



Canadian Cystic
Fibrosis Foundation
Fondation canadienne
de la fibrose kystique

Speaking Notes

Presentation to Canadian Board Services, Board of Directors

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Good afternoon. Thank you for the opportunity to speak with you today. My name is Kelly Gorman, I am the Manager, Government and Community Relations with the Canadian Cystic Fibrosis Foundation. The Foundation is a Canada-wide health charity, with 50 volunteer chapters. Our mission is to help people with cystic fibrosis. We do this by funding CF-related research, supporting high quality CF clinical and transplant care, raising awareness of CF, and advocating with, and on behalf of, the CF community.

The reason for my attendance is related to your mandate to develop a recommendation for a new national organ and tissue donation and transplantation system. As part of your recommendation, we ask you to consider the financial struggles faced by individuals, and their families, throughout the transplant process, and to incorporate a strategy to provide assistance to these individuals in your recommendation. To illustrate this issue, I will speak specifically about the challenges experienced by the CF community.

Cystic fibrosis is the most common, fatal genetic disease affecting young Canadians. CF is a complex, multi-organ disease, primarily affecting the lungs and digestive system. Despite the ongoing progress being made in CF treatment, cystic fibrosis remains fatal, and most CF deaths are caused by lung disease.

When a person with cystic fibrosis is at the end-stage of the disease, they may decide to have a transplant to extend and improve their quality of life. Currently, double-lung, heart-lung and liver transplants are the only definitive treatments for patients with advanced disease. The majority of transplants performed on individuals with cystic fibrosis are double-lung transplants.

In Canada, there are five lung transplant centres. Therefore, often individuals with CF and their caregiver, who is required to relocate with individual as part of the transplant program, must relocate to be close to the lung transplant centre. In addition to the emotional challenge of moving away from family, friends, and familiar surroundings, many individuals face significant financial challenges when required to relocate for a transplant.

Personal financial expense should not be a factor in making a decision to have life-saving surgery – unfortunately, we know this in fact does happen, and there are cases where the personal financial burden has been cited as a reason not to be listed for transplant.

Some provinces do provide modest financial support to help people that have to relocate out-of-province, or within their home province, for transplant. This support, while appreciated, does not provide sufficient financial assistance. As well, the support available varies significantly from province to province.

To help show the personal financial burden placed on Canadians with cystic fibrosis, I'd like to share a recent example of a young woman who relocated to Toronto from Newfoundland & Labrador for a lung transplant. She's agreed to share her story with you today.

This individual waited four months for her transplant, and then remained in Toronto for another three months post-transplant, a requirement of the program. She received some financial assistance from her home province for travel, accommodation and food. As well, she and her family did some fundraising to help cover her additional expenses.

Recently, she tallied her medical expenses – those eligible for the Medical Expense Tax Credit- related to her transplant, and it is over \$19,000.00! This total does not include expenses reimbursed through government assistance. Also, it is important to note that this does not include her mortgage, insurance, or other living expenses required to sustain her home in Newfoundland.

As well, both the individual and her caregiver (her husband) gave up their jobs when they moved to Toronto for the transplant, meaning they had no income. Even though they had assistance, they still faced a heavy financial burden, during a very stressful and emotional period.

Some individuals do not fundraise due to a lack of resources or because they find it too difficult to share such a personal matter with the general public. As well, the amount of assistance available through some provincial governments may be lower than the amount this individual received, or non-existent. In these circumstances, the financial cost to the individual would be unbearable to most.

Another factor in the calculation of expenses is the wait time for transplant. The wait time varies depending on a number of factors - it can be a few weeks to two or more years. As you can imagine, depending on the wait time, the costs can be very substantial, to the point of bankruptcy.

In moving forward with developing the recommendation, we strongly encourage CBS to provide solutions to the heavy financial burden placed on individuals and their families who undergo transplant, especially on those individuals who must relocate to specialized transplant centres.

We know a transplant can extend and improve lives - there are individuals with CF who are 5, 10, 15, even 20 years, post-transplant who continue to have a high quality of life, and are grateful for each and every day. In Canada, the personal financial costs associated with transplant should not deter a person with CF, or any Canadian, from receiving this potentially life-saving treatment.

On behalf of the CF community, thank you for listening.