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## Health & Wellness

# Working towards a cure for cystic fibrosis

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*Special to The CJN*

**O**f the 3,500 children and young adults in Canada who have cystic fibrosis (CF), 1,300 live in Quebec.

The most common genetic disease affecting young Canadians, CF is an incurable, chronic and progressive illness of the respiratory and gastro-intestinal system that can be passed down to offspring even if there is no family history.

In most cases, parents who are carriers are not aware of their status, as there are no symptoms.

There is a one in four chance that two carrier parents will pass the disease to their offspring, and half of their children will become carriers.

The risk in the Ashkenazi population – 1 in 23 to 28 – of being a CF carrier is similar to the risk in the general population. This is higher than the risk of carrying Tay Sachs Disease (1 in 30).

Larry Lands, professor of pediatrics, and director of pediatric respiratory medicine for the McGill University Hospital Centre, runs the cystic fibrosis clinic at the Montreal Children's Hospital.

He said that living with CF is a long and difficult grind with a gruelling daily regimen of treatments, including physiotherapy, daily clapping of the chest and back to loosen mucous-filled lungs, and the necessity of taking a large cocktail of drugs to reduce symptoms.

The diagnosis of CF can be devastating to a family, with 15 per cent of cases presenting in the newborn period as a bowel obstruction, 60 per cent diagnosed in the first year, and 90 per cent by the age of five.

Symptoms include poor growth; large, greasy pungent stools;

recurrent chest infections such as bronchitis and asthma; and overly salty sweat.

Great strides have been made in the development and treatment of CF. A child born in the 1960s with CF was destined to die a young death, but the most recent available statistics from 2006 show that for the first time, more than 50 per cent of all Canadians with CF are 18 years and older.

In 1989, it was Canadian researchers who discovered the gene responsible for CF, giving hope to families living with the disease.

Work being conducted by Lands and his team at the Montreal Children's Hospital and at McGill University, is part of the leadership role Canada is playing in striving for a cure.

"McGill is very active in CF research. One of our overriding goals is to slow the progress of the disease, thus adding years to the lives of our patients, who are living longer and healthier," said Lands.

Research at McGill and across the country is supported through the efforts of the Quebec and Canadian Cystic Fibrosis associations.

The Quebec Cystic Fibrosis Association, operating under the umbrella of the national foundation, was established in 1981 by a group of parents of children with CF. It actively raises funds for medical research, ensures the development of networks and services for persons with CF and their families, defends the rights of individuals affected by CF, educates the public and raises awareness of the disease, and facilitates the development of different forms of support and helps to address the needs of the people it represents and serves.

Lands said that 75 per cent of the money raised by the Quebec foundation supports ongoing research, and the rest supports the

hospital based clinics.

The clinic at the Montreal Children's Hospital is made up of a multi-disciplinary group of professionals including physicians, nurses, social workers, various therapists and dietitians.

"We provide a complete care package for our patients, and the success rate of children with CF followed at the Children's [Hospital] clinic is clear. It is unusual for one of our patients not to graduate from a pediatric clinic and move on to an adult clinic."

Lands has worked closely with both the Quebec and Canadian Cystic Fibrosis associations and reinforces the need for ongoing fundraising.

"The provincial and national CF foundations keep administration costs extremely low, one of the lowest of among all charitable foundation. Donors know that their donations are well-managed, and reach our research centres and patients."

Lands said that funds raised by the association do not replace the much needed government funding, but ensure that all patients receive the extras that they need.

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## McGill University is very active in CF research

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Lands and his team have had success looking at new approaches to attacking the fundamental problem underlying cystic fibrosis and not relying on better treatment options.

He advocates for newborn screening tests, which have been adopted in Ontario and Alberta, and will soon be used in British Columbia and Saskatchewan.

All but three American states have screening programs in place, and his goal is to promote this screening for Quebec. "Newborn screening gives us the opportunity to intervene and prevent problems, and help provide a better life," he said.

For more information, consult the Quebec Cystic Fibrosis website at [www.aqfk.qc.ca](http://www.aqfk.qc.ca) or the Canadian Cystic Fibrosis Foundation website at [www.cff.ca](http://www.cff.ca), or call 514-877-6161.