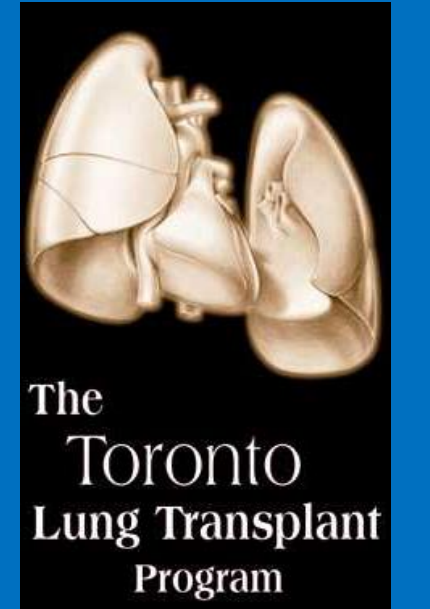
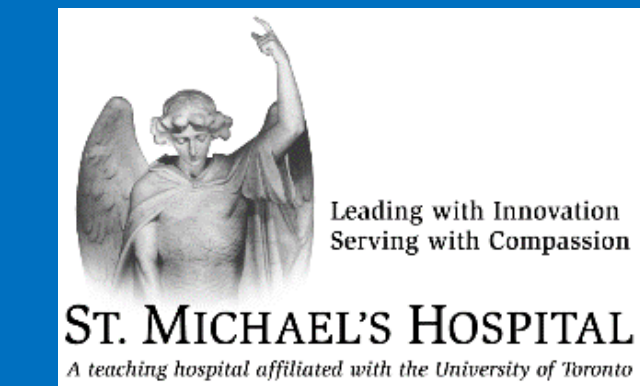


# Transition to Lung Transplant: Developing National Standards in Canada to Successfully Transition Patients with Cystic Fibrosis

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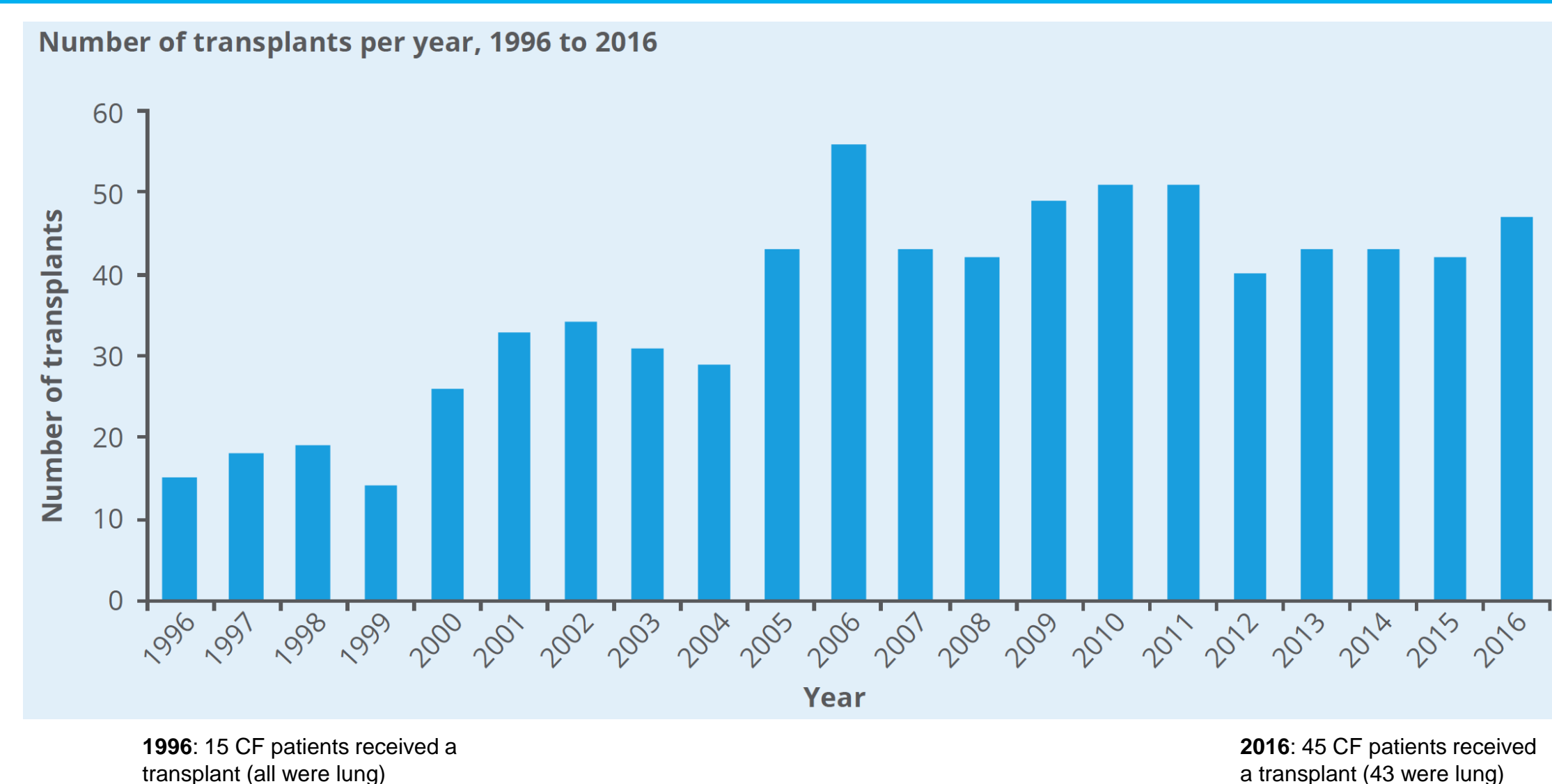
## Objectives

The collaborators set out to develop a national program to optimize the transition to transplant process and each patient's transplant journey.

The four-tiered program aims to:

- Conduct an environmental scan to understand current challenges and gaps in care.
- Develop and host virtual patient and caregiver educational webinars.
- Develop and host on-site and virtual workshops for healthcare professionals.
- Develop standardized protocols for transplant management in CF clinics.

Figure 1: Number of Annual Transplants for CF Patients<sup>1</sup>



## Audience

The environmental scan was targeted to:

- Adult (18 years +) post-transplant patients
- Caregivers of paediatric transplant patients
- Lung transplant coordinators at the four Canadian transplant centers
- CF Nurse coordinators from 42 clinic sites

The virtual patient and caregiver educational webinars are targeted towards:

- Post-transplant patients & caregivers

The virtual and on-site workshops for healthcare professionals, and the standardized protocols are targeted towards:

- The lung transplant team
- The CF clinic team

Other groups have expressed interest in the virtual webinars, namely, pre-transplant patients and patients not yet listed for transplant.

## Deliverables

### 1. Environmental Scan

Feedback was gathered through three independent surveys distributed via Cystic Fibrosis Canada's social media channels, direct to clinics, and direct to patients through clinic distribution lists. Survey results provided insight into current gaps in care and a roadmap for webinar topics. Surveys were completed by:

- 53 Adult Patients
- 8 Transplant Coordinators
- 31 Nurse Coordinators

### 2. Virtual Patient & Caregiver Educational Webinar Program (in development)

- Webinar 1: Preparing for a Transplant
- Webinar 2: Financial Considerations & Relocation
- Webinar 3: Psychosocial Challenges

### 3. Virtual Healthcare Provider Webinar Program

- Webinar 1: Overview of Transplant (Speaker: Dr. Cecilia Chaparro)
- Webinar 2: Pharmacy Overview (Speaker: Daniel Cortes)
- Webinar 3: Relocation & Financial Considerations (Speakers: Annie Thomas-Diceman & Laura Middleton)
- Webinar 4: CF-Related Diabetes (Speaker: Kate Gent)
- Webinar 5: Vaccines (Speaker: Kevin Curly)
- Webinar 6: Mental Health (Speaker: Dr. Kien Dang)
- Webinar 7: GI & Liver Disease (Speakers: Dr. Paul Pencharz, Brooke Stewart, & Dr. Tanja Gonska)
- Webinar 8: Infection Control Guidelines (Speaker: Dr. Shahid Husain)
- Webinar 9: Physiotherapy & Exercise (Speakers: Kenneth Wu & Lisa Wickerson)
- Webinar 10: Bone Health (Speaker: Dr. Erin Norris)
- Webinar 11: Sexual Health Issues (Speaker: Dr. Elizabeth Tullis)
- Webinar 12: Paediatric Transplantation (Speaker: Dr. Melinda Solomon)

### 4. Development of Standardized Protocols (in development)

- Protocols for CF-related issues pre- to post-transplant will be developed based on webinar content and discussions on the following topics after consultation and consensus with the other transplant centers in Canada:
  - Cystic Fibrosis-Related Diabetes
  - Gastrointestinal Complications
  - Vaccines
  - Fertility & Pregnancy

Figure 2: Survey Question: What Was the Most Stressful Aspect of Being on the Transplant List? Select Patient Responses Included:

The wait – an emotional rollercoaster	The long wait from testing to approval
Not being able to plan anything	Out of pocket costs
Relocating – being away from home and family	Nightmares – not knowing if I would get the lungs in time
Not knowing what to expect	The fear of it going badly
Feeling too sick to exercise but fearful of being removed from the list	Fear of not being ready and declining surgery

## Impact

- Survey responses indicated great appreciation from both patients and healthcare providers for a focus on this topic and for the opportunity to engage in the development of the program.
- Based on feedback, a new webpage has been developed on Cystic Fibrosis Canada's website dedicated to the pre- to post-lung transplant transition process. Traffic to this page will be monitored and evaluated at the end of the project.
- Recorded webinars will be made freely available on Cystic Fibrosis Canada's website and will be accessible by the global CF community. Metrics on viewings of recordings will be tracked.
- Post-webinar follow-up surveys will gather feedback from participants on the value of the webinars and opportunities for improvements.

## Challenges

Challenges encountered while developing this program included:

- Wait times for translating survey and website content
- Survey participation rates and follow-up reminders, which delayed the development of program content
- Scheduling convenient times to discuss webinar content with the expert speakers and convenient times to host the webinars, given the desire to engage a national audience across multiple time zones

## Ideal Next Steps

- Develop a more robust peer mentorship program for patients
- Greater outreach to the French-speaking community
- Global collaboration (LLC QI project) – in progress

## References

1. Cystic Fibrosis Canada (2017). The Canadian Cystic Fibrosis Registry: 2016 Annual Report *in press*

## Acknowledgments

The collaborators thank Vertex Pharmaceuticals, Inc. for supporting this initiative, all webinar speakers, and all survey participants for helping to shape the program content.