2022-2023
ANNUAL REPORT

Cystic Fibrosis Canada Accelerating Clinical Trials (CF CanACT)

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Cystic Fibrosis Canada
Fibrose kystique Canada

CF CanACT
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CF CanACT new **5-YEAR** strategic plan

10 sites representing **60%** of the Canadian CF population

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18 interventional clinical trials supported by CanACT

184 people with CF enrolled in interventional clinical trials in 2022-23

286 people with CF newly enrolled in observational clinical trials in 2022-23

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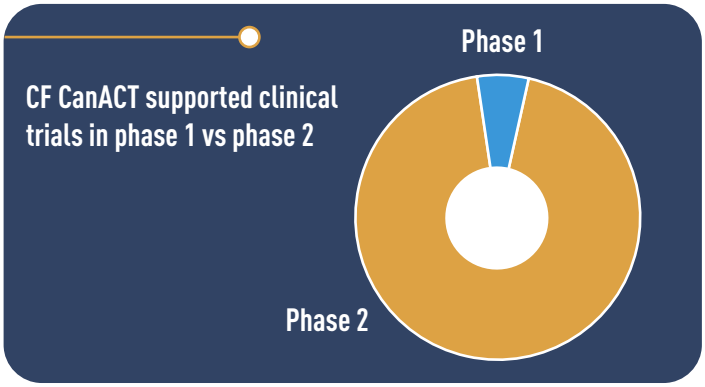
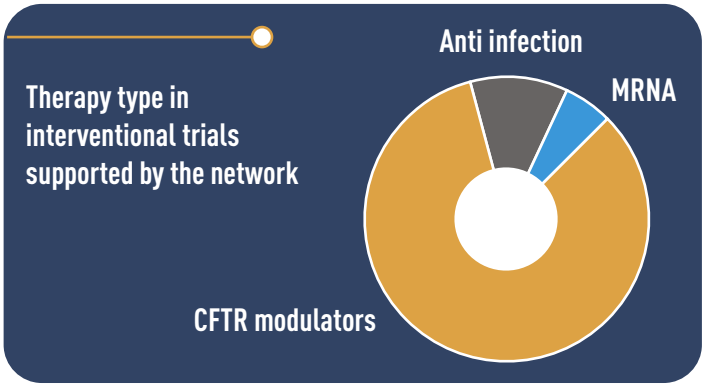
2 feasibility studies





Preparing CF CanACT for the Future

DR. PAUL ECKFORD

The past year has been one of change for our clinical trials network, CF CanACT, as we reflect on how to best position our cross-Canada network for impact into the future. In 2023, we said goodbye to Dr. John Wallenburg, Cystic Fibrosis Canada's former Chief Scientific Officer, who began his much-deserved retirement, and to Dr. Bradley Quon, the network's first Medical Lead, as his term came to a close. In the initial five-year period for the network under Dr. Wallenburg and Dr. Quon's leadership, we launched at six sites and then expanded the network to 10 sites across the country, including 13 adult and paediatric clinics. We've participated in 51 industry trials and five observational trials, and this year alone have recruited more than 360 Canadian CF patients into a clinical trial.

The network has played a pivotal role in bringing life-changing medicines like Trikafta to Canadians and improving the global understanding of who can benefit from the drug. Our network sites have participated in trials investigating the safety and efficacy of the drug for those with rare mutations and young children and, recently, Health Canada approved Trikafta for those 2-5 years old with the most common CF mutation, using data that are in part from our clinical trials network. To protect the health of CF patients before significant structural lung damage occurs, we hope to see our trial data contribute to the approval and expansion of access to Trikafta for all who can benefit, including those with rare mutations and even younger children.

The leadership of Dr. Wallenburg and Dr. Quon in navigating the team through the formation and first critical years of the network has been a key factor in our early and continued success and we thank them both for their vision, leadership and hard work. Dr. Quon will continue his involvement with the network as clinic director at St. Paul's Hospital and Dr. Jonathan Rayment at BC Children's Hospital will take on the role of Medical Lead at CF CanACT. I'd like to formally congratulate and welcome Dr. Rayment in his new role.

Moving into this next chapter, Dr. Rayment and I, as well as the network's leadership team have been focused on preparing CF CanACT for continued success. We have developed a strategy for the next five years that focusses on leaning into our strengths, improving our efficiency and preparing for the new types of trials coming to network sites, particularly those trials on RNA therapies and gene therapies for rarer mutations that are not anticipated to respond to drugs like Trikafta. We are also working to link our network and our activities to wider initiatives in Canada on impactful clinical trials for children and the rare disease space.

We've secured five years of stable funding for the network through a partnership with Cystic Fibrosis Canada and the Cystic Fibrosis Foundation, which will enable the network to do the work required to achieve these goals. We are grateful to share our vision for cystic fibrosis clinical trials in Canada with our partners and leadership team.

I hope you enjoy reading this report as a summary and introduction to the impactful work our clinical trials network is doing to improve the lives of everyone in Canada living with cystic fibrosis. It is the culmination of significant effort by our team at Cystic Fibrosis Canada, and the hard work of our research coordinators and teams across the country. But most importantly, the work we describe here would not be possible without the participation of hundreds of people with cystic fibrosis participating in clinical trials across the country, from Halifax to Vancouver.

Sincerely,

Dr. Paul Eckford
Chief Scientific Officer
Cystic Fibrosis Canada

Preparing CF CanACT for Future Success

Cystic Fibrosis Canada's Accelerating Clinical Trials (CF CanACT) network has matured to become one of the world's leading clinical trial networks for cystic fibrosis (CF). Over the past five years, the network has expanded to provide direct access to clinical trials to over 60% of the Canadian CF population, and access to all Canadians living with CF through the network's referral program. This year alone the network has recruited 363 individuals with CF to participate in trials and since the inception of CF CanACT five years ago, the network has supported 51 industry sponsored clinical trials and five observational trials.

Looking ahead to the next five years

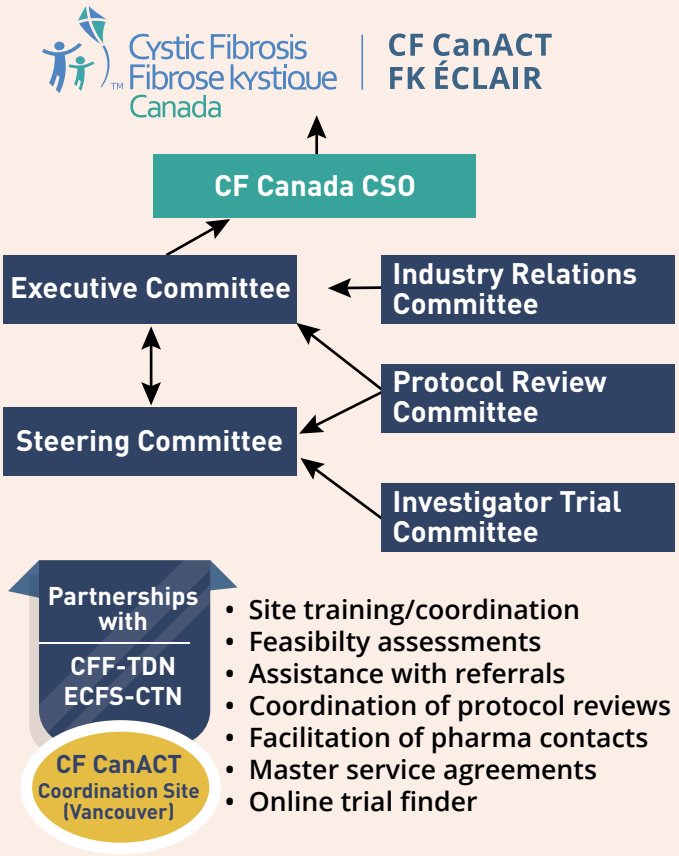
To strengthen and expand the CF CanACT network and better align our work internationally to support the future of CF clinical trials, the CF CanACT team has developed a five-step, five-year strategy.

1. Adapt to a new clinical trial environment by increasing support for nucleotide-based therapies and increasing our capacity to measure new clinical endpoints.
2. Increase the participation of people from hard-to-reach populations in clinical trials by supporting clinical care teams with education and training on how to connect with these communities.
3. Maintain a financially stable and well-coordinated network that aligns with global CF research priorities.
4. Develop and implement strategies to increase the number of high-quality, investigator-initiated clinical trials on priority issues.
5. Revise current committee and management structure, and implement new committees focused on industry trials and investigatorinitiated trials.

Changes to organizational structure

To better support the strategic goals of the network, the strategy includes changes to the organizational structure, which will see the separation of the Executive and Steering Committees and the creation of an Industry Relations Committee and an Investigator Trials Committee.

New CF CanACT Organizational Structure



Executive Committee is responsible for the Strategic direction of CF CanACT.

Steering Committee advises Executive Committee on operational issues.

Industry Relations Committee is the primary point of contact with pharmaceutical industry partners.

Protocol Review Committee provides independent or joint (global) protocol reviews for proposed pharmaceutical or investigator trials.

Investigator Trial Committee is the primary point of contact for Investigators wanting to conduct trials within the network.

Meet Dr. Jonathan Rayment the New Medical Lead of CF CanACT

DR. JONATHAN RAYMENT

Dr. Jonathan Rayment has recently taken over as Medical Lead of Cystic Fibrosis Canada's Accelerating Clinical Trials Network (CF CanACT), replacing Dr. Bradley Quon who has stepped down after five years in the role. Dr. Rayment is both a pediatric respirologist and clinician scientist at BC Children's Hospital (BCCH) and has been involved in the clinical trial network for many years.

How did you become involved with Cystic Fibrosis?

The time I spent in the cystic fibrosis clinic during my pediatric residency at SickKids in Toronto was what convinced me to go into respiratory medicine. I have been interested and inspired by the care that is provided for people with CF since early in my medical training. Once I finished my pediatric respiratory medicine fellowship in Toronto in early 2016, I was lucky enough to receive a clinical fellowship from Cystic Fibrosis Canada to do further training in CF clinical care and clinical research, which I pursued for about two years. In this role I learned more about the ins and outs of CF care, but I also developed my own research interest in using advanced diagnostic tools to detect early lung disease in CF.

What do you enjoy most about your work?

For me, its all about the families. Pediatrics attracted me because of my love for the families, kids, and building lasting relationships. The clinical side is immensely rewarding as it involves forming these connections with families, supporting them through challenges, and celebrating victories.

On the research front, I am driven by a discomfort of uncertainty. This connects me with my dedication to families; when perceptive parents ask questions, responding "I don't know" bothers me on a fundamental level. To me, translational medicine means actively pursuing answers. Whether the questions come from patients, families, or myself, having the tools to seek solutions is a privilege. Being in Vancouver grants me the advantage of a great team and resources, providing an amazing infrastructure to be able to ask and answer those kinds of questions.

These two aspects define my job satisfaction: forging meaningful bonds and the opportunity to unravel the unknown.

How would you describe your role as the Medical Lead of CF CanACT

My new position as medical lead will work in concert with CF Canada's Chief Scientific Officer, Dr. Paul Eckford, and the Network Manager, Dr. Maggie McIlwaine, to make important decisions about the network's direction and operational strategies. As the medical lead, I will work to also ensure the seamless integration of the network and align its priorities with our global partners, primarily in the US and Europe.

What is the main goal or purpose of the network and why is this network so important?

Our intention is to ensure that any person living with CF, no matter where they live in Canada, will have access to participate in clinical trials. It's about granting all individuals living with CF, as well as those caring for them, the opportunity to willingly partake in clinical trials. Whether its Saskatoon, Vancouver, Quebec Toronto, Halifax, or any other region, the goal remains consistent.

The network's impact is evident as the participation in CF clinical trials has risen since the introduction of CF CanACT five years ago. People can engage at their nearby site, or, if resources are limited, they can use CF CanACT as a reference hub to identify trials and local hubs. This way, interested patients can be referred to nearby hubs efficiently, leveraging the resources of CF CanACT.

What do you see for the future of CF CanACT?

There are two major directions that I hope to see the program move towards achieving.

The first advancement is the need to focus on the small group of people who are ineligible for, or intolerant of Trikafta. We need to leverage the power of CF Canada and the network to know where the people who are CFTR ineligible or intolerant are and help them get involved in clinical trials if they are eligible and interested. We also need to work closely with our global partners to make sure we are working in lockstep and moving in the same direction to ensure every study sees completion, while being as efficient and transparent as possible.

The second direction where I hope to see advancements is, that people have said for a very long time that there has been this idea that CF is a disease of people of Northern European ancestry. And although it is certainly more common in this population, it's also present in the non-white populations. Historically, these non-white populations have been underrepresented in clinical research, and we are working to ensure that everyone has the same opportunity to participate in clinical research by identifying the systemic barriers across the country. The centralization of research infrastructure and training gives us a good opportunity to be able to do that. This will be a large area of focus over the next five years for the network.

What challenges do you see the network facing?

I see distance as a huge barrier for many people, and we need to continue to overcome that hurdle by continuing to build our geographic diversity to reach across Canada. The challenges that we are talking about are ones of scarcity and how to rigorously conduct clinical trials in such a small population. Determining how to make sure that the trials that we are supporting as part of the network are aligned within Canada and aligned globally to make sure the best possible product and protocol are used is a critical aspect as well.

We need to work closely with our partners across the world to make sure we are pulling in the same direction because scarcity and rarity, in my mind, is the biggest hurdle to achieving those goals.

What are you most proud of with what the network has been able to accomplish?

I take immense pride in witnessing CF CanACT evolve into a real and impactful network. Reflecting on the past five years, there was an uncertainty of whether this network was going to work and become a valuable resource. However, it didn't take long for us to see the widespread interest from patients, physicians, clinics, and families across Canada.

This network began as a spark in the mind of CF Canada's Chief Scientific Officer and led to the establishment of the initial network in six cities. Since then, it has continued to grow to become the strong network we witness today. I am extremely proud of the relationships we have forged with world-wide partners and can confidently say that we are now sitting at these decision-making tables as Canadians, which we couldn't say before.

I am excited and optimistic to continue to advance our agenda and grow partnerships with networks globally. There are still great things to come, and I am eager to see the milestones we reach as a network.

What message do you have for an individual who is contemplating participating in a clinical trial? Is it safe?

My message to you is that we cannot do it without you. And if you decide to participate, thank you, but if you choose not to, that is okay. However, I urge you to visit CF CanACT trial finder to learn more about the trials that are currently in our program. In my experience, every clinical researcher in CF recognizes the commitment that it takes to participate in a trial and we are thankful everyday to have such a committed and engaged community. It's this kind of collaboration that has led to such incredible advances in the care for people with cystic fibrosis.

I also think it is important to understand that there are different kinds of clinical trials with different levels of risk. And every type is important. All clinical trials, no matter if they're interventional or observational, CFTR based or non CFTR based therapy, are important. And participation to any extent is incredibly valuable. The associated risk with each study will be outlined very clearly by the study team that you are working with, and if at any point you have any questions or concerns, I urge you to reach out to them. Whether it's before you sign the consent form, after you sign the consent form, or eight months into the study, talk to the team because it is quite literally our job to look out for you. You are the top priority.

Meet a Patient Representative: Mike Hamilton

MIKE HAMILTON

Mike Hamilton, lives with cystic fibrosis and joined the CF CanACT Steering and Protocol Review committees in 2018 after participating in multiple clinical trials for CF. Read more about Mike's clinical trial experiences, and his involvement with CF CanACT below.

Tell us a little about yourself.

I was diagnosed with CF at 12 years of age, at that time my lung function was 90%. By the time I was in my late 20s my lung function had declined to 77%. Meanwhile, I had completed an undergraduate degree in chemistry and when the new modulator Ivacaftor came onto the market, I was intrigued to find out how it bound to the cystic fibrosis transmembrane conductance regulator (CFTR)--this led me to complete a PhD in synthetic chemistry in 2022.

What clinical trials have you been involved in?

The first clinical trial I participated in was a Phase 2 trial on the medicine Symdeko for people with one copy of F508del. However, this trial did not show any effect for me. The next trial was for the drug Trikafta, and within a month of commencing this trial my lung function popped up to 91%. At the end of the trial, I was able to stay on the drug. Since being on Trikafta, I no longer cough and can breathe easier. I have noticed that for the first time, I've started to gain weight, my dietician even said I should go on a diet as there is the potential to becoming diabetic.

What were your initial expectations, thoughts, or concerns with getting involved in the clinical trials?

From the initial studies on the drug, I knew that safety was not a problem, my greatest concern was being on the placebo arm and not getting the drug, but that was a chance I was willing to take. It's critically important for people to participate in clinical trials if they are willing and able. Trials allow us to test what works and what does not work and, in the end, brings better treatment for people living with CF.

Can you share your experience being on both the CF CanACT Steering Committee and the Protocol Review Committee?

The steering committee is fun, it's important to identify gaps in care and have input into the direction on which trials the network should undertake. Within the network there is close collaboration across Canada.

I find the protocol review committee very interesting. It's important to have someone on this committee who does not think like a doctor but rather looks at the protocol from a patient perspective on how difficult the trial is going to be for a patient to participate in.

What have been the highlights of your participation on these committees?

Over the past five years since I have been on the committees, things have changed. Previously as a patient I would scan various websites looking for trials to participate in, then I would go to my CF doctor and ask why my clinic was not doing these trials--there was no coordinated effort across Canada. Now we have a world-class network which fosters collaboration across sites, and I have been privileged to participate in this journey.

What would you tell other people with CF who may want to participate in a CF CanACT committee?

CF Canada tries very hard to integrate the patient's perspective and are not top down, they involve patients in decision making. If you are invited onto a committee, ask questions.

From an early age: Pediatric Modulator Trial

When Ashley received a call from her daughter's cystic fibrosis clinic in Edmonton about a clinical trial that would be starting in Vancouver two weeks later, she didn't hesitate to say yes.

Ashley's cystic fibrosis journey began almost two years earlier when, 10 days after Cali was born, her newborn screening came back positive for cystic fibrosis. It was a complete shock to the family. Both Ashley and Cory were blindsided and couldn't believe the news. They didn't know anyone on either side of the family who had cystic fibrosis.

That numbness lasted until their first appointment at the Edmonton pediatric CF clinic. "Our Edmonton clinic brought me back to life after Cali's diagnosis. Amanda was the first person I met there, and I will remember her for the rest of my life. It brought me back from the dark place. They are the best I have ever dealt with," said Ashley.

So, when Amanda, registered nurse at the Edmonton clinic, called the family earlier this summer with an opportunity for Cali to participate in a clinical trial for 12–24-month-olds to test the efficacy and safety of a modulator therapy, Ashley jumped at the opportunity. "This community needs people to participate in clinical trials in order to get new treatments out there for everyone. I like that we were able to help in that sense," said Ashley.

While the trial would last over two months, Cali would only need to take the medication for two weeks. But the family would be required to travel from Alberta to Vancouver six times during the trial for visits to the clinic site. The research coordinator in Vancouver made things as easy as possible for the family. Expenses were covered by the drug manufacturer and the research coordinator would book the flights and coordinate the hotel.

The first clinic visit in Vancouver as part of the trial was the longest as there were a few extra tests that Cali needed to do, including bloodwork, a hearing test and an eye test. At each appointment, Ashley and Cali would meet with the research coordinator and the trial team in Vancouver, who would go over everything in detail and ensure all of their questions were answered. "Knowing Cali would be closely monitored by the team at the clinical trial site was a lot of comfort. It was a great opportunity," said Ashley.

Between two of the visits, the family was able to coordinate their love of travel with the clinical trial, making a mini vacation out of it, with Cory coming to Vancouver as well.

Another bonus of participating in the clinical trial was that Cali got to be closely monitored by two care teams, at her clinic in Edmonton for typical CF care and the trial team in Vancouver. Participating in the clinical trial also gave Cali the opportunity to access a medication not yet available for her age group, and, if the medication does become available, Ashley now knows what to expect and how Cali will react.

Ashley explains they noticed positive changes in Cali's health almost immediately. "Cali had been starting to develop a cough, but once she started the clinical trial, she purged a lot of the built up mucous in her lungs and even now, the cough has not returned, said Ashley. "We've even noticed that her bowel movements became a bit more regular."

"We had no misconceptions about clinical trials because we went into it not knowing what to expect, but we were in great hands throughout the trial and we felt very assured," said Ashley. "The team in Vancouver made everything so easy for us, from booking the travel and sending the itinerary, it was all so organized."

What advice does Ashley have for anyone considering participating in a clinical trial? "I would say absolutely go ahead and do it. You never know what kind of opportunity it might present or what doors it could open up. For me, the trial took away a lot of concern, if we had the opportunity to participate in another, it would be hard to turn down."

Next in Clinical Trials: Exploring Gene Therapy

What to expect in clinical trials in the coming year

Modulators are now available for close to 90% of people with cystic fibrosis living in Canada. Of the remaining approximately 10%, some could benefit from existing modulator therapies but currently have no access, while others have mutations that will not benefit from these types of therapies. Cystic Fibrosis Canada is focused on ensuring all those who can benefit from modulators have access. However, while this work is underway, there are new therapies on the horizon, bringing hope to those with rare CF mutations that don't respond to existing therapies. In 2024, CF CanACT will focus on the use of these new types of therapies in the category of gene therapy.

What is gene therapy?

Gene therapy is any method of providing a correct (normal or non-mutated) copy of the cystic fibrosis transmembrane conductance regulator (CFTR) gene to targeted cells of the body. There are various types of gene therapies, including messenger RNA (mRNA) therapy, DNA therapy and gene editing.

The network will first be investigating the safety of these therapies, followed later by larger trials looking at efficacy (ie, do they help people with CF).

In order to understand these new types of therapies, it's vital to first understand how the information in genes in cells is used to make proteins. DNA contains two copies of most genes, including the CFTR gene. When the cell needs to make the CFTR protein, it makes a temporary copy of one of the CFTR genes out of RNA. This RNA, called messenger RNA, or mRNA, only last a short time, but can be used by the cells to make the protein that the gene codes for. In this case the mRNA instructions make the CFTR protein, which in people who don't have CF, moves out to the cell surface where it helps move chloride, which plays a role in keeping the surface of the lungs moist and clear of bacteria. In people with CF, there is a defect in both copies of the CFTR gene. Usually, the mRNA still gets made but proteins made from it have a defect. Either the protein doesn't work properly, it doesn't get to where it needs to be, or for some mutations, the full protein can't be made because of the errors in the mRNA instructions. The idea behind gene therapies is to provide new instructions in the cell to make the protein without defects.

RNA therapy

In 2024, mRNA trials will be the first gene therapy trials that the network will host. In these trials, copies of the CFTR gene, made of RNA, are placed inside a "vector", which is a carrier that protects the RNA and helps its delivery to the target location (in this case, cells of the lungs). The RNA therapy is inhaled into the lungs through the use of a nebulizer. mRNA does not permanently change the existing CFTR gene in these cells. To note, mRNA is a temporary copy of a gene that can be used by the cell to make the CFTR protein in the target cells. This temporary copy doesn't stay long in the cells (perhaps a week or two at most), and thus will require repeated dosing.

DNA therapy

The network will support DNA therapy trials next. These trials will use a DNA copy of the CFTR gene, which is just like the CFTR gene in your DNA. In this case it will be a copy without any CF mutations. It will also be placed inside a "vector" to protect the DNA and help it get to its target (again the lung cells). This DNA copy can be used by the cell to make mRNA, which is used to make the normal CFTR protein. DNA copies are more permanent (they don't break down quickly) so they last a lot longer than the mRNA copies. The cell can keep making mRNA copies of the DNA, and then make more CFTR protein from the mRNA. So, in trials of DNA therapies it is believed that this treatment will have a longer lasting effect and won't need to be re-dosed as frequently as mRNA, but still these DNA copies aren't in the cell's nucleus and won't last forever. As we start these trials later this year or in 2025, it will be essential to look at safety first. Once we know that they are safe we'll start to look at efficacy in people with CF, to learn more about how long the therapy will be effective.

Gene editing

Finally, gene editing is a method where tools are delivered to the cells to correct the genetic defect in the CFTR gene of the cells. This can be thought of like a little toolbox of tools that can cut out the mutation, replace it with the correct sequence, and then put the two pieces of the gene back together. The DNA of the gene itself is changed to the correct instructions to produce the CFTR protein without any defect. This would mean that the therapy would be provided only once or minimal times and the change would be permanent in the lung cells that were targeted. While promising, more time is needed to develop this type of technology before clinical trials can begin. It is important to note that with this gene editing therapy, cells that aren't targeted would not be changed. For example, a person treated with a therapy like this might still have liver or pancreas disease and could still pass on the CFTR mutation to their child.

Gene therapy clinical trials coming to CF CanACT

RNA gene therapy clinical trials will begin in 2024 for adults with rare mutations and will require intensive visits for both the participant and the CF CanACT sites involved. CF CanACT will work closely with the Canadian Cystic Fibrosis Registry to determine where people with rare mutations are located, and the network will work to minimise travel for participants.

The network is excited to play a role in advancing alternative treatments for individuals living with rare CF mutations.

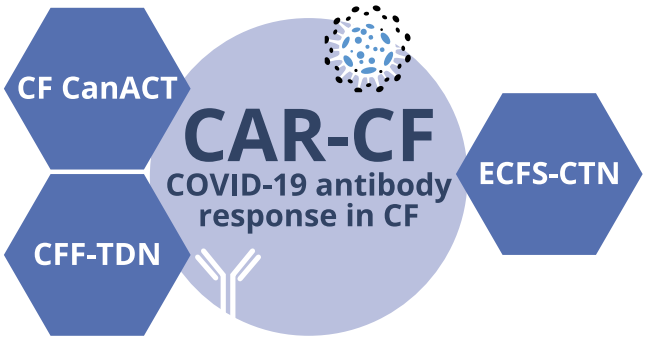
Looking to stay up to date or get involved in a clinical trial you may be eligible for?

Check out the networks clinical trial finder: https://trialfinder.cysticfibrosis.ca

Supporting Clinical Trials beyond the Pharmaceutical Landscape

While the focus of CF CanACT has largely been on pharmaceutical clinical trials, the network has also endeavoured to assist with both investigator and observational trials by performing protocol reviews and utilizing the CF CanACT research coordinators at each site to promote the trials. Investigator trials are initiated by researchers that are actively in the lab and clinical settings, while observational trials measure without intervention.

Below are two examples of non-pharmaceutical trials that the network has supported.



COVID-19 Antibody Response in Cystic Fibrosis (CAR-CF)

COVID-19 Antibody Responses in Cystic Fibrosis (CAR-CF) is a clinical trial looking at antibody responses to COVID-19 in the CF population.

This trial will provide a better understanding of the COVID-19 infection, immunity and impact within the CF population. The trial is being conducted jointly with the European Cystic Fibrosis Clinical Trials Network (ECFS-CTN) and the Cystic Fibrosis Foundation's Therapeutic Development Network (CFF-TDN). CAR-CF Canada began recruitment in November 2020 and enrolment was completed as of December 31, 2022.

This is a two-year trial for individuals with CF whether they have had COVID or not. Once enrolled, blood is drawn for antibody testing at three stages; first at 6 months, once again at 12 months and a final follow-up at 24 months. The first patient completed the study in December of 2022, with other patients in various stages in the two year-long follow-up period.

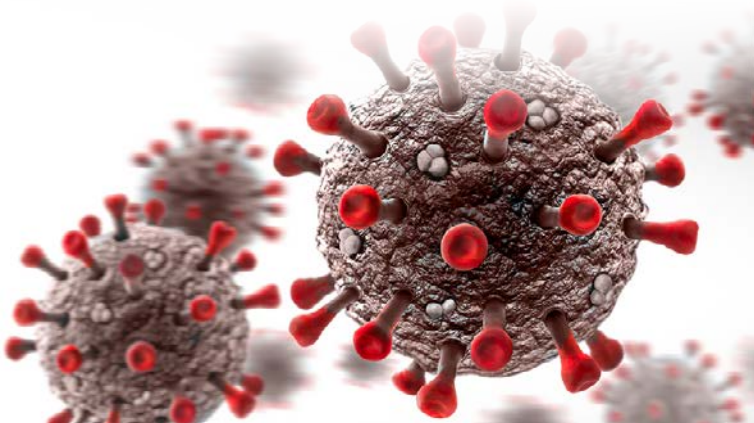
In Canada, there are nine clinical trial sites participating in the CAR-CF trial with a total of 472 individuals with cystic fibrosis enrolled in the trial.

Long-term evaluation of CTFR modulators on people with CF (Can-Impact-CF)

Can-Impact-CF is an observational trial evaluating the real-world effectiveness of cystic fibrosis transmembrane conductance regulator (CTFR) modulators on people living with cystic fibrosis.

The trial leverages data from the Canadian Cystic Fibrosis Registry and utilizes the infrastructure of CF Canada's clinical trial network. Data is collected prior to an individual starting on a CFTR modulator and at every clinic visit. As well as typical clinical endpoints, such as lung function, weight, number of respiratory infections etc., people are asked to complete questionnaires on mental health, work productivity and exercise. Additionally, individuals participate in the Cystic Fibrosis Questionnaire-revised (CFQ-R) which measures CF specific health related quality of life on a scale of 0 to 100. Several sites will also collect blood and sputum biomarkers.

To date, 249 people living with CF have been enrolled in the trial across 15 sites. The study is expected to last for five years and will provide insight into the long-term effects of modulators on various aspects of an individuals life.

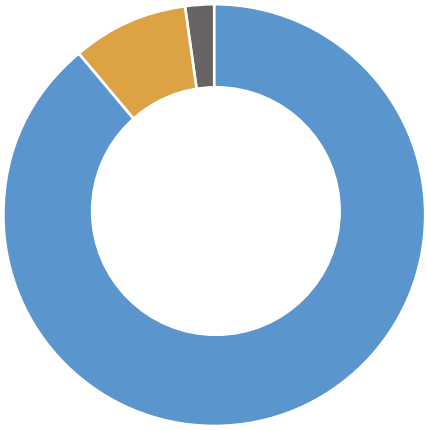


Funding

CF CanACT is partially funded by grants from Cystic Fibrosis Canada and the Cystic Fibrosis Foundation. Additional revenue is generated by charging fees for scientific services to pharmaceutical companies such as for performing protocol reviews or feasibility studies across network sites.

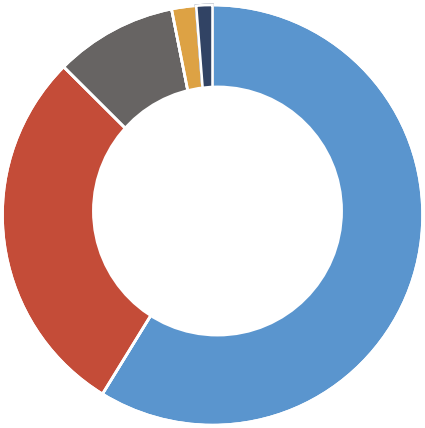
It is important for the network to be financially independent of pharmaceutical companies so that there is no conflict of interest when providing scientific advice on clinical trials.

Income 2022-2023



- CFF Grants
- CF Canada
- Income from Services provided

Expenditures 2022-2023



- Research Coordinator (10)
- Administration
- Travel and Training
- Referrals
- Video Conferencing

* During 2022-2023, there was continued partial support for research coordinators' time at the ten operating sites and there were two training sessions for research coordinators.

* Community training was to be budgeted in year five of the grant but has been moved to the new grant cycle and will include community engagement for gene therapy trials.

Principal Investigators and Lead Research Coordinators

Vancouver Adults, St Paul's Hospital

Principal Investigator: Dr. Brad Quon
Research Coordinator: Carolina Bevanda

Vancouver Paediatrics, BC Children's Hospital

Principal Investigator: Dr Jonathan Rayment
Research Coordinator: Alam Lakhani

Calgary Adults, University Of Calgary, Foothill's Hospital Site

Principal Investigator: Dr. Mike Parkins
Research Coordinator: Clare Smith

Saskatoon Adults and Pediatrics, Royal University Hospital

Principal Investigator: Dr. Julian Tam
Research Coordinator: Dawn Johnson

Toronto Adults, St. Michael's Hospital

Principal Investigator: Dr. Elizabeth Tullis
Research Coordinator: Arunan Selvarajah

Toronto Paediatrics, Sickkids Hospital

Principal Investigator: Dr. Felix Ratjen
Research Coordinator: Stephanie Jeanneret-Manning

Montreal McGill Site Adults and Pediatrics, Montreal Children's Hospital

Principal Investigator: Dr. Larry Lands
Research Coordinator: Joanie Gonthier

Montreal Adults, Centre Hospitalier Universitaire de Montreal (CHUM)

Principal Investigator: Dr. François Tremblay
Research Coordinator: Nadia Beaudoin

Quebec City Adults, Institut Universitaire de Cardiologie et de Pneumologie de Québec Paediatrics, Centre Mère-Enfant du Chu de Québec

Principal Investigator: Dr. Lara Bilodeau and Dr. Patrick Daigneault
Research Coordinator: Nathalie Vadeboncoeur

Halifax Adults Queen Elizabeth II Hospital

Principal Investigator: Dr. Nancy Morrison
Research Coordinator: Andrea Dale

Cystic Fibrosis Canada
Fibrose kystique Canada

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