

Dear Ministers of Health,

We are writing to you today regarding the recent CADTH recommendations for Trikafta, an innovative medication that has revolutionized the treatment of cystic fibrosis (CF).

If followed, CADTH's recommendation will limit access to Trikafta to only those patients with lung function of  $\leq 90\%$ . **We strongly disagree with this opinion and are writing to provide you with an alternate recommendation** from the physicians, researchers and health care professionals who specialize in cystic fibrosis.

We have detailed why we disagree with this eligibility criteria in recent correspondence to you, which can be found here, but the most important thing for you to know is that *one in four Canadians who could benefit from Trikafta will not have access* to it if you choose to accept the access criteria recommendations from CADTH.

The CADTH recommendation ignores the real-world clinical evidence that Trikafta improves lung function for patients with greater than 90% lung functions. **Waiting until a patient has less than 90% lung function means allowing structural and irreversible lung damage to accumulate before treatment can begin. The best treatment for CF is preventing the disease from progressing.** That is why your province has implemented newborn screening for CF and why treatment starts immediately on diagnosis. That is why, with only one exception, no other jurisdiction in the world has imposed this barrier to access.

This threshold also unjustly discriminates against adolescents and children with CF. Many teens with CF and three quarters of 6-11 yr-olds with CF have lung function above the 90% threshold, but still have to suffer with progressive lung damage, infections, hospitalizations, and complex daily treatment regimens.

**It is not an exaggeration to say that the impact of this new therapy, Trikafta, is dramatic.** A study, led by researchers at Dalhousie University, The Hospital for Sick Children (SickKids) and St Michael's Hospital, demonstrated that early introduction of Trikafta in 2021 would result in life-changing health improvements by 2030 in comparison to no drug available, including:

- 15% fewer deaths
- Increase in estimated median age of survival by 9.2 years
- 60% fewer people living with severe lung disease due to cystic fibrosis, and
- 18% increase in people living with only mild lung disease
- 19% fewer hospitalizations or home intravenous courses for chest infections
- A reduction in the number of transplants that are required for severe lung disease

As you know, the CADTH recommendation is not binding on any government. You can make Trikafta available to every Canadian in your province who can benefit from this drug.

In its final recommendation, CADTH recommends “(p)rescribing of ELX-TEZ-IVA [, or Trikafta,] and monitoring of treatment response should be limited to CF specialists.” We sincerely recommend that you extend that trust of CF specialists to the proper initiation and coverage criteria as well. We, Canada’s cystic fibrosis medical experts, are sharing with you our recommendations on the appropriate use of Trikafta. **We recommend that you immediately fund Trikafta for all who could benefit and that you empower your CF physicians to manage their patients’ access based on the evidence based clinical guidelines they have developed.**

Ministers, time is of the essence. With every day that passes, the health of many of our patients who could benefit from this drug worsens. We ask that you give us the tools we need to save lives and improve the lives of thousands of Canadians. Because CF can’t wait.

Yours sincerely,

First name	Last name	Job title	Clinic	Province
Musawir	Ahmed	Respirologist, CF adult clinic	HSC Winnipeg	Manitoba
Tareq	Alabdoulsalaam	Respirologist Pediatric CF clinic	Children’s Hospital Winnipeg	Manitoba
Wendy	Alexander	Paediatrician	Saint John Regional Hospital	New Brunswick
Christian	Allard	Adult respirologist	CIUSSS Saguenay-Lac-St-Jean	Québec
Jocelyn	Arpin	Cf Nurse Clinician	Children’s Hospital Winnipeg	Manitoba
Paula	Barrett	CF Nurse Coordinator for 32 years	IWK Heath Centre, Halifax	Nova Scotia
Christelle	Bergeron	Adult Respirologist	CIUSSS de l'Estrie - CHUS	Quebec
Deb	Bester	Registered Respiratory Therapist	Grand River Hospital Pediatric CF Clinic	Ontario
Graham	Bishop	Respirologist, CF adult clinic	Saint John Regional CF Clinic	New Brunswick
Jerry	Boun	Pharmacist	Grand River Hospital	Ontario
André	Cantin	Respirologist, CF adult clinic	CIUSSSE CHUS	Québec
Juliegh	Clarke	Physiotherapist	Jim Pattison Children's Hospital	Saskatchewan
Sophie	Corriveau	Respirologist, CF Adult Clinic	McMaster	Ontario
Patrick	Daigneault	Pediatric Respirologist-Clinic director	Centre Mère-Enfant du CHU de Québec	Québec
Karen	Doyle	Nurse practitioner CF program	Janeway Children's Health and	Newfoundland and Labrador

			Rehabilitation Centre/ HSC	
Christopher	Ewing	Pediatric Respiriologist	Edmonton Pediatric CF Clinic	Alberta
Majdeline	Farah	Respirologist, CF adult clinic	CISSSAT	Quebec
Mallory	Fox	Pediatrician	Grand River Hospital Pediatric CF Clinic	Ontario
Kirsten	Gordon	CF Nurse Coordinator	Victoria Adult Clinic	British Columbia
Steeve	Goulet	adult respirologist	CISSS Rimouski	Quebec
Jody	Hainstock- Beavis	CF Nurse Clinician	HSC Winnipeg	Manitoba
Joanne	Hammel	CF Nurse Coordinator	Children's Hospital of Eastern Ontario	Ontario
Peter	Hogan	Pharmacist	Saint John Regional CF Clinic	New Brunswick
Shaikh	Iqbal	Respirologist Pediatric CF clinic	Children's Hospital Winnipeg	Manitoba
Amanda	Jobe	RN- Nurse Coordinator	Edmonton Pediatric CF Clinic	Alberta
Steven	Kent	Paediatrician	Victoria Pediatric Clinic	British Columbia
Grace	Lam	Adult Respirologist	Edmonton Adult CF Clinic	Alberta
Larry	Lands	Pediatric Respirologist	McGill University Health Centre-Montreal Children's Hospital	Quebec
Winnie	Leung	Adult respirologist	Edmonton Adult CF Clinic	Alberta
Diane	Lougheed	Adult Respirologist	Kingston Adult CF Clinic	Ontario
Elizabeth	MacCready	CF Nurse Coordinator	Saint John Regional CF Clinic	New Brunswick
Dimas	Mateos	Pediatric Respirologist	IWK	Nova Scotia
Marianne	McKenna	Pediatrician	SJRH	New Brunswick
Martha	McKinney	Pediatric Respirologist	Edmonton Pediatric CF Clinic	Alberta
Solomon	Melinda	Pediatric Respirologist	SickKids Hospital, Toronto	Ontario
Marcel	Milot	Pediatrician	CIUSSS Saguenay-Lac- St-Jean	Québec
Julie	Milot	Adult respirologist	IUQCP	Quebec
Laura	Moniz	CF Nurse clinician	Children's Hospital Winnipeg	Manitoba
Lenna	Morgan	Paediatrician	Windsor Pediatric CF Clinic	Ontario

Nancy	Morrison	Respirologist, CF Adult Clinic	QE II HSC, Halifax	Nova Scotia
Linda	Pineau	Paediatrician	Grand River Hospital	Ontario
Nancy	Porhownik	Respirologist, CF adult clinic	HSC Winnipeg	Manitoba
Bradley	Quon	Respirologist, CF adult clinic	St. Paul's Hospital	British Columbia
Jonathan	Rayment	Pediatric Respirologist	BC Children's Hospital	British Columbia
Joe	Reisman	Pediatric Respirologist	CHEO CF Clinic, Ottawa Ontario	Ontario
Lyne	Rivard	Pediatrician	CIUSSSS CHUS Sherbrooke	Quebec
Eve	Routhier	CF Nurse Coordinator	IUCPQ	Quebec
Maryanne	Schlosser	Pharmacy Technician	Grand River Hospital Pediatric CF Clinic	Ontario
Mary Jane	Smith	Pediatrician	Janeway Children's Health and Rehabilitation Centre	Newfoundland and Labrador
Anne	Stephenson	Respirologist, CF adult clinic	St. Michael's Hospital	Ontario
Sarah	Sutherland	CF Nurse Coordinator	Nova Scotia Health	Nova Scotia
Julian	Tam	CF Clinic Director	Royal University Hospital	Saskatchewan
Laurie	Trace	Registered Social Worker	Grand River Hospital Pediatric CF Clinic	Ontario
Arlene	Valenta	CF Nurse Coordinator	Grand River Hospital Pediatric CF Clinic	Ontario
Rafiaa	Valji	Respirologist Pediatric CF clinic	Children's Hospital Winnipeg	Manitoba
Amy	Washington	Registered Dietitian, Certified Diabetes Educator	Adult CF Clinic, Victoria	British Columbia
Pearce	Wilcox	Adult Respirologist	St Paul's Hospital/UBC	British Columbia
Pierce	Wilcox	CF Clinic Director	St. Paul's Hospital	British Columbia
Aaron	Young	Respirologist, Adult CF Clinic	Adult Clinic Victoria	British Columbia
Zofia	Zysman-Colman	Pediatric Respirologist	CHU Sainte-Justine	Québec