



## **Ontario Congenital Anomalies Committee**

### **Terms of Reference**

#### **Scope**

Congenital anomalies include anatomic, metabolic or other abnormalities that are apparent in utero, at birth or detected during early childhood. Such anomalies may result from a wide variety of causes including genetic disorders (e.g. phenylketonuria, chromosomal abnormalities (e.g. Down syndrome), tumors (e.g. Wilms' tumor), infections (e.g. cytomegalovirus, HIV), exposure to teratogenic agents (e.g. alcohol), maternal disease (e.g. maternally transmitted autoantibodies, phenylketonuria), and other genetic or environmental factors.

This committee will provide scientific and technical leadership advice on congenital anomalies surveillance and related activities to BORN Ontario (Better Outcomes Registry & Network) in its mission of creating and maintaining an authoritative and definitive source of accurate and timely information to monitor, evaluate and plan for the best possible beginnings to lifelong health. This will include providing advice and direction on:

- Developing, maintaining and enhancing congenital anomalies surveillance systems in Ontario
- Determining the quality and scope of congenital anomalies data collection across the province
- Determining the case definitions for congenital anomalies surveillance

#### **Tasks**

1. Advise on the overall strategy for congenital anomalies surveillance in Ontario, including its relation to national and international systems.
2. Evaluate and make recommendations regarding the scope, definitions, processes and methods for collection of congenital anomalies data.
3. Advise on the allocation of resources (operations, research, initiatives, training/education) for systems related to congenital anomalies (e.g. BORN Information System (BIS), Astraia, etc.)
4. Refer policy questions to the appropriate subcommittee of the Provincial Council for Maternal and Child Health (PCMCH) for policy analysis and to work collaboratively with them to consider the operational and implementation issues raised by their policy analysis.
5. In conjunction with the BORN Executive Team, provide scientific guidance, advice and program evaluation for specific initiatives.
6. Provide advice on addition of existing data sources for enhancing congenital anomaly surveillance (e.g. paediatric cardiac surgery database)

#### **Reporting**

The committee will report to the BORN Executive. The committee will interact with other internal and external bodies as required to accomplish its tasks.

## **Membership**

The membership will be interdisciplinary and the following areas of expertise may be represented. Members will be chosen to meet the required content expertise and, where possible, to also provide geographic/regional/ subspecialty representation. The committee will be comprised of a maximum of 10 members, plus a chairperson and a vice-chairperson. In the inaugural term of the committee, both the chairperson and the vice-chairperson will be chosen by the Nomination Committee. Thereafter, these two positions will be filled through a nominations process. In order to ensure continuity, the vice-chairperson will work together with the chairperson with the expectation that he or she would assume the chair in due course.

- Content experts on congenital anomalies could include:
  - Neonatology
  - Epidemiology
  - Genetics / Teratology
  - Fetal / neonatal surgery
  - Metabolic diseases
  - Maternal Fetal Medicine
  - Perinatal pathology
  - Medical imaging
  - Information technology / coding
  - Neonatal follow-up
  - Paediatric Cardiology
- 1 BORN Science representative
- 1 BORN Technology representative
- 1 research representative
- A maximum of three others to balance program responsibilities as required by the committee

The Ontario Congenital Anomalies Committee may add ex officio or ad hoc members as required (e.g. health records, Provincial Council for Maternal Child Health).

Committee members will have been selected as individuals to represent a specific expertise, rather than various interest groups or geographic regions; therefore, alternative delegates will not normally be invited to meetings.

## **Nomination Process**

BORN will issue a call for Expressions of Interest for membership on this committee. The nominations committee established by BORN will review all submissions and nominate individuals based on the aforementioned membership criteria, excluding any individuals with conflicts of interest (as detailed below).

## **Terms**

The chair will have a term of two years, but should remain as a committee member for an additional year, for continuity. The position is renewable once, but a person can return as chair for another term after a cycle of a different chair.

Members of the committee will have terms of three years, renewable once. Appointments will be staggered, with some initial renewals made for 1 or 2 years, to ensure continuity among the membership. Subsequent appointment renewals will be for 3 years.

A member of the committee can for any reason request to end their term early by formally contacting the Chair or Vice-Chair.

### **Meetings**

Meetings will be held at the call of the chair at least three times a year by teleconference or face to face, with no interval between meetings of more than 6 months and a maximum of two face-to-face meetings per year. The Ontario Congenital Anomalies Committee is expected to operate by consensus. However, should a more formal conduct be desired, the Robert's rule of order shall prevail.

### **Functions**

The Ontario Congenital Anomalies Committee may, if deemed appropriate, create subcommittees and working groups to achieve its mandate.

### **Conflict of Interest**

Members will not include any person who's personal or professional activities constitute a conflict of interest. Such activities include, but are not limited to: direct ties to private industry and personal interests in developing related technologies, including patents and patents pending. Incumbent and existing members will disclose to the chair, without delay, any actual or potential situations that arise which might be reasonably interpreted as either a conflict of interest or a potential conflict of interest.

### **Confidentiality**

Every member will respect the confidentiality of matters brought before the committee. All materials will be treated as confidential. It will be clearly stated when material is no longer confidential.

### **Compensation**

Service as a committee member is voluntary. Members will be reimbursed for expenses incurred to attend meetings as per the BORN Travel Reimbursement Policy and Procedure.

### **Formal Review**

The Terms of Reference shall be reviewed annually.

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