combined Immune Deficiencies (SCID) to Ontario’s newborn screening panel.

This recommendation, rigorously prepared by the Newborn and Child Subcommittee of the Maternal–Child Screening Committee (MCSC), was reviewed and endorsed by both MCSC and PCMCH.

NSO is targeting April 22, 2013 to begin screening. SCID screening will be performed from the same samples currently being collected for newborn screening and therefore, no additional blood collection will be required.

Based on communications with other jurisdictions already screening for SCID, it is estimated that approximately 50 infants will screen positive each year and about 5-10 will have SCID.

Newborns with SCID appear healthy at birth but are vulnerable to multiple life-threatening infections within the first few months of life. Early diagnosis and treatment with stem cell transplant improves the long-term outcome of affected infants. Since SCID is not apparent at birth and early recognition is essential for lifesaving treatment, SCID has been added to the newborn screening panel.
In January the PCMCH approved the Report of the Transition to Adult Healthcare Services Work Group. The Work Group, convened in February 2012, was co-chaired by Cynthia Weaver, Administrative Director, Adolescent Services, Ontario Shores Centre for Mental Health Sciences and Jan Willem Gorter, Physiatrist at McMaster Children's Hospital, investigator at the CanChild Centre for Childhood Disability Research and the newly appointed Director of CanChild and the Scotiabank Chair in Child Health Research at McMaster University.

The Work Group had a mandate to make recommendations to the PCMCH regarding a provincial approach to the transition of youth affected by a chronic and/or complex clinical condition, including physical, developmental and/or mental health conditions, to adult healthcare services. The recommendations emanating from the review and contained in the Report are intended to be generic rather than organization, geography and/or condition-specific, so that they can be better adapted to each patient, patient population, the unique characteristics of an organization and the geographical area.

Recognizing that, historically, the majority of this patient population has not experienced a well-coordinated, well organized and/or well-planned transition to adult healthcare services, the Work Group began its identification of key issues affecting transition by analyzing the strengths, weaknesses, opportunities and challenges of the current system and how they affect each component of the system, including patients/families, paediatric healthcare providers and adult healthcare providers, including family physicians.

Recommendations span the health care continuum and are founded on the underlying principle that, regardless of the age of the patient and in order to prepare for the eventual transfer to adult healthcare services, no matter how far off it is, preparation (e.g. attaining knowledge and assuming responsibility for health care needs) must start as early on in the child/family’s involvement with the healthcare system as is deemed appropriate, well before the formal transition process commences.

Recommendations are specific to such areas as:
- assessment of and planning for transition needs
- developing interventions based on the identified needs, for example, involvement of current and future team members before, during and after the transition in order to optimize the continuity of care and ultimately, strengthen patient outcomes
- the need to ensure information is available and understood by youth and their families
- access to information and expertise for adult healthcare providers both in general and specific to the youth who is being transferred
- accreditation standards for organizations
- the development of databases and leveraging of eHealth initiatives
- evaluation of the impact of the transition recommendations and
- the development of a multi-ministerial resource centre focusing on system navigation for youth and their families.

A process was used to vet the recommendations in order to ensure they were useful, relevant and made sense from the perspectives of youth, parents and adult and primary healthcare providers involved with youth transitions. The recommendations were also prioritized by members of the Work Group, taking into consideration the importance of each recommendation and its ease of implementation. It was recognized that many of the recommendations are inter-dependent and that, in some instances, their successful implementation is contingent upon the availability of reliable data and the ongoing facilitation of integration across the system.

The Work Group believes that implementation of the recommendations has the potential to have a positive impact on health outcomes, the quality of health care that is provided and the costs to youth, families, and the entire healthcare system. PCMCH will begin looking at implementation strategies for the recommendations in the upcoming fiscal year.
Leading Dialogue on Integrated Care for Medically Fragile/Technology Dependent Children

In May, 2011 PCMCH hosted a meeting of an Advisory Group on the Coordination of Care for Children who are Medically Fragile and/or Technology Dependent. The Advisory Group was charged with identifying priorities and recommending strategies for the achievement of a coordinated system of services delivered in community and hospital settings.

Forty participants from across the province explored two objectives:

- Opportunities to improve care/service coordination while leveraging successful models, and;
- Enablers and system barriers that must be considered when planning changes.

As a result, 27 recommendations were put forward, with several priorities emerging. A Steering Committee on Medically Fragile and/or Technology Dependent Children and Youth was then commissioned to develop an implementation plan focusing on policy barriers and service improvement.

Chaired by Stacey Daub, CEO of the Toronto Central CCAC, the Steering Committee finalized the resulting Action Plan with input from the Ministries of Health and Long-Term Care, Children and Youth Services, Education and Community and Social Services.

The Action Plan calls for transformation in five key areas:

- Accessing Services and Funds
- Care Planning and Coordination
- Control and Choice
- Caregiver Capacity
- Transitional and Adult Services

Key enablers to successful implementation of the Action Plan include inter-ministerial leadership and the engagement of families.

Having fulfilled its mandate, the Steering Committee has concluded its work. Strategy-specific working groups will be developed as needed to advance transformation in the five key areas.

To advance progress towards integrated care planning and coordination, PCMCH, in collaboration with the Norman Saunders Complex Care Initiative (NSCCI), held a two-day Provincial Symposium on February 28 and March 1, 2013. The symposium brought stakeholders representing the continuum of care in each LHIN together to:

- Leverage emerging models and research to begin developing shared goals, principles, core components and operating guidelines for

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The Challenge and The Opportunity

Less than 1% of the paediatric patients in Ontario account for 32% of child healthcare spending. These children live in communities across the province and are recipients of care and service in every LHIN.

The miracles of modern medicine have enabled these children, who once would have died in infancy, to live longer and with a dramatically increasing complexity of care and social needs.

While the amount of care these children receive is substantial, the coordination of that care is less than ideal.

Targeted, structured and integrated interventions are seen to have high potential for improving outcomes and mitigating system expenditures.

The system has an opportunity to leverage emerging models and research to collectively advance integrated complex care for children with medical complexity in Ontario.
In the next fiscal year, PCMCH will begin its work on implementation of the recommendations contained in the Report of the Paediatric Palliative Care (PPC) Work Group. The Report is the culmination of collaboration between the PCMCH and the Paediatric Oncology Group of Ontario (POGO).

The Group, Co-chaired by Drs. Christine Newman, Staff Physician, Palliative and Bereavement Care Services, The Hospital for Sick Children and Mark Greenberg, Senior Adviser, Policy and Clinical Affairs at POGO, had an overarching purpose of making recommendations regarding a provincial approach to the delivery of PPC for children, youth and their families and expectant parents in need of palliative care services.

In an effort to ensure seamless, comprehensive, integrated and coordinated care, recommendations were developed that span the care continuum. Collaboration and communication is key amongst all providers of PPC, whether they are hospital or community-based. Efforts must be made to develop PPC expertise both within and beyond the walls of tertiary organizations.

Teledmedicine, videoconferencing and other electronic means are useful tools to facilitate the support available to both patients/families and community health care providers involved with the provision of PPC.

Supporting community providers with 24/7 access to consultation with specialized PPC clinicians will provide immediate and essential advice, thereby increasing the community care provider’s comfort level with the provision of PPC.

A regionalized model of PPC care would ensure that, regardless of where in the province a patient receives PPC, the same standard of care is guaranteed and the patient receives appropriate care in the appropriate setting within the appropriate time frame.

Having common tools and guides to practice that are used province-wide would facilitate a consistent language across providers, therefore maximizing continuity of care for patients/families.

A phased-in approach to implementation of the recommendations was suggested, with end-of-life care identified as a first priority followed by the introduction and integration of the broader components of paediatric palliative care (PPC) at the beginning of the illness trajectory for children who are living with life-limiting conditions.
New Birth Centres Announced for Toronto and Ottawa Region

Deb Matthews, Minister of Health and Long-Term Care has announced new birth centres in Toronto and the Ottawa Region, scheduled to open this summer.

The Toronto Birth Centre and the Ottawa Birth and Wellness Centre will each provide mothers-to-be and their families with a broad range of programs and services led by midwives and, in the case of the Ottawa centre, provide special attention to meeting the needs of the Francophone population. Each centre expects to assist with 450-500 births each year, offering more choice as to where women can deliver healthy babies, while helping to keep hospital beds free to focus on higher risk births. Creating midwife-led birth centres is part of the government’s Action Plan for Health Care and its commitment to providing Ontarians with the right care, at the right time, in the right place.

Leading Dialogue on Integrated Care for Medically Fragile/Technology Dependent Children...

Leading Dialogue on Integrated Care for Medically Fragile/Technology Dependent Children...

Integrated complex care models for children with medical complexity in Ontario
- Establish a provincial network of practice
- Celebrate research enabled by the Norman Saunders Complex Care Research Initiative (NSCCI).

The symposium, coordinated by Laura Visser, Lead, Integrated Family Centred Care for Children with Health Complexity, PCMCH and the Toronto Central CCAC, included sessions on:
- leading practices for achieving integration at the point of care
- patterns and costs of health care use of Children with Medical Complexity in Ontario
- highlights from the Norman Saunders Complex Care Research Initiative, and
- facilitated group discussion to inform continued work towards shared principles and guidelines for operationalizing an integrated complex care model for children with medical complexity.

Symposium participants included representation from each LHIN and included those from primary care, community care, children’s treatment centres, acute paediatric complex and palliative care, as well as family caregivers and government representatives.

PCMCH Website Re-Launch

Over the past few years PCMCH’s work has evolved significantly, with many of Council’s recommended best practices, clinical guidelines and other resources in higher demand than ever before and, as a result, being used and applied in healthcare organizations across the Province and beyond.

These “real-life” experiences and success stories, the growing depth and breadth of the issues that Council addresses and Council’s increased visibility, engagement and impact at the provider, planner and decision-maker levels, have greatly enhanced the relationship between PCMCH and its stakeholders. In response, PCMCH will be refreshing its website to better meet the needs of its audience(s).

In particular, the new website will be designed to more readily accommodate the needs and interests of the provider community, using intuitive navigation, more easily accessible information and downloads and the inclusion of a social media component. It is anticipated that the re-launch will take place in the late spring. There will be no change in the URL.
The Panel was formed in 2012 as part of the government’s goal of keeping Ontario healthy, a priority of Ontario’s Action Plan for Health Care. This expert Panel had 17 members, and provided advice to the Minister of Health and Long-Term Care on reducing childhood obesity by 20 per cent over five years.

The Healthy Kids Panel was led by co-chairs, Alex Munter, President and CEO of the Children’s Hospital of Eastern Ontario, and Kelly Murumets, President and CEO of ParticipACTION, the national voice of physical activity and sport participation in Canada.

The Panel was made up of 17 independent experts who are recognized leaders in their fields, including:

- academia and research
- health care and public health
- physical activity
- community-based organizations
- media for parents and consumers
- advertising and social marketing
- education
- food retail and manufacturing
- consumer products
- health promotion
- human development
- Aboriginal communities

The scope of the Panel’s work included:

- Identification of the specific factors that affect childhood obesity rates in Ontario, and;
- Identification and prioritization of the multi-sectoral interventions that could address childhood obesity in Ontario. Recommended interventions had to consider:
  - Evidence-based solutions,
  - Fiscal sustainability, and;
  - Viability for implementation.

The Healthy Kids Panel accepted submissions from organizations and members of the public throughout last spring and into the fall. Based on those submissions, research and expert opinions, the Panel’s 66-page Report strongly recommends a bold, yet feasible and achievable, three-part strategy – one that will have the greatest positive impact on child health as well as a substantial return on investment for Ontario and which recognizes that no one policy, program or strategy will solve the problem of childhood overweight and obesity:

1. **Start all kids on the path to health.**
   Laying the foundation for a lifetime of good health begins even before babies are conceived and continues through the first months of life. We must provide the support young women need to maintain their own health and start their babies on the path to health.

2. **Change the food environment.**
   Parents know about the importance of good nutrition. They told us they try to provide healthy food at home, but often feel undermined by the food environment around them. They want changes that will make healthy choices easier.

3. **Create healthy communities.**
   Kids live, play and learn in their communities. Ontario needs a co-ordinated all-of-society approach to create healthy communities and reduce or eliminate the broader social and health disparities that affect children’s health and weight.

Quick Facts

1. 75 per cent of obese children grow up to become obese adults.

2. In 2009, the estimated direct and indirect costs associated with obesity to Ontario’s health care system were $4.5 billion.

3. In Ontario, 25.6 per cent of children ages two to 17 are overweight or obese.

4. Childhood obesity rates for Canadian children ages two to 17 have risen from 15 per cent in 1979 to 26 per cent in 2004.

The PCMCH welcomes the Report and will be reviewing it in detail over the coming weeks to determine its implications and the potential opportunities it presents for Council’s work. The full Report is available at:


November 7 and 8, 2013
SickKids Research and Education Tower, Toronto

Congenital Heart Disease is one of the most common congenital abnormalities, occurring in 0.5% of newborns. Due to the improvement in care and survival, there is a growing population of adults with congenital heart disease. Echocardiography is the primary diagnostic modality for this population but requires specific skills and knowledge.

In an effort to address quality issues related to paediatric echocardiography identified by the Office of the Chief Coroner of Ontario, PCMCH’s Paediatric Echocardiography Provincial Planning Committee has taken the lead in defining training and practice guidelines for paediatric and congenital echocardiography. A key goal is to improve the training of sonographers and physicians who perform and/or interpret echocardiograms in newborn and paediatric patient populations.

The Congenital and Paediatric Echocardiography course is the first of the Planning Committee’s recommendations to be implemented and is the first of its kind offered in Ontario. The course will focus on the specifics of congenital and paediatric scanning and will examine the echo-morphology correlations of the major congenital lesions in a systematic way. Dr. Andrew Cook (London, UK), a world renowned expert in the field, will conduct the morphology demonstrations; these will be followed by systematic reviews of congenital heart disease, all presented by leading faculty from across the province.

The course will take place in the brand new SickKids Research Tower, a truly unique venue. Further information will soon be available on the PCMCH website.

We hope to see you there!!