



Canadian Cystic Fibrosis Foundation
Fondation canadienne de la fibrose kystique

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July 31, 2003

Charles Smyth
Technical Advisory Committee on Tax Measures
for Persons with Disabilities
140 O'Connor Street
Ottawa, ON KIA 0G5

Dear Mr. Smyth,

Thank you for the opportunity to comment on the Disability Tax Credit (DTC) with respect to Canadians affected by cystic fibrosis (CF), for the members of the new Technical Advisory Committee on Tax Measures for Persons with Disabilities.

Cystic Fibrosis

As you may be aware, CF is an inherited disease which affects breathing and digestion. In the lungs, CF causes severe breathing problems. A build-up of thick mucus makes it difficult to clear bacteria and leads to cycles of infection and inflammation, which causes progressive damage to the delicate lung tissues. From the time of diagnosis, usually in the first year of life, individuals with CF must follow a demanding daily routine of physical therapy to keep the lungs free of congestion and infection, and to facilitate breathing. In the digestive tract, CF makes it extremely difficult to digest and absorb adequate nutrients from food. Thick mucus also blocks the ducts of the pancreas, preventing enzymes from reaching the intestines to digest food. Therefore, persons with CF must consume a large number of artificial enzymes (up to 40 pills a day) with every meal and snack. Unfortunately, CF is always fatal, and virtually all CF deaths are caused by chronic and progressive lung disease.

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Life-Sustaining Therapy

A few years ago, following intensive consultations between representatives of the Canadian Cystic Fibrosis Foundation (CCFF) and the Department of Finance, the DTC eligibility criteria were changed to extend access to the credit on a more equitable basis to young Canadians with CF who were experiencing severe and prolonged disability, primarily because they could not breathe. The change to include “life-sustaining therapy” was made in respect of the 2000 and subsequent taxation years. Prior to 2000, the families of at least two young Canadians with CF who had died were pursued by government assessors for reimbursement of the DTC, as the deceased individuals were deemed by the Revenue Canada not to have suffered from disability. The principal rationale seemed to be that there were no grounds for recognition of breathing as a “basic activity of daily living”.

Our Foundation’s members remain profoundly grateful that a positive solution was identified for individuals with CF who require extensive therapy to alleviate health problems which – as the disease progresses – are severely disabling. They would be very concerned should this eligibility be restricted. It is our understanding that the Technical Advisory Committee is not revisiting the criteria for “life-sustaining therapy”.

Breathing

While we are aware that “breathing” remains off the list of basic activities of daily living used to determine eligibility for the DTC, we would like to draw your attention to a recently updated World Health Organization document, “*International Classification of Functioning, Disability and Health*” which now recognizes breathing as a basic daily function. It follows, accordingly, that severe deficits in breathing, which are often experienced by persons with CF, may have severely disabling consequences with respect to carrying out normal routines of daily living.

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If the Technical Advisory Committee is considering, as recommended in the Report of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities “*Tax Fairness for Persons with Disabilities*” released December 2002, adding “breathing” to the list of basic activities of daily living for the purpose of assessing eligibility for the DTC, the CCFF would be pleased to comment on or assist your committee in evaluating the merits of this approach. Advisors to our Foundation, who are clinical specialists in CF care, have done considerable research on the disabling effects of deficits of breathing, and would be willing to share their research and views with the Technical Advisory Committee.

“Qualified Persons”

We agree with the finding of the Sub-Committee on the Status of Persons with Disabilities in the March 2002 Report “*Getting it Right for Canadians: the Disability Tax Credit*” that individuals residing in remote areas may not have ready access to the practitioners listed as persons qualified to complete Form T2201 as set out in paragraph 118.3(1)(a.2) of the *Income Tax Act*. We support the Sub-Committee’s recommendation that the *Income Tax Act* should be amended to include “registered nurses” for these individuals. We would also suggest that the Technical Advisory Committee give consideration to adding “nurse practitioner” to the list, in their review of persons qualified to complete Form T2201.

Redesigning Form T2201 and Public Awareness

The CCFF supports the initiative of the Canadian Customs and Revenue Agency (CCRA) to revise and redesign Form T2201 with the primary objective to clarify and increase the awareness of the DTC legislative criteria for taxpayers and health professionals.

The Foundation is encouraged that the CCRA recognizes the need to give better information to persons with disabilities, and their families, regarding the criteria, and eligibility for the DTC. We hope the CCRA and the Government of Canada continue this positive initiative by mounting a program to educate and raise awareness of all tax measures available to persons with disabilities and their families. We believe it is important that the individuals concerned know about, and understand the tax measures available to them.

To assist in this effort the CCRA might find it useful to consult with the community of persons with disabilities, including organizations that provide support within this community, and seek their input in the development of plain language information brochures and other resources on tax measures. Assistance from organizations, such as the CCFE, could be sought in helping to disseminate and raise awareness of the tax measures available to persons with disabilities and their families.

For your information, the Canadian Cystic Fibrosis Foundation is a non-profit, charitable organization dedicated to improving life expectancy, and the quality of life, of persons with CF. The Foundation pursues this goal principally by providing incentive grants to enhance the availability and effectiveness of specialized medical and transplantation services, and by seeking a cure or effective control for CF, through research.

We appreciate this opportunity to provide input. Should your committee members wish additional information about CF and its impact on Canadians, we will be pleased to consult further. We look forward to receiving and reviewing the recommendations of the Technical Advisory Committee.

Yours sincerely,

Cathleen Morrison
Chief Executive Officer

cc. Dr. Carolyn Bennett, MP
Dr. Elizabeth Tullis, CF Clinic Director, St. Michael's Hospital