



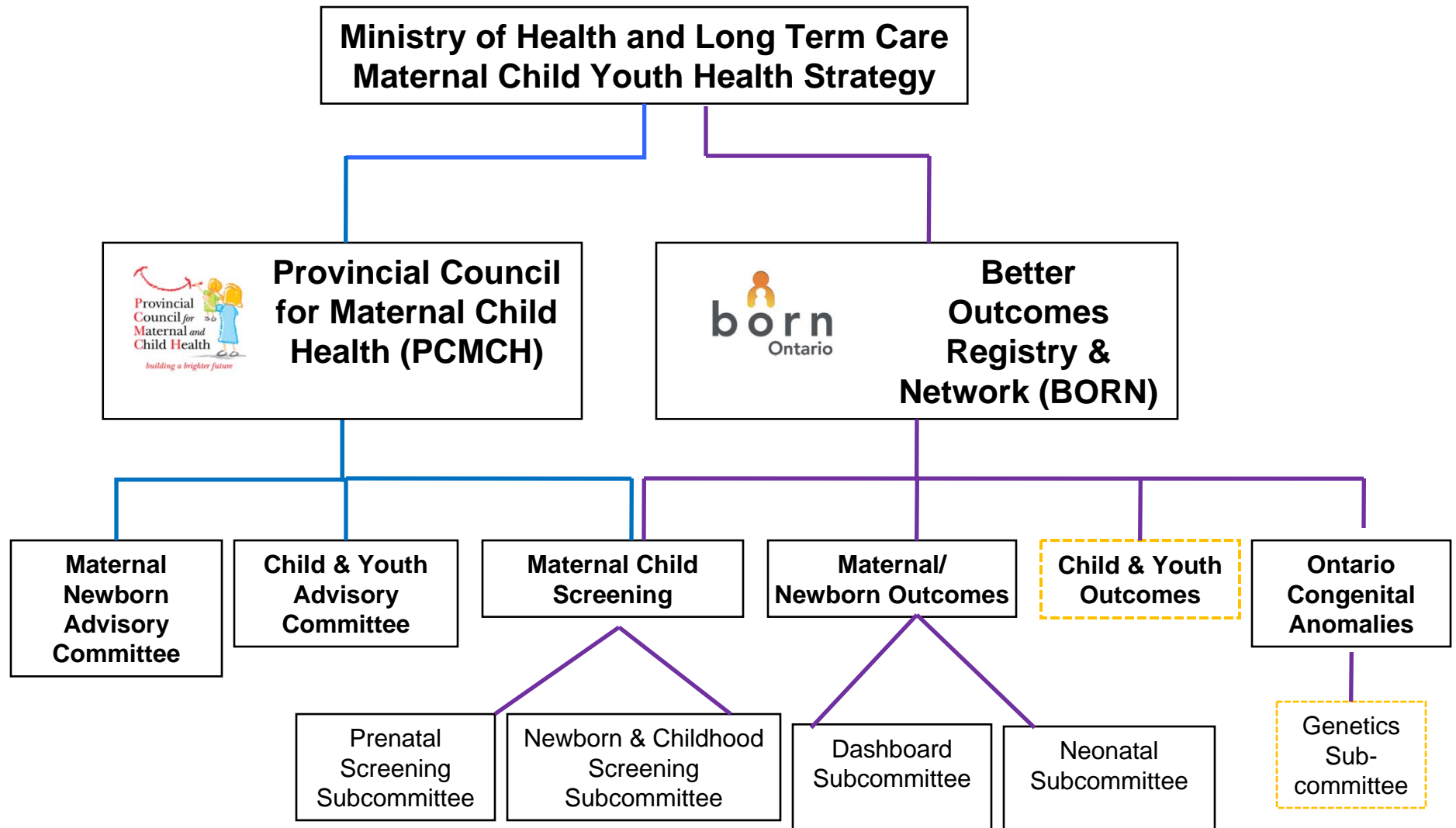
Early health. Lifelong health.  
Début en santé. Longue vie en santé.

# **BORN Ontario Briefing**

## **BORN SCREENING COMMITTEES**

**March 15, 2012**

# BORN: Governance Structure



# What is Screening?

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- Systematic, population-based application of a test or inquiry to individuals who do not have symptoms of a specific disease or condition in order to identify those who warrant further investigation and/or intervention to achieve better outcomes.



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# Maternal-Child Screening Committee (MCSC)

# History

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- Prenatal and Newborn-Child screening were separately considered:
  - Newborn-Child:
    - to 1994: NBS advisory committee to MOH
    - 2006: OACNCS reconvened
    - 2009: Mandate due for renewal
  - Prenatal:
    - 1995: Ontario Multiple Marker Screening Group
    - 2005- Funding to global budgets
      - Consultative group (no formal status)

# MCSC Scope

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- Screening is an important practice in the maternal – child population aimed at early identification of significant health risks to allow early intervention and improved outcomes.
  - Many health issues and diseases span the preconception to late childhood spectrum, optimally involving an integrated approach to ensure:
    - recommendations regarding policy are sound and consistent
    - operation of the screening programs corresponds to the highest possible standards of effectiveness, efficiency, and evidence.
- Prenatal Screening and Newborn Screening are essential services offered to pregnant women, and to newborns throughout Ontario.

# MCSC Scope

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- The MCSC will provide advice to the MoHLTC and MCYS, via the Provincial Council for Maternal and Child Health and BORN Ontario as appropriate:
  - the scope and operation of prenatal, newborn and childhood screening in Ontario meets the changing needs of the population
  - consistent general principles of screening are applied to all aspects of prenatal, newborn and childhood screening,
  - the operations of prenatal, neonatal, and childhood screening programs are integrated to the extent that relevant issues are considered in the full context of the reproductive cycle;
  - policy decisions are based on sound scientific evidence;
  - relevant stakeholders are identified and consulted with regard to proposed changes to the screening programs; and
  - other issues, as required.

# MCSC Committee Membership

- **Dr. P. Chakraborty (Chair)** Director, Newborn Screening Ottawa
- Dr. Michael Geraghty Metabolic Genetics Ottawa
- Dr. Robin Hayeems Ethics and Public Policy Toronto
- Dr. Alan Hudak Primary Care / Paediatrics Orillia
- Dr. Martyn Hyde Otolaryngology / Research Toronto
- Dr. Julian Little Epidemiology Ottawa
- Dr. Stephen Lye OBGYN/Research Toronto
- Ms. Fiona Miller Health Policy / Health Sciences Toronto
- Dr. Isaac Odame Pediatric Hematology Toronto
- Dr. Nan Okun Maternal Fetal Medicine Toronto
- Dr. Murray Potter Medical Biochemistry Hamilton
- Ms. Stacey Weber MCYS Liaison Toronto
- **Ms. Shelley Dougan** Genetic Counselling / BORN Resource Ottawa



# MCSC Meetings

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- Sept 8/10 (inaugural)
- Jan 7/11
- Sept 27/11
- Dec 20/11
- *Future meetings:* April 12, June 15, Sept 21, Dec 7 2012

# MCSC Working Groups

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- Definition of Screening
- Neonatal Jaundice / Bilirubin Encephalopathy  
Leads: Dr. Julian Little  
Dr. Thierry Lacaze
- Future Targets of Prenatal Screening  
Leads: Dr. Stephen Lye  
Dr. Robin Hayeems
- Congenital Heart Disease (under discussion)

# MCSC in action

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- Emerging issues relating to screening
- Considerations involving integration between existing screening programs
- Open for questions!



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# Prenatal Screening Subcommittee (PSSC)

# PSSC Scope

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- Provide advice to the MoHLTC via the PCMCH and BORN Ontario, as appropriate, regarding provincial policies, standards and guidelines for Ontario's prenatal screening program. :
  - Monitoring and reporting on program effectiveness and program quality;
  - Making recommendations for change to improve the program.
  - Responding to questions referred to the Subcommittee from the Maternal/Child Screening Committee;
  - Performance indicators and related data to monitor and report on program effectiveness and quality, in conjunction with other agencies involved with prenatal screening;
  - Making recommendations on policy and knowledge translation
  - Evaluating and advising on new technology;

# PSSC Scope

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- To advise on:
  - and facilitate implementation of specific prenatal screening protocols;
  - and facilitate implementation of procedures for handling of screen negative and screen positive results, including genetic counseling issues;
  - educational programs for patients and health care providers, to reflect any significant changes in prenatal screening;
  - research necessary to enhance understanding of matters related to program effectiveness; and
  - Other issues as required.

# PSSC Members

|                                    |   |                |
|------------------------------------|---|----------------|
| • <b>Dr. Nan Okun (Chair)</b>      | <b>Maternal Fetal Medicine</b>                | <b>Toronto</b> |
| • <b>Dr. Ritu Aul (Vice Chair)</b> | <b>Clinical Genetics</b>                      | <b>Toronto</b> |
| • Dr. Nicolette Caccia             | Obstetrics                                    | Weston         |
| • Dr. June Carroll                 | Family and Community<br>Medicine / Education  | Toronto        |
| • Dr. David Chitayat               | Clinical Genetics                             | Toronto        |
| • Dr. Gregory Davies               | Maternal Fetal Medicine                       | Kingston       |
| • Dr. Alan Dennis                  | Clinical Biochemistry                         | London         |
| • Ms. Mary Duquette                | Nursing / Genetics                            | Thunder Bay    |
| • Ms. Tiffany Haidon               | Midwifery                                     | Toronto        |
| • Dr. Tianhua Huang                | Research                                      | Toronto        |
| • Ms. Danna Hull                   | Genetics Counselling                          | Kingston       |
| • Dr. Walter Romano                | Radiology                                     | London         |
| • <b>Ms. Shelley Dougan</b>        | Genetic Counselling /<br><b>BORN Resource</b> | Ottawa         |

# PSSC Meetings

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- Sept 8/10 (inaugural)
- Oct 25/10
- Jan 6/11
- March 1/11
- May 17/11
- Sept 27/11
- Jan 20/12
- *Future meetings:* April 12, June 15, Sept 21, Dec 7 2012



# PSSC Working Groups

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- Clinical Advisory Working Group
- Chemistry Advisory Working Group
- Evaluation Working Group
- Nuchal Translucency QA Working Group
- Education/Website Working Group
- Prenatal Ultrasound Working Group

# PSSC - Progress to date

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- Finalized terms of reference
- Website developed:  
[www.prenatalscreeningontario.ca](http://www.prenatalscreeningontario.ca)
  - Currently static with periodic updates
- Updated Requisition
  - Will be available on website
- Nuchal Translucency Quality Assurance
  - Mock-up of Report

# Other PSSC Tasks

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- Monitor technological advances in prenatal screening
- Evaluation of prenatal screening software
- Future targets of prenatal screening
- Role of ultrasound
  - First trimester scan as early fetal health assessment
  - Second ultrasound to incorporate fetal structural anomalies



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# Newborn and Childhood Screening Subcommittee (NCSC)

# NCSC Scope

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- Provide advice to the Ministry of Health & Long-Term Care (MoHLTC), via the Provincial Council for Maternal and Child Health (PCMCH) and BORN Ontario, as appropriate, regarding provincial policies, standards and guidelines for Ontario's newborn and childhood screening program(s).
- Advise Newborn Screening Ontario (NSO) directly, as appropriate.
- Including:
  - Monitoring and reporting on current program effectiveness and program quality;
  - Making recommendations for change to improve the program;

# NCSC Scope

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- Responding to questions referred to the Committee from the Maternal/Child Screening Committee;
- Developing, implementing, analyzing and evaluating performance indicators;
- Evaluating and advising on new technologies;
- Making recommendations on policy and knowledge translation;
- Advising on and facilitating implementation of
  - protocols
  - procedures for handling of screen negative and positive results, including genetic counseling issues;
- Advising on educational programs for patients and health care providers; and
- Advising on research necessary to enhance understanding of matters related to program effectiveness.

# NCSC Members

- **Dr. Michael Geraghty (Chair) – Clinical, Molecular genetics- Ottawa**
- **Dr. Murray Potter (Vice-Chair) – Lab Medicine, Biochemical Genetics- Hamilton**
- Ms. Cathie Badeau – PCMCH Liaison - Toronto
- Dr. David Cole – Laboratory medicine - Toronto
- Dr. Andrew Latchman – pediatrician - Hamilton
- Dr. Sarah Lawrence – endocrinologist - Ottawa
- Dr. Jennifer MacKenzie - Metabolic Geneticist - Kingston
- Dr. Beth Potter – epidemiologist - Ottawa
- Dr. Tony Rupar – Biochemical Genetics - London
- Ms. Karen Tam – Genetic Counsellor - Toronto
- Dr. Richard van Wylick – Pediatrician - Kingston
- Ms. Stacey Weber – MCYS Liaison - Toronto
- Dr. Pranesh Chakraborty (ex officio-NSO director)- Pediatrics, Lab Medicine, Biochemical genetics/metabolics- Ottawa
- Ms. Janet Marcadier (BORN Resource Person) – Genetic Counsellor - Ottawa

# NCSC Meetings

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- Sept 8/10 (inaugural)
- Jan 7/11
- March 31/11
- July 14/11
- Sept 27/11
- Jan 20/12
- *Future meetings:* April 12, June 15, Sept 21, Dec 7 2012



# NCSC Working Groups

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- Quality Indicators Task Force (completed)
- Process for Addition Task Force (completed)
- SCID Working Group (completed)
- Review of NSO Test Menu Task Force
- Storage, Usage and Dissent Task Force

# NCSC - Progress to date

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- Developed a process for the addition of diseases to the NBS panel
- Recommended adding SCID to the newborn screening panel
- Completed Quality indicators and short term follow up
- Developed a BORN Report Inventory

# How to get involved with BORN committees?

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