

# The Fetal Alert Network: An Innovative Program of Access to Care, Surveillance, and Education for Birth Defects in Ontario

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## Abstract

Optimal pregnancy outcomes rely on coordinated timely access to appropriate evidence-based clinical care. This is particularly true for pregnant women carrying fetuses diagnosed with birth defects. A systematic approach to prenatal care is ideal, but Ontario has traditionally lagged behind other regions in this regard. In 2004, in response to this challenge, the Fetal Alert Network (FAN) was established with funding support from the Ontario Ministry of Health and Long-Term Care. FAN is composed of five multidisciplinary regional health care teams of nurse coordinators working in close collaboration with primary obstetrical care providers, medical geneticists, specialists in maternal fetal medicine, and pediatric specialists. The teams facilitate access to subspecialists through patient triage and referral, provide outreach education, and act as local experts and change agents to improve care. A key objective is to go beyond a traditional surveillance system to the linkage of service provision with outcomes and effectiveness.

FAN's objectives are to ensure optimal health care access and delivery at all levels, to promote coordination and collaboration among providers, to provide timely and accurate information about health system utilization and clinical outcomes, and to educate patients and primary care providers about prenatal diagnosis. Program evaluation is currently underway. Preliminary analyses indicate that achievement of these objectives has resulted in seamless coordinated access to service for the targeted group of patients, as well as enhanced communication among providers; accessible education and information; and precise, accurate, and timely health care data and information.

## Résumé

L'obtention d'issues de grossesse optimales dépend d'un accès coordonné et opportun à des soins cliniques factuels appropriés. Cela s'applique tout particulièrement aux femmes enceintes portant des fœtus pour lesquels un diagnostic d'anomalies congénitales a été établi. Une approche systématique envers les soins prénatals s'avère idéale; cependant, par le passé, l'Ontario a

toujours accusé un certain retard dans ce domaine, par comparaison avec d'autres régions. En 2004, en réponse à ce défi, le *Fetal Alert Network* (FAN) a été mis sur pied avec le soutien financier du ministère de la Santé et des Soins de longue durée de l'Ontario. Le FAN compte cinq équipes de soins de santé multidisciplinaires régionales composées de coordonnateurs en soins infirmiers travaillant en étroite collaboration avec des fournisseurs de soins obstétricaux primaires, des généticiens médicaux, des spécialistes en médecine fœto-maternelle et des spécialistes en pédiatrie. Ces équipes facilitent l'accès aux sous-spécialistes par l'intermédiaire du triage et de l'orientation des patientes, fournissent des activités de sensibilisation à la prise de contact et agissent à titre d'experts locaux et d'agents de changement visant l'amélioration des soins. Un des objectifs clés consiste à aller au-delà d'un système de surveillance traditionnel pour parvenir à lier l'offre des services aux issues et à l'efficacité.

Les objectifs du FAN sont d'assurer le caractère optimal de l'accès aux soins de santé et de leur offre à tous les niveaux, de promouvoir la coordination et la collaboration parmi les fournisseurs, de fournir des renseignements opportuns et précis au sujet de l'utilisation du système de santé et des issues cliniques, et de sensibiliser les patientes et les fournisseurs de soins primaires au sujet du diagnostic prénatal. Le programme est actuellement en cours d'évaluation. Les analyses préliminaires indiquent que l'atteinte de ces objectifs a permis un accès coordonné et uniforme aux services pour le groupe de patientes ciblées, ainsi qu'une amélioration de la communication entre les fournisseurs, une sensibilisation et des renseignements accessibles, et des données précises et opportunes sur les soins de santé.

J Obstet Gynaecol Can 2006;28(12):1099-1102

## BACKGROUND

Birth defects are the leading cause of infant mortality and the fifth leading cause of years of potential life lost.<sup>1,2</sup> In particular, major birth defects, occurring in 1% to 6% of live born infants, have significant impact on survival.<sup>3,4</sup> Both acute and long-term medical care is required, with many affected individuals experiencing marked psychological or physiological impairments or both.<sup>3,4</sup> In the United States, up to 12% of pediatric hospitalizations are related to birth defects and genetic diseases, and on average these children are younger, stay longer, incur significantly higher

**Key Words:** Prenatal care, maternal health services, abnormalities, congenital, hereditary, and neonatal diseases and abnormalities, Ontario, Canada

Competing Interests: None declared.

Received on June 29, 2006

Accepted on August 30, 2006

hospital costs, and have over 400% greater in-hospital mortality rate than children who are hospitalized for other reasons.<sup>5</sup> Direct and indirect costs to the health care system and hospitalization rates are even higher when totally or partially hereditary conditions are included, ranging from 36% to 53%.<sup>6</sup> In Canada, the cost of birth defects for all ages was estimated at \$706 million. Almost half of that amount was spent on children under 15 years of age.<sup>7</sup>

These are significant challenges. Without an integrated systematic approach to health care for mothers whose pregnancies are affected by fetal anomalies, Canada lags behind many developed nations. This is a particularly important issue in view of the fact that recent advances in diagnostic and interventional technology are fundamentally changing the nature and natural history of many anomalies treated today.

Developed countries are reporting decreases in infant mortality rates due to birth defects, primarily attributed to improvements in diagnosis, care, and prevention. For example, in the United States, a 46% decline from 1980 to 2001 has been documented,<sup>4</sup> and in Canada the decline was 39% between 1985 and 1995.<sup>8</sup> It has been suggested that the decline can be attributed to antenatal interventions, although this research was based on limited data excluding that of Ontario (40% of Canada's population), where the lack of availability of accurate data limits analysis.<sup>9</sup>

Access to precise, accurate, and timely data, including cost and utilization information, is essential for effective health care delivery and policy development. This is particularly relevant as effective antenatal diagnosis can help design optimal care, and the provision of timely, appropriate antenatal care has enormous medical, social, and economic impact.

## **THE ISSUES**

In Ontario each year, an estimated 4000 newborns require specialized, complex, long-term care for congenital anomalies.<sup>10,11</sup> This is a significant health care challenge, yet the province of Ontario does not have an integrated, systematic health care plan to manage these patients or an accurate, accountable means to assess the impact of these patients on the health care system.

Triple marker maternal serum screening has been available in Ontario since 1993, and the emergence of new enhanced prenatal screening options, together with anatomical ultrasound examinations at 18 to 20 weeks' gestation, is increasingly helpful in detecting birth defects at an early stage. However, the use of prenatal screening remains highly variable from region to region in the province. Once an abnormality is suspected, referral to the next level of care may be

arranged. Subsequent referral to a high-risk or maternal fetal unit at a tertiary institution may then be necessary for the specific type of care required.

Because of variability in the consistency and quality of organization and coordination of locally available health care services, a number of fetuses with birth defects are not brought to tertiary care units until late in the gestation, sometimes requiring acute emergent care. This compounds clinical outcomes for patients and accompanying health care costs for payers. Information flow, both into and out of the tertiary site may be delayed and incomplete, thus potentially resulting in duplication and thereby reducing quality of care.

Overall, the traditional system for managing fetal birth defects presents a number of challenges:

- Access to expert tertiary care can be uncoordinated, subjective, and random, which means that health care delivery can be uneven, duplicated, and delayed, and therefore more costly than necessary.
- The flow of relevant clinical information can be delayed and incomplete.
- Continuity of care and follow-up with primary care providers can be weak or absent.
- Accurate data collection on the incidence of birth defects is lacking, which affects policy development and efficient resource allocation.

## **DATA COLLECTION ON BIRTH DEFECTS IN CANADA**

There are currently a number of registries and programs collecting information on birth defects in Canada. These represent traditional models of surveillance systems, primarily measuring numbers and types of birth defects (listed from west to east):

- BC: the Health Status Registry; the BC Reproductive Care Program
- Alberta: the Alberta Congenital Anomalies Surveillance System
- Manitoba: the Manitoba Maternal Serum Screening Program
- Ontario: the Ontario Maternal Serum Screening Program
- PEI: the PEI Reproductive Care Program
- Nova Scotia: the Nova Scotia Atlee Perinatal Database; the Fetal Anomaly Database
- Newfoundland: the Provincial Medical Genetics Program

In addition, the Canadian Congenital Anomalies Surveillance Network (CCASN) was established in 2002 to enhance the quality of surveillance nationwide, allowing

increased understanding about congenital anomalies. CCASN is described as “a national framework to support interdisciplinary collaboration and networking, bringing together research, surveillance, and clinical and public health practices.”<sup>12</sup>

## **THE ONTARIO FETAL ALERT NETWORK**

In 2003, a proposal to establish a Fetal Alert Network (FAN) for Ontario was supported by the provincial Ministry of Health and Long-Term Care (MHLTC). A key objective was for FAN to go beyond traditional surveillance systems to the linkage of essential antenatal care and service provision with outcomes and effectiveness.

An environmental scan, including stakeholder feedback, was conducted to minimize duplication, improve efficiency, enhance access, and assure high quality health care delivery. FAN was designed as a provincial network of multidisciplinary regional teams, each team coordinated by a nurse with enhanced knowledge and skills in the care of women with complex pregnancies. Teams also include experts such as primary obstetrical care providers, medical geneticists, specialists in maternal fetal medicine, and pediatric specialists.

FAN was established on April 1, 2004, supported by the Primary Health Care Transition Fund of the MHLTC. Early objectives focused on project infrastructure (hiring key personnel, obtaining office space, and project planning), followed by the establishment of regional teams. Nurse coordinators were hired in 2004–2005, and five regional centres are now in operation. FAN’s primary goal has been to provide coordinated access to optimal prenatal care for pregnant women whose babies are diagnosed with birth defects. This has been accomplished through timely and appropriate high-quality specialist care, as required, through a provincial network of health care delivery units.

A leader and a project director from Toronto’s Hospital for Sick Children and three co-leaders from Mount Sinai Hospital are augmented by five regional teams located at the province’s major maternal fetal centres: Mount Sinai Hospital, the Hamilton Health Sciences Centre, St. Joseph’s Health Care, London, Kingston General Hospital, and The Ottawa Hospital. A nurse coordinator at each regional centre is the focal point of efforts to attain timely access for women to appropriate levels of care, to deliver care, to minimize duplication of services, and to support primary obstetrical care providers through the referral and follow-up processes.

## **THE FAN DATABASE**

Currently, data collection is incomplete on this cohort of patients in Ontario, as the first phase of FAN was

implemented in high acuity centres. In the next phase, data on all birth defects in the province will be collected. FAN’s goal is to collect comprehensive data and, for the first time, key indicator information about health care access and utilization.

Traditional birth defect registries retrospectively capture limited surveillance data on frequencies and types of occurrences. This means analysis of access and utilization is not possible, yet this type of information is essential for planners, decision-makers, and the public. The FAN database allows for the capture of relevant risk factors for birth defects, including maternal demographics and obstetrical histories, antenatal interventions, and health service factors that may affect pregnancy outcomes and neonatal health. In addition, the FAN database captures waiting times and health care utilization, including fetal diagnostics and referrals among health care providers. This robust database will allow assessments of

- geographic and temporal trends in birth defects
- effectiveness of various interventions and prevention programs
- health care services

The FAN database sets a new benchmark in North America for birth defect surveillance with inclusion of linkages to prenatal care and fetal outcomes.

Ethical aspects of data collection and maintenance have been carefully addressed. FAN has been designated as a prescribed registry under Ontario’s Personal Health Information Protection Act, and the network’s staff have worked with the office of Ontario’s Information and Privacy Commissioner to ensure that all relevant practices meet privacy standards. As the network is responsible for the personal information under its control, policies and procedures have been established to protect FAN data and to limit its collection, use, and disclosure.

## **FUTURE DIRECTIONS**

FAN will move towards the collection of data on all birth defects in Ontario. Management of information will be enhanced through future collaboration and possible integration with other databases, e.g., the Ontario Maternal Serum Screening Database and the Provincial Perinatal Surveillance System. Optimally, FAN will enrol all pregnant women carrying babies diagnosed with birth defects and genetic syndromes, as well as eligible women who present in the early postpartum period.

FAN has been successful in bringing together a team of provincial experts committed to maximizing the care provided to women with complex pregnancies. The network will continue to focus on capacity building through outreach education for health care providers, further

integration of providers and patients in northern Ontario through remote access initiatives, and systems improvement through ongoing evaluation and benchmarking. Comprehensive evaluation of FAN is underway, and currently preliminary datasets are being analyzed. Results will be presented in subsequent publications.

### **THE FETAL ALERT NETWORK MEMBERS:**

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