In 1960 the founding leaders of the Canadian Cystic Fibrosis Foundation (CCFF) had a vision – that their tiny, ailing infants should survive to go to school. They refused to accept that their babies – lacking in doctors and clinics, treatments and medications – should die in infancy.

Unwilling to wait for a miracle, the parents set about creating a miracle themselves. Over time, they enlisted the interest and support of caring physicians, health professionals, and scientists. With the passage of time, countless ordinary Canadians were captivated by their vision, and rallied to their side.

Together, they sought not only to remedy the immediate and pressing needs of the sick children, but to secure a future in which cystic fibrosis would be defeated, once and for all. In establishing and raising funds to support a program of research, which has grown to achieve international recognition, they took aim at the cause of the children's distress - they took aim at cystic fibrosis itself. Today, more than 40 years later, the CCFF is one of the leading, non-governmental granting agencies in the field of cystic fibrosis research. Over the same period, the median survival age of Canadians with cystic fibrosis (CF) has risen to 35.6 years.

While progress has been remarkable, the fact remains that cystic fibrosis is still fatal. Thus the urgency of the CF cause is undiminished. In the eyes of the Canadian Foundation's current leaders (who now include many adults with CF), research remains the surest way to invest in lasting change; and the program in Canada of CF research, supported entirely by voluntary and charitable dollars, continues to break new ground.
Many of the milestones on the road to a cure have been achieved by researchers working at institutions across Canada, with the aid of funding from the CCFF. As you probably know, a team of investigators led by Canadians announced the landmark discovery, in 1989, of the gene responsible for cystic fibrosis. This discovery is fuelling the international CF research effort today. Canadian investigators also pioneered the world’s first successful double lung transplant involving a person with CF.

At the same time, the most immediate need of every adult and child with CF in Canada has been for specialized, clinical care. In this country, the provincial governments provide core funding for clinical and hospital services. Thus, with its charitable dollars, the Canadian Cystic Fibrosis Foundation supplements government financing through a system of ‘incentive grants’ which are intended to promote a high standard of clinical and transplant care for adults and children with CF, and to provide care-giving personnel with opportunities to further their professional training and education.

Specifically, the Canadian Cystic Fibrosis Foundation invests in team-based care, offering to 37 designated CF clinics and five lung transplant centres across the country supplementary salary and professional development dollars, in order to harness the time and expertise of physicians and surgeons, nurses, physiotherapists, nutritionists, social workers and pharmacists towards the goal of optimal health for every Canadian with CF. This team approach is one of the most important dimensions of CF clinical care in Canada.

Dr Elizabeth Tullis, Director, CF Adult Clinic,
St. Michael’s Hospital, Toronto

In recent years, the publicly-funded system of health care in this country has been challenged by constraints in spending. And the requirement for user contributions towards the cost of drugs and medications has been rising sharply. In view of these challenges, the Foundation’s leaders have been playing an increasingly important role in advocacy. They have led deputations aimed at preserving public support of CF clinical and hospital care, as well as public coverage of life-sustaining CF drugs and medications.

And in these advocacy efforts, adults with CF have taken up leading roles. For example: during 2002, three individuals with CF in three different provinces appeared before a federally-appointed, travelling commission on the future of health care in Canada. Debra Mattson of Victoria (who participated in the founding meetings of CFW in Genoa) was one of these leaders. Among a number of concerns, they discussed the impact on individuals and families of rising drug costs, and the need to improve health care for persons with CF living in rural areas. Their interventions – widely reported in the Canadian news media – have been influential, and the commission report has capitalized on their arguments to recommend change.
Change, of course can be slow in coming; and time – to wait for change to happen – is in very short supply. The need for advocacy is likely to intensify.

In the mean time, who supports the CF cause in Canada? Volunteers in 52 chapters raise approximately half the revenue of the Canadian Foundation: through community events, coin collections, raffles, and other local projects. Nationally co-ordinated fundraisers include a ‘signature’ FrightLites® campaign at Halloween (based on the sale of coloured ‘glow sticks’ for children), campaigns by mail, and Shinerama, an annual, Canada-wide student campaign carried out on 60 campuses, by 25,000 university and college students.

Since 1964, the Foundation has also benefited enormously from the loyal support of the Kinsmen and Kinette Clubs of Canada, a national network of community service clubs, and since 1985, from the generous proceeds of a Canada-wide walk-a-thon – the Zellers Friends of the Family Walk for Cystic Fibrosis – sponsored by the Zellers family of department stores.

The committed leadership of chapter and community volunteers, the outstanding contributions of national partners such as the Kinsmen and Zellers, the friendship of Celebrity Patron, Céline Dion, and of Honorary Director, Mrs. Mila Mulroney, are all vitally important to advancing the goals we share.

The CCFF’s Kin-CF Liaison Committee

As the search for a cure or an effective control for cystic fibrosis enters a new phase, there is a strong awareness in Canada that the volunteer leaders and supporters of the national and the international CF effort – including individuals with CF, and their families – are the single most important asset in the campaign for a brighter future.

Editor’s Note:

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