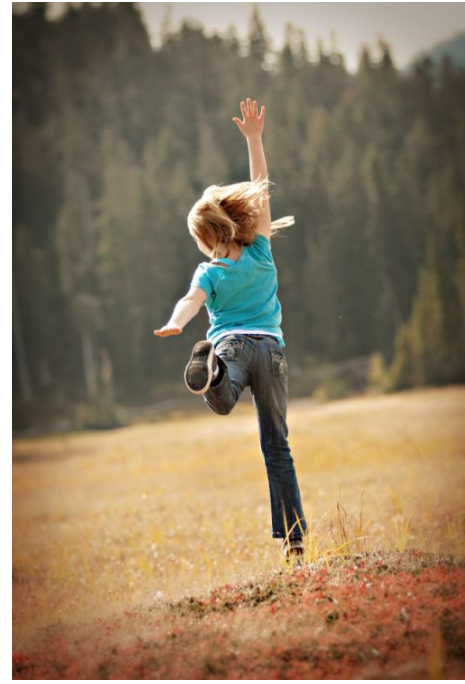




Canadian Cystic
Fibrosis Foundation
Fondation canadienne
de la fibrose kystique



Presentation to Canadian Blood Services December 3, 2009



Cystic Fibrosis and Transplant

Presentation Overview

- The Canadian Cystic Fibrosis Foundation
- Cystic Fibrosis
- Cystic Fibrosis and Transplantation
- Transplant and Financial Challenges/Struggles
- Recommendation



The Canadian CF Foundation



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- The Foundation is a Canada-wide health charity, with 50 volunteer chapters. 2010 marks the 50th anniversary of the Foundation.
- CCFF raises funds to support high quality cystic fibrosis research, clinical and transplant care, and public education.

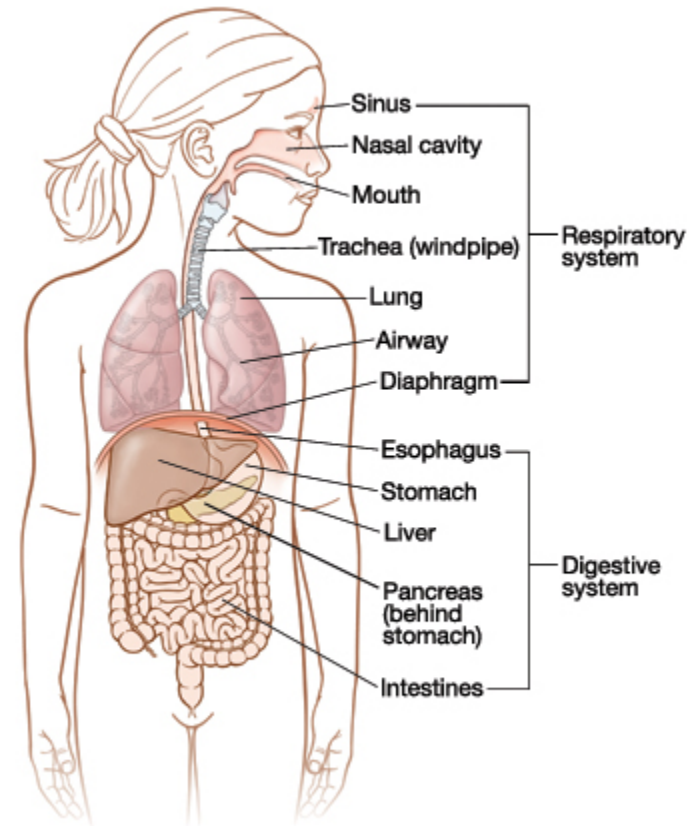




Cystic Fibrosis



Cystic fibrosis is a hereditary disorder characterized by lung congestion and infection and malabsorption of nutrients by the pancreas



Cystic Fibrosis



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- Cystic fibrosis (CF) is the most common, fatal genetic disease affecting young Canadians.
- CF primarily affects the respiratory & digestive system.
- In the lungs, the mucus clogs the airways and leads to chronic infection and inflammation making it difficult to breathe.
- In the digestive system, the mucus blocks the pancreatic enzymes from entering the intestine and making it difficult in digesting essential nutrients from food.
- In 1960, most children with cystic fibrosis did not live long enough to attend kindergarten. Today, thanks to advances in CF research and top-quality care, half of all Canadians with cystic fibrosis may expect to live into their late 40s, and even beyond.





Cystic Fibrosis and Transplant

- When a person with cystic fibrosis is at the end-stage of the disease, transplant may be considered.
- Currently, double-lung, heart-lung and liver transplants are the only definitive treatments for patients with advanced disease.
- The majority of transplants in people with CF are double-lung transplants.





Lung Transplantation

- There are 5 lung transplant centres across Canada (Montreal, Toronto, Winnipeg, Edmonton, and Vancouver).
- Often individuals with CF and their caregiver must relocate for transplant.
- Individuals and their families face significant financial challenges when required to relocate for transplant.
- Some provincial governments offer modest financial assistance and support.
- Wait times for transplant varies –it can be a few weeks to 2 or more years.





Personal Example

Pre and Post Transplant Expenses

Accommodations	\$ 7,458.89	
Meals	12,240.00	
Travel	<u>1,175.75</u>	\$20,874.64
Less Government Assistance		<u>- 5,148.52</u>
Difference		\$15,726.14

Follow-up Post-Transplant Expenses

Accommodations	\$2,535.54	
Meals	2,664.00	
Travel	<u>2,345.64</u>	\$ 7,545.18
Less Government Assistance		<u>- 3,581.31</u>
Difference		\$ 3,963.87

TOTAL OUT-OF-POCKET **\$19,690.01***

* does not include mortgage, insurance or other expenses required to sustain home in Newfoundland





Recommendation

- We strongly encourage Canadian Blood Services to provide solutions in their recommendation to the heavy financial burden placed on individuals who undergo transplant, especially when they must relocate to specialized transplant centres.
- In Canada, the personal financial costs associated with transplant should not deter a person with CF, or any Canadian, from receiving this life-saving treatment.



Thank you!



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