CORD Canadian Organization for Rare Disorders

2025 Election Toolkit for Patients

How to use this Rare Disease election toolkit

This election toolkit is designed to provide ideas and help patients, caregivers and family members that are part of the rare disease community to navigate the 2025 federal election and ensure that their voices are heard. The goal is to make it VERY, VERY EASY for you to prepare and to engage with candidates and campaign teams in your riding.

CHEAT SHEET

STEP 1: Send them a letter via CORD's campaign

Visit the campaign page **here** and complete the form.

---CONTENT---

Dear X,

I know you want to get elected in my riding, and I want to tell you what I expect the next government to do to help people like me and those I care for in the rare disease community.

It has been six full years since the government promised a rare disease drug strategy. Six years in – despite agreements in all provinces – not one patient has seen improved access to diagnosis or treatment. Yes, there's more money for provinces and territories – but it's not evident that health systems are providing more treatments for rare disorders than they already would have.

The answer is clear: the next government's plan must be more than just an ATM for provinces and territories. Canada's health systems are ready, patients and clinicians are already on the ground making a difference, and that's where we need to invest.

What needs to happen:

1. Federal party leaders must endorse and implement CORD's National Strategy for Rare Disorders to create a coordinated national approach to rare disease care.
2. At the provincial and territorial level, action and investment focused on rare diseases are essential. Quebec has already committed to investing in its rare disease action plan, but the other provinces and territories must step up as well.
3. CORD will hold governments accountable. We've launched a comprehensive survey on the burden and cost of illness, and we will be reviewing and reporting on every jurisdiction in the coming months. We will demonstrate how real action by governments and health system leaders can help save and improve the lives of Canadians living with rare diseases.

It's time to turn promises into results. Let's work together to ensure these investments lead to better care and support for all patients with rare diseases.

Thank you,

[First name] [Last name]

---END OF DRAFT LETTER---

Remember – you can personalize your email to candidates - share your experiences with rare diseases and how they have affected you or someone you know.

NOTE: Many of the ridings do not have CONFIRMED CANDIDATES – however if you fill out the form letter, it will go to the national campaign or another email address. Your voice will be heard!

We must hold governments to account so that the huge investment gets to patients with rare diseases

STEP 2: Start engaging!

Election candidates will already be very active in your community, hosting town halls and taking part in meetings invited by or alongside community leaders. The best way to follow candidates is through their Facebook pages and X accounts, emailing or visiting their campaign office, or even when they knock on your door – more on this below.

Lastly, don't forget to tag CORD (@raredisorders) when engaging via social media (Facebook, X, LinkedIn) @raredisorders_cord on Instagram.

YOUR COMPREHENSIVE GUIDE TO THE 2025 ELECTION

PLEASE DO NOT SIT OUT THIS ELECTION!

With the 2025 federal election fast approaching, **patients with rare diseases need your voice now more than ever**. This is a critical moment to push for real action that will change lives. We have a responsibility to make sure political candidates understand the urgent needs of the rare disease community and commit to tangible solutions.

We've waited long enough. Since the federal funding for rare diseases was first announced in Budget 2019, **not one patient** has seen better access to diagnosis or treatment. Provinces and territories may have signed bilateral agreements, but that hasn't translated into the improvements patients so desperately need. It's time to change that.

We need to raise these key issues with political candidates:

- The federal plan has not delivered results. Despite billions in funding, patients are still waiting for better access to diagnosis and treatment. The government must take responsibility and ensure that funding actually reaches those who need it most. We can't afford more empty promises.
- The federal government must lead the way. We need strong, national leadership to implement a comprehensive approach that addresses all aspects of rare disease care. Candidates must commit to fully endorsing and implementing CORD's National Strategy for Rare Disorders, which focuses on improving early detection, providing timely care, enhancing community support, ensuring access to promising therapies, and promoting innovative research.

- Provinces and territories need to step up—but it’s the federal government that must ensure accountability. While Quebec is taking steps to implement its own rare disease action plan, we need the other provinces and territories to do the same. The federal government must hold them accountable for delivering results and ensuring that investments benefit patients.
- Tracking and accountability are crucial. CORD is launching a nationwide survey to measure the burden and cost of rare diseases. This fall, we will report on every province and territory to ensure that the funds are being used effectively and reaching the people who need it. Federal candidates must commit to real accountability to ensure that the money is being spent where it’s needed most.

Now is the time to act. We need you to meet with political candidates in your riding and raise these issues. Ask them to commit to concrete actions that will improve the lives of Canadians living with rare diseases. This is a pivotal moment, and we have the power to shape the future of care in Canada.

Set up meetings with candidates—whether in person or virtually—and make sure they know what’s at stake for people with rare diseases. We can’t afford to wait any longer. The future of rare disease care depends on the decisions made in this election. We need to ensure that those decisions are the right ones.

1. BACKGROUNDER ON POLITICAL PARTIES’ PROMISES/PLATFORMS

Liberal Party

Party leader: Mark Carney
This snap election was called following Prime Minister Justin Trudeau’s resignation.

As of now, key health and rare disease policies the Liberals have discussed under Mark Carney’s leadership include the following:

- All provinces and territories have reached bilateral agreements in the context of the National Strategy for Drugs for Rare Diseases.
- Newly appointed Health Minister Kamal Khera says a re-elected Liberal government would work to get on board the nine provinces and territories that have not signed pharmacare bilateral agreements.
- She and Mark Carney alluded to continuing the single-payer approach for diabetes medicines and contraceptives.
- Of note, the Trudeau government pledged to contribute $500 million per year after 2026-27 to maintain the strategy.

Conservative Party

Party leader: Pierre Poilievre

- As of now, it is assumed that Conservatives will likely pull back from engaging in areas of provincial responsibility, which includes health.
- However, more recently, Poilievre said “We will protect these programs and no one who has them will lose them”, referring to dental care and pharmacare. His office said they would “honour existing commitments”, without specifying what that meant.

New Democratic Party (NDP)

Party leader: Jagmeet Singh
Nothing had been said yet.

2. KEY MESSAGES

Patients Are Still Waiting – The Federal Plan Must Deliver Real Results

- All provinces and territories have signed bilateral agreements, yet patients are still waiting.
- Since the funds for the strategy were first announced in Budget 2019, not a single patient has seen improved access to diagnosis or treatment.
- The government's rare disease strategy must be more than an ATM for provinces and territories. Patients and clinicians are ready - investments need to go where they will make a real impact.

Federal Leadership Is Essential – Endorse and Implement CORD's National Strategy for Rare Disorders

- Federal party leaders must publicly commit to implementing CORD's National Strategy for Rare Disorders**,** which is a comprehensive plan to improve care for people with rare diseases across Canada.
- CORD's National Strategy includes the following key goals:
    1. Improving early detection and prevention by enhancing screening programs and increasing awareness to ensure timely identification of rare diseases.
    2. Providing timely, equitable, and evidence-informed care to ensure that all Canadians have access to the most effective treatments and support, regardless of where they live.
    3. Enhancing community support to build networks that provide individuals and families with the resources they need to manage the complexities of rare diseases.
    4. Providing sustainable access to promising therapies by ensuring that life-changing treatments are available and affordable to those who need them.
    5. Promoting innovative research to drive advancements in rare disease treatments and support the development of new, effective therapies.
- Canada needs a national, coordinated approach to ensure patients with rare diseases have equitable access to life-changing treatments.

Provinces and Territories Must Step Up – Quebec Is Leading the Way

- Quebec has committed to investing its federal funding in a dedicated rare disease action plan.
- The rest of Canada must follow suit to ensure the investment leads to real improvements in patient care and access.

CORD Will Hold Governments Accountable

- CORD has launched a nationwide survey on the impact and cost of rare diseases.
- This fall, we will report on every province and territory, ensuring transparency and accountability.
- We will make the case for real action that delivers results for Canadians living with rare diseases.

Key Asks

- Federal parties must fully implement CORD's National Strategy for Rare Disorders.
- Federal funding must be directed toward rare disease diagnosis, treatment, and care—rather than disappearing into general healthcare budgets.

- Accountability measures must be put in place to track how provinces and territories use federal funding for rare diseases.
- The federal government must commit to ongoing investment to ensure sustainable access to rare disease treatments for all Canadians.

Patients have waited long enough. It's time for action. Canada's rare disease community needs leaders who will ensure funding delivers real results.

3. HOW TO MEET / ENGAGE WITH YOUR CANDIDATE(S)

How Candidates Campaign

Election candidates will already be very active in your community, hosting town halls and taking part in meetings invited by or alongside community leaders. The best way to follow candidates is through their Facebook and LinkedIn pages, emailing or visiting their campaign office, or even when they knock on your door. There are several venues that will allow you to engage with them through written messages and posts, know where they will be campaigning in person, and engage with them through virtual and in-person meetings.

If you have an association or patient group, you could invite a candidate to one of your meetings or events, so that you can explain your positions on these key issues and the candidate(s) can explain why you should vote for them.

You can also engage with your candidates by sending them a letter via this **campaign** CORD is leading. Feel free to edit the template and provide examples of your own lived experience.

4. SOCIAL MEDIA

A great way to engage with candidates is to post on social media, calling on them to act on the key issues of interest. Here are some sample social media posts:

- 🚨 Over 3.2M Canadians live with rare diseases. We need **sustained funding** to ensure the $1.5B National Strategy for Drugs for Rare Diseases delivers real impact. Let's make it last & expand beyond drugs to care coordination & diagnosis. Speak up for change! 💬 #RareDisease #CDNpoli
- Patients deserve a voice! Canada needs a **comprehensive Rare Disease Strategy**: early diagnosis, coordinated care, equitable resources. Join us in urging candidates to engage with the rare disease community & commit to meaningful change. Your voice matters! 🗳️ #Election2025 #RareDiseases