



**INSTITUT DE
CARDIOLOGIE
DE MONTRÉAL**

PRESS RELEASE

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THE MONTREAL HEART INSTITUTE MARKS THE OFFICIAL OPENING OF ITS ADULT CONGENITAL HEART CENTER

MONTREAL (Quebec) – April 7, 2004 – The Montreal Heart Institute marks the official opening of the Adult Congenital Heart Center. Under the direction of Dr. Lise-Andrée Mercier, the Center already follows close 1,700 patients, making it the largest centre of its kind in Quebec and second largest in Canada. Its mission is to ensure medical follow-up of adult patients with congenital heart defects and develop and validate tools for intervening effectively with these patients, from a medical, psychological and social standpoint. The Center serves clients aged 18 years and over referred by the cardiology department at Hôpital Sainte-Justine, as well as clients from adult referral centres in Western Quebec.

Context

In 1989, the Montreal Heart Institute (MHI) set up a follow-up clinic for adults with congenital heart problems in response to requests from pediatric cardiologists at Hôpital Sainte-Justine. The intention was to establish ties with the adult cardiology setting to facilitate the transfer of patients once they reached adulthood. Over the years, this clinic has grown significantly. Since 1998, the number of patients followed annually has increased spectacularly by almost 80%. In order to respond in a more effective, continuous and comprehensive manner to the specific needs of this growing population, the MHI has decided to bolster its team with the addition of new specialists and to concentrate its activities in a designated physical space.

Owing to progress in the fields of prenatal care and genetic screening, improved socio-economic conditions and the advances in pediatric surgery and interventional hemodynamics, 85% of neonates with congenital defects now reach adulthood. We estimate that there are currently 88,000 adults living with a congenital heart defect in Canada. Roughly

one quarter of these patients, or 22,000 adults, live in Quebec. This number is expected to rise to 30,000 by 2006. Their pathologies are varied and often more complex as a result of earlier surgical procedures.

“Because of the rarity of their condition, this new group of adult patients requires the medical expertise of an ultra-specialized medical centre – expertise not available in general cardiology centres – to administer innovative treatment”, says Dr. Lise-André Mercier, Director of the Montreal Heart Institute’s Adult Congenital Heart Center. “The size of this population is currently underestimated. After 15 years of concentrated work in the field, the Institute and its Adult Congenital Heart Center are pleased to be able to offer patients more continuous follow-up care, optimal transfer mechanisms and privileged access to the ultra-specialized care they require. Thanks to the services we make available, these patients are better able to adapt to the challenges of adulthood.”

A unique problem

Young adults are often ill prepared to assume responsibility for the particularities associated with their cardiac condition and the limitations it imposes. This is due to several factors:

- In order to protect the adolescent, parents and the health care team often hide the nature and severity of the disease, not to mention the potential complications during adulthood and the importance of long-term follow-up;
- Young adults tend to trivialize their state of health and are reluctant to consult in an unfamiliar setting;
- After a childhood and adolescence marked by repeated hospitalisations, a phenomenon of denial of the disease sometimes occurs.

These factors often lead the patient to stop consulting the medical milieu once he or she reaches adulthood. Moreover, a survey carried out with 100 new patients referred to the Adult Congenital Heart Center determined that:

- 35% of patients were not aware of their diagnosis;
- 66% of women had never discussed the potential risks involved in pregnancy;
- 28% had not seen a cardiologist in over five years.

These statistics highlight the need to maximize the transition program with the pediatric setting as to ensure follow-up of each patient transferred to the adult setting and support these young adults at a pivotal stage in their lives.

The Adult Congenital Heart Center team is made up of six cardiologists, one cardiac surgeon, a nurse clinician, a research nurse and a medical secretary. The team works in close collaboration with various MHI services, notably electrophysiology, cardiac catheterization, heart transplant and medical imaging. The Adult Congenital Heart Center also takes in residents from the cardiology program at Université de Montréal for training periods in congenital cardiology.

The Montreal Heart Institute, which celebrates the 50th anniversary of its founding this year, is an ultra-specialized centre dedicated to care, research, teaching, prevention as well as the assessment and development of new technologies in cardiology; the MHI is affiliated with the Université de Montréal.

– 30 –

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