

NAVIGATING CANADIAN HEALTHCARE SYSTEMS:

**A GUIDE TO SELF-ADVOCACY
AND MEDICAL BENEFITS FOR
INDIGENOUS PEOPLES WITH
RARE DISORDERS**

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in partnership with

CANADIAN ORGANIZATION
FOR RARE DISORDERS (CORD)

www.law.utoronto.ca | www.raredisorders.ca



How to Use This Guide

This guide is designed to help Indigenous peoples with rare disorders navigate Canada's complex healthcare systems. It can also help medical professionals, healthcare centres, patient advocates, and other parties who may have an interest in Indigenous health, to better understand who can access these healthcare systems and how they operate. The focus of this Guide is primarily on prescription drug coverage (including appeals) and medical travel benefits, which are commonly required by people with rare disorders.

This Guide will clarify how Indigenous peoples can access federal or provincial health benefits, or both, depending on their situation.

Federal Programs

Non-Insured Health Benefits (NIHB), Nunatsiavut Non-Insured Health Benefits and Nunavik Insured/Non-Insured Health Benefits (INIHB) are the three federal programs that provide health benefits to Status Indian and eligible Inuit persons.

A Status Indian is someone who is registered or eligible to be registered in the Indian Registry maintained by Indigenous and Northern Affairs Canada (INAC). Eligible Inuit include beneficiaries of one of four Inuit land claim organizations.

These programs are designed to provide health benefits to Status Indian and eligible Inuit persons who do not have third party insurance or other provincial or territorial health benefits, or who do not have sufficient third party, provincial or territorial coverage to meet their health needs.

Provincial/Territorial Programs

Provincial programs include the First Nations Health Authority (FNHA), the Northwest Territories' Métis Health Benefits program and every provincial or territorial program that provides health benefits to their residents.

The FNHA provides benefits to Status Indians who are residents of British Columbia. The NWT Métis Health Benefits program provides benefits to Métis persons who are registered with a Métis Nation and are residents of the NWT. Other provincial programs provide benefits to any person who meets their program criteria, regardless of Indigenous ancestry.

How to Use This Guide

Like the federal programs, the provincial and territorial programs are designed to provide prescription drug benefits to those who do not have third party insurance or who have insufficient coverage to meet their needs.

How to Use This Guide

Step 1

For a brief overview of rare disorders and a few self-advocacy skills, start with the "What is a Rare Disorder?" and "Self-Advocacy Skills" sections. These sections will help anyone reading the guide understand how the experience of people with rare disorders can differ from someone with a common disorder.

Step 2

If you are an Indigenous person who wants to learn more about the health benefits available to you, start by locating the section of the guide that applies to you.

- If you are a Status Indian person living outside of British Columbia, read the section on the Non-Insured Health Benefits (NIHB) program
- If you are a Status Indian person living in British Columbia, read the section on the First Nations Health Authority (FNHA) program
- If you are a Métis person living in the Northwest Territories or Ontario, find the Métis section and read about the program applicable to your province. If you are a Métis person who does not live in either of these provinces, go to the Provincial Programs page listed for your province
- If you are a non-Status Indian person, read the section on Non-Status Indians and then go to the Provincial Programs page listed for your province

Within each section are details about the particular program and an explanation of any appeals processes available. Some programs have extensive and helpful information on their program websites - you will find links to external websites throughout the guide if you want to learn about a particular program in greater depth.

How to Use This Guide

Step 3

After you have read the program section that applies to you, you can consult the Resources section for information on advocacy groups, patient navigators or other resources that may be available.

For non-Indigenous people reading the guide, it may be helpful to do a quick skim of the entire guide to get an idea about the different healthcare systems available to Indigenous peoples. No matter what order you read the guide in, you will probably learn something new that will provide greater context about the benefits but also the challenges that Indigenous peoples face receiving adequate healthcare.

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What is a Rare Disorder?

"A rare disorder is a condition that affects less than 1 out of 2000 people in their lifetime. There are over 7000 known rare disorders and many more are discovered every year. In total, about 1 in 12 Canadians will be affected by a rare disorder."

-Canadian Organization for Rare Disorders
(<https://www.raredisorders.ca/about-cord/>)

It takes an average of 10-15 years to receive a diagnosis for a rare disorder. Once diagnosed, rare disorders often require expensive drugs or treatments to control symptoms. Many of these drugs and treatments are not covered by federal or provincial health benefit programs, or require patients to navigate complicated appeals procedures to try and access life changing and life saving treatment.

Indigenous peoples with rare disorders often face complex challenges in receiving adequate treatment and care. For those in remote communities, even accessing a family doctor can be difficult.

Self-Advocacy Skills

Having a rare disorder usually means interacting with many different healthcare professionals. Often, patients with rare disorders need to become their own advocate in order to achieve the best possible health outcome.

1

Ask Questions

Your family doctor is often your first point of contact with the healthcare system. Ask them about any unusual symptoms you are experiencing and whether a referral to a specialist would be appropriate. If your doctor makes a referral, make sure to follow up to check that the specialist received the referral.

2

Do Your Own Research

Patients with rare disorders often become the experts on their condition. If it seems like your family doctor, or even your specialist, is not listening to your concerns, it is usually because they are not familiar with the disorder or how it can affect different people.

You can get in touch with patient advocacy groups for your particular disorder for more information or support.

You can also use Google to learn more about your disorder or symptoms. However, please be careful when gathering information from the internet. Sometimes it is incorrect or may not apply to your situation.

3

Listen to Your Body

You are the expert on how your body is feeling. If your symptoms are not getting better or continuing to get worse, be sure to tell your doctor. You might need to switch medications or make some lifestyle changes to see improvement.

Self-Advocacy Skills

4 Bring a Trusted Family Member or Friend with You to Appointments

Sometimes, bringing someone you trust to appointments can help make you feel more comfortable. It may be helpful to have your family member or friend take notes. They can also help you ask the doctor questions or ask for clarification.

5 Ask for a Copy of Your Medical Records

Get into the habit of collecting your medical records from each doctor you visit. If you are still waiting for a diagnosis, it will help you keep track of the tests you have tried and whether certain conditions have been ruled out.

It will also help keep your doctors accountable. Remember that you usually become the expert on your disorder - if a doctor disagrees with you or is resistant to your suggestions, having a copy of your medical records will be helpful.

6 Connect With Advocacy Groups

Support from other people who share some of your experiences can help give you comfort and confidence. A quick Google search can show you whether there are local advocacy groups nearby.

Depending on your location, you can also get involved with provincial or national advocacy groups. To learn more about rare disorder advocacy groups, please see Resources on page 46.

Helpful Tip

If you would like advocacy support, check out Resources on page 46 for a list of Patient and System Navigators who may be able to help!

Status Indians and Eligible Inuit

Status Indians and Inuit beneficiaries of the Nunavut Land Claim Agreement or Inuvialuit Final Agreement are covered by the **Non-Insured Health Benefits program (NIHB)**.

Please note: if you are a Status Indian and you live in British Columbia, you are probably covered by the First Nations Health Authority. Please go to page 15 for information on this program.

Status Indians

A Status Indian is someone who is registered or is eligible to be registered in the Indian Registry maintained by Indigenous and Northern Affairs Canada (INAC). If you are a Status Indian, you probably have a Status Card that confirms your registration.

If you are unsure whether you are eligible to be registered as a Status Indian and would like to find out more information, please visit the **INAC website**.

Non-Insured Health Benefits Program (NIHB)

NIHB provides coverage for a wide variety of prescription drugs, medical supplies and equipment and medical travel.

However, people with rare disorders often require prescriptions, medical supplies/equipment and medical travel that are only covered if Special Authorization is obtained. NIHB requires the patient and their doctor/specialist to fill out forms to get coverage for more uncommon or expensive prescription drugs. Sometimes, it is necessary to go through the Appeals Process to obtain approval for your specific prescription or medical travel.

This section of the guide will explain how each of these processes work and provide advice that may improve your chances of successfully obtaining coverage.

Status Indians and Eligible Inuit

How Do I Know Whether My Prescription is Covered Under NIHB?

It is a good idea to let your doctor know that you are covered by NIHB so they can prescribe you medication that is covered by the program whenever possible. However, not all doctors are familiar with NIHB or may not know whether a particular drug is covered, especially if it is not commonly prescribed.

A good first step is to check the NIHB formulary. The formulary lists every drug covered by NIHB and explains whether it is an Open Benefit, Limited Use Benefit, Exception Benefit or Exclusion. You can access the formulary by **clicking here**.

Open Use Benefit

There are no restrictions on drugs in this category. No prior approval is required to receive coverage.

Limited Use Benefit

There are two different kinds of Limited Use Benefit drugs that may be required by patients with rare disorders:

1. Quantity or frequency limit

There may be a maximum number of doses of the drug that NIHB will cover within a specified amount of time. For example, you might only be allowed 14 tablets every 14 days.

2. Prior Approval Required

Your doctor may have to fill out a "Limited Use Drugs Request Form" for you to receive coverage. NIHB will fax this form to your doctor to complete.



For a full list of Limited Use Benefit drugs, please see:
Appendix A of the NIHB Drug Benefit List

Status Indians and Eligible Inuit

Exception

Exception drugs are not listed in the Drug Benefit List. NIHB will only provide coverage for drugs in this category under special circumstances. Your doctor will need to complete a Drug Exception Form. NIHB will fax this form to your doctor to complete.

One of the three scenarios below must apply to you for NIHB to consider your exception request:

Scenario 1

- The drug and its dosage will be used to treat a symptom(s) or disorder that is clinically recognized by published evidence or authoritative opinion
- There is significant evidence that the drug is better than drugs already listed in the Drug Benefit List

Scenario 2

- You have experienced an adverse reaction with a lower cost drug and your doctor is requesting a higher cost drug

Scenario 3

- There is supporting evidence that available alternative drugs are ineffective, toxic or contraindicated

Exclusion

Items in this category are not covered and are not available through an exception request or appeal. For a list of some excluded products, please see **Appendix G of the NIHB Drug Benefit List**.

Status Indians and Eligible Inuit

Lowest Cost Alternative and No Substitutions

NIHB is a "lowest cost alternative" program. For example, if your doctor prescribes you a brand name drug but there is a generic version available, NIHB will only pay the cost of the generic drug. If you still wish to take the brand name drug, you will have to pay the remaining cost after NIHB pays their portion.

However, NIHB may pay the entire cost of a brand name drug if your doctor writes "No Substitution" on the prescription and you meet one of the two scenarios below:

Scenario 1

- You have tried at least 2 generic versions and you experience an adverse reaction while taking them

Scenario 2

- There is supporting evidence that available alternatives are ineffective, toxic or contraindicated

Your doctor will also have to include either an adverse reaction form or a letter explaining why you cannot take the generic versions of the drug when faxing the request to NIHB.

Medical Travel Benefits

NIHB may provide medical travel benefits if you are required to travel outside of your home community in order to visit a specialist.

Eligibility

To be considered for financial assistance, you must meet the following criteria:

- The medical service you require is not available locally;
- You have already used up all other transportation benefits available from other federal, provincial/territorial or private programs;

Status Indians and Eligible Inuit

- Travel is to the nearest appropriate health professional or health facility. When health professionals are brought into the community to provide the service, the community facility is considered the nearest appropriate facility
- The most economical and efficient means of transportation is used, taking into consideration the urgency of the situation and the medical condition
- Transportation to health services is coordinated to ensure maximum cost-effectiveness
- Public transit is not available
- You must receive prior approval from FNIHB or a First Nations or Inuit Health Authority or organization. However, in emergency situations, expenses without prior approval may be reimbursed when appropriate medical justification is provided to support the medical emergency

Medical travel benefits include ground, water and air travel, meals and accommodations. You may also receive coverage for a medical or non-medical escort to accompany you on your travels. A medical escort is a physician or a registered nurse who is needed to monitor the condition of the your health during travel. A non-medical escort, such as a family member or friend, may be covered at the request of a health professional.

To access medical travel benefits, please contact your regional NIHB office to start the prior approval process.

Atlantic (P.E.I., N.S., N.B., N.L.)

Non-Insured Health Benefits
1505 Barrington Street, Suite 1525
Halifax, NS B3J 3Y6
Toll-free: 1-800-565-3294

Manitoba

Non-Insured Health Benefits
391 York Avenue, Suite 300
Winnipeg, MB R3C 4W1
Toll-free: 1-877-983-0911

Status Indians and Eligible Inuit

Saskatchewan

Non-Insured Health Benefits
South Broad Plaza
2045 Broad Street, 1st Floor
Regina, SK S4P 3T7
Toll free: 1-866-885-3933

Ontario

Non-Insured Health Benefits
Sir Charles Tupper Building
2720 Riverside Drive, 4th Floor,
Address Locator: 6604E
Ottawa, ON K1A 0K9
Toll-free: 1-800-640-0642

Northwest Territories and Nunavut

Non-Insured Health Benefits
2720 Riverside Drive
Address Locator: 6604C
Ottawa, ON K1A 0K9
Toll-free: 1-888-332-9222

Québec

Non-Insured Health Benefits
200 René-Lévesque Boulevard West
Guy-Favreau Complex, East Tower,
Suite 202
Montreal, QB H2Z 1X4
Toll-free: 1-877-483-1575

Alberta

Non-Insured Health Benefits
Canada Place
9700 Jasper Avenue, Suite 730
Edmonton, AB T5J 4C3
P: 780-495-2708
Toll free: 1-800-514-7106

Northern Region (Yukon Office)

Non-Insured Health Benefits
300 Main Street, Suite 100
Whitehorse, Yukon Y1A 2B5
Toll-free: 1-866-362-6717

For detailed information on NIHB's Medical Transportation policy, please visit the **NIHB Medical Transportation webpage**.

What if NIHB denies my prescription drug or medical travel claim?

Many rare disorders require treatment with uncommon or expensive drugs, or the expertise of a specialist who is not available in your home community. You may need to appeal an NIHB denial to be eligible for coverage. This next section of the guide will explain when you are eligible to appeal a denial and how to maximize your chance of a successful appeal. Please keep in mind that there is no guarantee of coverage, even after following these steps.

Status Indians and Eligible Inuit

Drug Coverage Appeals

You may need to start the drug coverage appeals process if:

1. NIHB denies full coverage of a brand name drug because there are acceptable generics available; or
 2. NIHB denies coverage because the drug is not listed in the Drug Benefit List, and it is not listed under Exclusions
-

To start an appeal, you will need to send a letter and provide the following information:

- The condition the drug is treating
 - Diagnosis and prognosis - these documents usually come from your doctor and will explain what disorder you have and whether it is short term, long term or life long. Your doctor will also need to explain what other drugs, if any, have been tried
 - Any relevant diagnostic tests
 - Reason for the requested drug
 - Any additional supporting documents, such as case notes from your doctor
-

Levels of Appeal

There are three levels of appeal. There is a different decision-maker who evaluates your appeal at each level. You must mail or fax your letter of appeal and supporting documents to NIHB headquarters.

If you are mailing your appeal, you must use a double envelope. The inner envelope should have your letter of appeal and supporting documents. It should be sealed and have APPEAL-CONFIDENTIAL written on the outside. Then, place this inner envelope into an outer envelope. Write the NIHB address on this outer envelope.

Status Indians and Eligible Inuit

NIHB Headquarters

Non-Insured Health Benefits Program
First Nations and Inuit Health Branch
Department of Indigenous Services Canada
200 Eglantine Driveway
Address Locator: 1909A
Ottawa, Ontario K1A 0K9
Fax: 613-954-5265

Level 1 Appeal

Address your letter of appeal to the Manager, Pharmacy Policy Development Division.

Level 2 Appeal

You may submit a Level 2 Appeal if:

- You do not agree with the Level 1 Appeal decision
- There is new information available since the last appeal

You must include the new supporting documentation with your letter. Address your letter of appeal to the Director, Benefit Management and Review Services Division.

Level 3 Appeal

You may submit a Level 3 Appeal if:

- You do not agree with the Level 2 Appeal decision
- There is new information available since the last appeal

You must include the new supporting documentation with your letter. Address your letter of appeal to the Director General, NIHB Program.

Status Indians and Eligible Inuit

Medical Travel Coverage Appeals

You may need to start the appeals process if NIHB denies your request for medical travel coverage. To start an appeal, you will need to provide the following information:

- The condition for which the benefit is being requested
 - Diagnosis and prognosis, including what other options have been tried. These documents usually come from your doctor and will explain what disorder you have and whether it is short term, long term or life long
 - Relevant test results
 - Reason for the proposed treatment
 - Any additional supporting information, such as case notes from your health provider
-

Levels of Appeal

There are three levels of appeal. There is a different decision-maker who evaluates your appeal at each level. You must mail or fax your letter of appeal and supporting documents to your regional NIHB office.

If you are mailing your appeal, you must use a double envelope. The inner envelope should have your letter of appeal and supporting documents. It should be sealed and have APPEAL-CONFIDENTIAL written on the outside. Then, place this inner envelope into an outer envelope. Write the NIHB address on this outer envelope. Please see page 8 for a list of regional offices.

Level 1 Appeal

Address your letter of appeal to the Regional Manager, NIHB Program.

Status Indians and Eligible Inuit

Level 2 Appeal

You may submit a Level 2 Appeal if:

- You do not agree with the Level 1 Appeal decision
- There is new information available since the last appeal

You must include the new supporting documentation with your letter. Address your letter of appeal to the Regional Executive, First Nations and Inuit Health Branch.

Level 3 Appeal

You may submit a Level 3 Appeal if:

- You do not agree with the Level 2 Appeal decision
- There is new information available since the last appeal

You must include the new supporting documentation with your letter. Address your letter of appeal to the Director General, NIHB Program headquarters.

NIHB Headquarters

Non-Insured Health Benefits Program
First Nations and Inuit Health Branch
Department of Indigenous Services Canada
200 Eglantine Driveway
Address Locator: 1909A
Ottawa, Ontario K1A 0K9
Fax: 613-954-5265

Status Indians and Eligible Inuit

Letter Writing Tips

When writing your appeal letter, there are a few things to keep in mind:

- NIHB does not use a strict list of criteria to evaluate your appeal. Each claim is evaluated on a case-by-case basis. This means the program's opinion can change based on any number of factors, such as the type of disorder you have or your test results
- Remember that the committee members who are evaluating your claim are human - use words that express your emotional experience living with a rare disorder and why it is important for you to receive coverage. Describe yourself - for example, are you a student, parent, or someone with limited access to financial resources? Explain how your situation impacts your health
- If you are appealing the denial of drug coverage, make sure you clearly outline the reasons why you cannot take alternative drugs that are covered by the program. If you are appealing medical travel coverage, clearly outline the reasons why you cannot access treatment in your home community. NIHB wants to spend the least amount of money on the largest number of patients as possible, so presenting an effective argument about why you should receive coverage for an expensive drug or medical travel is key.

Eg. If you had an adverse reaction with a cheaper drug, tell NIHB this. Explain that your doctor is strongly recommending the more expensive drug. Talk about the many health benefits you are receiving or could receive from taking the more expensive drug

- At the end of your letter, make sure to ask NIHB to provide you with clear, detailed information if they choose to deny your request. Knowing why you received a denial is very important if you are going to appeal the decision. You will use this information to gather new or additional evidence to send with your appeal

Status Indians and Eligible Inuit

First Nations Health Authority (FNHA)

The FNHA is now in charge of health benefits for Status Indians who are residents of BC. The program is very similar to NIHB, with a few minor changes.

Pharmacy Benefits

Pharmacy benefits are now administered through the BC Pharmacare Program under Pharmacare Plan W. If the drug you require is not covered by Plan W, then the claim can then go to your private insurer, if you have one. If you do not have private insurance, the claim will go to NIHB.

If none of the above plans will cover your drug, you will need to go through an appeals process. The FNHA is still finalizing an appeals procedure, but you can still access the NIHB appeals procedure in the meantime. Please see page 10 for information on NIHB appeals.

Eligibility

- You are a registered Status Indian
- You are a resident of BC and live in BC for at least 6 months in a calendar year
- You must be enrolled with the Medical Services Plan (MSP), which is the medical insurance plan provided by BC

For more information, including how to enrol with MSP or the FNHA, please visit the **FNHA Eligibility and MSP page**.

To check whether the drug you require is eligible for coverage, please see the **Pharmacare Formulary** and select "First Nations Health Benefits" in the drop down menu when performing your search.

Medical Travel Benefits

The FNHA may provide coverage for medical travel to help you access medical services with the nearest appropriate health care professional or at the nearest appropriate health care facility.

Status Indians and Eligible Inuit

The FNHA has a Medical Travel Checklist that explains what steps you must take to access this benefit. You can download the checklist by **clicking here**.

All medical travel must receive prior approval except in cases of a medical emergency. For a full list of requirements and to access the mandatory forms, please visit the **FNHA Medical Travel webpage** or contact the FNHA directly.

First Nations Health Authority
P: 1-800-317-7878
E: HealthBenefits@fnha.ca

Nunatsiavut NIHB Program

The Nunatsiavut NIHB program is for Inuit persons who are beneficiaries of the Labrador Inuit Land Claims Agreement. If you have a Nunatsiavut membership card, you are eligible for this program.

If you do not have a membership card, or are unsure if you are eligible for the Nunatsiavut NIHB program, please visit the **Nunatsiavut Government webpage** for more information.

Program Information

The Nunatsiavut NIHB program follows the same guidelines as the federal NIHB program. The main difference is that the Nunatsiavut government is in charge of administering benefits instead of the federal NIHB program.

For more detailed information about the NIHB program, such as the type of drug and medical travel coverage available and the appeals process, please see the NIHB section beginning on page 4.

For more information about how the Nunatsiavut NIHB program is administered, please visit the **Nunatsiavut NIHB webpage** or contact your local Department of Health and Social Development (DHSD).

Status Indians and Eligible Inuit

Nunavik Insured/Non-Insured Health Benefits Program (INIHB)

The Nunavik INIHB program is for Inuit persons who are beneficiaries on the register of the James Bay Northern Quebec Agreement and whose main residence is in Nunavik. This also includes those temporarily absent from Nunavik, such as a post-secondary student, an inmate in a correctional centre or halfway house, or a client requiring medical care outside of Nunavik.

If you have a Nunavik Inuit Beneficiary Card and currently live in Nunavik, you are eligible for this program. If you are unsure if you are eligible for the Nunavik INIHB program, please visit the **Nunavik Enrolment Office webpage** for more information.

Pharmacy Benefits

The INIHB program provides coverage for drugs listed in the Régie de l'assurance maladie du Québec (RAMQ) List of Medications. Please see the **RAMQ (English)** or **RAMQ (français)** to access the formulary.

Exception Drugs

Exception drugs are drugs that are not listed in the RAMQ formulary. Many rare disorders require treatment with uncommon or expensive drugs. If the drug you require is an exception drug, your pharmacist must contact the INIHB program for prior approval. INIHB will then approve or deny coverage and provide a response to your pharmacist.

What if INIHB denies my prescription drug claim?

You may need to appeal an INIHB denial to be eligible for coverage. This next section of the guide will explain when you are eligible to appeal a denial and how to maximize your chance of a successful appeal. Please keep in mind that there is no guarantee of coverage, even after following these steps.

Status Indians and Eligible Inuit

Appeals

To start an appeal, you will need to write a letter and provide the following information:

- The condition for which the benefit is being requested
- The diagnosis and prognosis, including what other alternatives have been tried. This information usually comes from your doctor
- Relevant test results from your doctor; and
- Justification for the proposed treatment and any additional supporting information, such as case notes from your doctor

Criteria Used to Evaluate Your Appeal

The INIHB program uses the following criteria to evaluate your appeal:

- Your eligibility and rights under the program standards
- Medical necessity, as determined by a physician. An additional medical opinion will be necessary when appealing exception drugs or a previous denial by INIHB

Levels of Appeal

There are two levels of appeal available.

Level 1 Appeal - An appeal can be submitted in person or in writing to the Executive Director of the Nunavik Regional Board of Health and Social Services (NRBHSS). If you disagree with the Level 1 appeal decision, or if there is new evidence or information available for review, you may have the appeal reviewed at Level 2

Level 2 Appeal - An appeal can be submitted in writing to the NRBHSS Board of Directors. Clearly mark "Appeals-Confidential" on the envelope.

Status Indians and Eligible Inuit

Both Level 1 and Level 2 Appeals must be sent to the following address:

Chairperson of NRBHSS Board of Directors
Nunavik Regional Board of Health and Social Services
P.O. Box 900
Kuujjuaq, Quebec
J0M 1C0

A written explanation of the decision will be sent to you within 45 days of submitting the appeal. If you do not receive a response within 45 days, contact the Nunavik Regional Board of Health and Social Services.

Nunavik Regional Board of Health and Social Services
P: (819) 964-2222
Website: www.rrss17.gouv.qc.ca

Letter Writing Tips

The personal letter you write is very important. Your letter should explain why you require the drug and how it will improve your quality of life. When writing your appeal letter, there are a few things to keep in mind.

- INIHB evaluates claims on a case-by-case basis. This means the program's opinion can change based on any number of factors, such as the type of disorder you have or your test results
- Remember that the committee members who are evaluating your claim are human - use words that express your emotional experience living with a rare disorder and why it is important for you to receive coverage. Describe yourself - for example, are you a student, parent, someone with limited access to financial resources? Explain how your situation impacts your health

Status Indians and Eligible Inuit

- Make sure you clearly outline the reasons why you cannot take alternative drugs that are covered by the program. INIHB wants to spend the least amount of money on the largest number of patients as possible, so presenting an effective argument about why you should receive coverage for an expensive drug is key.

Eg. If you had an adverse reaction with a cheaper drug, tell INIHB this. Explain that your doctor is strongly recommending the more expensive drug. Talk about the many health benefits you are receiving or could receive from taking the more expensive drug

- At the end of your letter, make sure to ask INIHB to provide you with clear, detailed information if they choose to deny your request. Knowing why you received a denial is very important if you are going to appeal the decision. You will use this information to gather new or additional evidence to send with your appeal
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Métis

Métis Living in the Northwest Territories

If you are Métis and living in the Northwest Territories (NWT), the NWT government has created a program that is very similar to NIHB, but also includes coverage for Métis peoples.

Eligibility Requirements

- You are a Registered Métis; and
- You are a Permanent Resident of the NWT; and
- You are registered with the NWT Health Care Plan

You will need to fill out an application form, which you can access by **clicking here**.

Pharmacy Benefits

The program will provide 100% coverage of drugs listed in the NIHB formulary. A prior authorization request can be submitted to Alberta Blue Cross for coverage of drugs that are not included by filling out an **Exception Approval Drug Request form**.

The information required is very similar to the NIHB appeal process for exception drugs, except a personal letter from the patient is not required.

Medical Travel

You may be eligible for reimbursement of accommodation, transportation, and meal costs when travel is required for medical treatment that is not available in your home community. You must receive prior approval for any medical travel costs.

Eligible expenses (subject to prior approval) include:

- Travel (air or ground) to the nearest clinic or hospital
- Private accommodation
- Commercial accommodation
- Boarding facilities
- Meals
- Escorts and/or interpreter services
- Emergency Ambulance Services that originate in the NWT

Métis

For more information, please visit the **Métis Health Benefits webpage** or contact the program directly.

Health Benefits Program
Health Services Administration
Department of Health and Social Services
Government of the Northwest Territories
Bag #9, Inuvik, NWT X0E 0T0
Toll-free: 1-800-661-0830
P: 867-777-7400
E:healthcarecard@gov.nt.ca

Métis Nation of Ontario

The Métis Nation of Ontario (MNO) may provide medical travel coverage to self-identified Métis persons through their Community Support Services Program.

For clients who meet the criteria, transportation can be arranged via a volunteer driver, coordinator, bus tickets, mobility bus services, Via Rail, Hope Air or other affordable means that are available to the particular community. If you have a private vehicle available but need financial assistance in order to travel, the program will make every effort to help.

The program has several sites throughout Ontario. You can visit the **MNO webpage** for more information or contact your local site using the numbers below.

- | | |
|-----------------------------------|--------------------------------|
| • Kenora – 807-467-2555 | • North Bay – 705-474-2767 |
| • Dryden – 807-223-4535 | • Ottawa – 613-798-1488 x 126 |
| • Fort Frances – 807-274-6230 | • Bancroft – 613-332-2575 x 22 |
| • Thunder Bay – 807-624-5010 | • Toronto – 416-977-9881 x 105 |
| • Sault Ste. Marie – 705-254-1768 | • Midland – 705-526-6335 |
| • Timmins – 705-264-3939 | • Welland – 905-735-1112 x 303 |
| • Sudbury – 705-671-9855 x 228 | • Windsor – 519-974-0860 |

Non-Status Indians

Right now, Non-Status Indians are not eligible for benefits through the NIHB program. Instead, most Non-Status Indians will be eligible for provincial drug plans and may have access to provincial medical travel funding. Please see the Provincial Programs on page 24 for more information.

It is also a good idea to check with your band office about any possible coverage for medical expenses. Some bands have resources for medical travel, including grants and transportation. There may also be funds available for emergency medical expenses.

Provincial Programs

British Columbia

Pharmacy Benefits

BC provides prescription drug coverage through its Fair Pharmacare program.

If you are not sure whether you are registered for the Fair Pharmacare Plan, please visit the **Fair Pharmacare Registration Page**.

Fair Pharmacare will provide 70% coverage on all eligible drugs until you have spent the maximum amount required based on your family income. Once you reach the maximum amount, Fair Pharmacare will pay 100% of your costs for the rest of the year.

To determine the maximum amount you must spend before Fair Pharmacare pays 100%, please see the **Family Income Tables**.

Appeals

If Pharmacare denies coverage, you may be eligible to apply for Special Authority. Your doctor must fill out a Special Authority form and fax it to the program. Pharmacare may grant Special Authority for:

- Limited Coverage Drugs - drugs that are not usually first line therapies or are more expensive than acceptable alternatives
- Partially Covered Drugs - for patients who experience an adverse reaction or treatment failure on a drug listed under the Reference Drug Program
- Alternate Products - for patients who cannot take a lower cost drug because of an allergy
- Drugs not marketed in Canada - includes drugs eligible through the Health Canada Special Access Program

Provincial Programs

You must meet certain criteria for the particular drug in order to receive coverage. The criteria varies depending on the drug.

If the drug you require is not listed under any of the Special Authority categories, Pharmacare will evaluate your claim on a case-by-case basis. In this case, it can be helpful to write a personal letter and ask your doctor to submit it with the Special Authority request.

Letter Writing Tips

- Pharmacare does not use a strict list of criteria to evaluate your appeal. Each claim is evaluated on a case-by-case basis. This means the program's opinion can change based on any number of factors, such as the type of disorder you have or your test results
- Remember that the committee members who are evaluating your claim are human - use words that express your emotional experience living with a rare disorder and why it is important for you to receive coverage. Describe yourself - for example, are you a student, parent, or someone with limited access to financial resources? Explain how your situation impacts your health
- Make sure you clearly outline the reasons why you cannot access treatment in your home community. Pharmacare wants to spend the least amount of money on the largest number of patients as possible, so presenting an effective argument about why you should receive coverage for an expensive drug travel is key

Eg. If you had an adverse reaction with a cheaper drug, tell Pharmacare this. Explain that your doctor is strongly recommending the more expensive drug. Talk about the many health benefits you are receiving or could receive from taking the more expensive drug

- At the end of your letter, make sure to ask Pharmacare to provide you with clear, detailed information if they choose to deny your request. Knowing why you received a denial is very important if you are going to appeal the decision. You will use this information to gather new or additional evidence to send with your appeal

Provincial Programs

If Special Authority is denied, you can appeal the decision. You will need to submit a copy of the denial, the Special Authority form submitted by your doctor, and any other supporting documentation like tests results or case notes from your doctor. If you wrote a personal letter to the Special Authority team, you can also submit it, along with a new letter stating why you believe the Special Authority team's decision was wrong.

You can submit the appeal to the following address:

Attention: Operations Director
Health Insurance BC
PO Box 9035 Stn Prov Govt
Victoria, B.C. V8W 9E3
Fax: 250 405-3595

If you disagree with the response from the operations director of Health Insurance BC, you can send a letter of appeal to the Ministry of Health:

Director
Medical Beneficiary Branch
Ministry of Health
PO Box 9652 Stn Prov Govt
Victoria, B.C. V8W 9P4
Fax: 250 952-3133

Medical Travel Benefits

BC offers a Travel Assistance Program (TAP) that may provide coverage for transportation expenses if you are required to travel outside of your home community in order to visit a specialist. TAP covers expenses such as ferry fares (including vehicle), mileage and provides discounts on airfares and rail travel with partnered companies.

Eligible Services

- Non-emergency medical specialist services available at the closest location outside your community; and
- Diagnostic procedures, laboratory procedures, diagnostic radiology, nuclear medicine procedures, BC Cancer Agency, Transplant Units, HIV/AIDS treatment at St. Paul's Hospital, specialty clinics at BC Children's Hospital and other tertiary care hospital services

Provincial Programs

Patient Eligibility

To be eligible for TAP:

You must be a B.C. resident and be enrolled in the Medical Services Plan (MSP);

- You must have a referral from a physician or nurse practitioner for MSP insured specialist medical services which are not available locally; and
- Your travel expenses must not be covered by third party insurance, such as an employer plan, extended medical plan, Insurance Corporation of BC (ICBC), WorkSafeBC or federal government program (e.g. NIHB).

Your doctor will need to fill out most of the TAP form and then give it to you to complete.

For a detailed list of steps and requirements, please see the **TAP webpage** or contact the program directly.

Travel Assistance Program
P: 1 800 663-7100 (Elsewhere in B.C.)
P: (604) 683-7151 (Vancouver)

Provincial Programs

Alberta

Pharmacy Benefits

Alberta provides prescription drug coverage through the Alberta Blue Cross Non-Coverage Group program.

Eligibility

You are eligible for the program if:

- You are under 65 years old
- You are registered with the Alberta Health Care Insurance Plan (AHCIP)
- You do not owe any money on your AHCIP Account

Premiums

The Non-Coverage Group program charges monthly premiums based on your family income. The full premium for a single individual is \$63.50/month and \$118.00/month for a family.

If you are single and make less than \$20,970/year, you qualify for a subsidized premium of \$44.45/month. If you and your spouse/partner have a combined income of \$33,240/year, you qualify for a subsidized premium of \$82.60/month. If you are a family with children and make less than \$39,250/year, you also qualify for a \$82.60/month premium.

Copayment

You will have a 30% copayment, up to \$25 per prescription drug.

Special Authorization

Only doctors have access to the Special Authorization form. If you require Special Authorization, please ask your doctor for assistance.

Provincial Programs

Indigenous Health Services

There are support programs and other programming available, including wellness counsellors and cultural helper services. Please visit the **Alberta Health Services** page for more information about services available in your area.

Saskatchewan

Family Health Benefits Program

Under the Family Health Benefits Program, children under 18 receive formulary drugs at no charge. Parents must pay a \$200/year deductible before the program will begin paying 35% of drug costs.

Eligibility

- You must meet the standards of an income test, based on the previous years' income and number of children in the family, determined by the Ministry of Social Services, Revenue Canada; or
- You receive the Saskatchewan Rental Housing Supplement; or
- You receive the Saskatchewan Employment Supplement

For more information on this program, please visit the **Family Health Benefits Program website**.

Special Support Program

Saskatchewan also offers a Special Support program for high cost drugs. Eligibility is based on income information gathered from the program application form, income tax documentation and Drug Plan records. Using this information, the program will calculate an adjusted deductible and patient copayment.

Please visit the **Special Support Program website** or contact the **Drug Plan and Extended Benefits Branch** for more information.

Provincial Programs

Exception Drug Status Program

For drugs that are not listed in the formulary, your doctor or pharmacist can apply for coverage under the Exception Drug Status Program. You will receive a letter in the mail explaining the approval or denial of coverage.

If coverage is denied, it is usually because the program requires further information from you. However, some drugs are not covered under this program. You will be notified if this is the case.

For a list of eligible drugs, please see **Appendix A** of the Saskatchewan Drug Program.

Drug Plan and Extended Benefits Branch
P: (306) 787-3317
E: DPEB@health.gov.sk.ca

Manitoba

Pharmacare

Manitoba's Pharmacare program is designed to help individuals whose income is greatly affected by high cost prescription drugs. To be eligible, you must meet the requirements based on total family income and drug cost. A yearly deductible will be set based on your family income.

Eligibility

- You must be eligible for Manitoba Health, Seniors and Active Living Coverage; and
- You are not covered by any other federal or provincial plan

Once you have met your yearly deductible, Pharmacare will provide 100% coverage for your prescription drugs for the rest of the year. Pharmacare will only provide coverage for drugs on the formulary. Please use the **Drug Formulary Lookup Tool** to see if the drug you require is eligible.

Provincial Programs

For more information, please visit the **Manitoba Pharmacare website** or contact the program directly.

Manitoba Health, Seniors and Active Living
Provincial Drug Programs
P: 1-800-297-8099
E: pharmacare@gov.mb.ca

Out of Province Medical Travel

While Manitoba does not offer a medical travel program for within-province travel, there is a subsidy program if you need to see a specialist outside of Manitoba.

Eligibility

- You must receive prior approval from Manitoba Health, Seniors and Active Living; and
- An appropriate physician must recommend that you require a necessary, specific insured medical service (care or treatment); and
- That recommended treatment is not available in Manitoba

For more information please visit the **Transportation Subsidy Program website** or contact the program directly.

Transportation Subsidy Program
P: 1-800-392-1207 extension 7303

Provincial Programs

Ontario

Pharmacy Benefits

Trillium Drug Benefit Program

Under this program, you will pay an annual deductible that is calculated based on your income. After you have paid the deductible, you pay up to \$2 for each prescription drug, per person, that is filled or refilled.

Eligibility

To qualify for the program, you must meet the following criteria:

- You spend approximately 3-4% of your household income on prescription drugs
- You are under 65 years old
- You are not enrolled in a program such as Ontario Works
- You have a valid Ontario health card

To download an application form, please **click here**. Applications can be mailed to the address in the red box below.

For more information on this program, please visit the **Trillium Drug Benefit webpage** or contact the program directly.

Trillium Drug Program
Ministry of Health and Long-Term Care
PO Box 337
Station D
Etobicoke, ON M9A 4X3
P: 1-800-575-5386

Provincial Programs

OHIP+

OHIP+ provides drug coverage for children and youth under age 25. All individuals under 25 years old were automatically enrolled in this program as of January 1, 2018.

There are no deductibles or copayments under this program. OHIP+ provides 100% coverage for eligible drugs in the **Ontario Drug Benefit list**.

For more information on this program, please visit the **OHIP+ webpage** or contact ServiceOntario directly.

ServiceOntario
P: 1-866-532-3161
E: OHIPplus@ontario.ca

Ontario Drug Benefit Program

This program provides coverage to individuals 65+ years old, or those enrolled in Home Care programs through the Ontario government, Ontario Works (OW), or the Ontario Disability Support Program (ODSP). The program provides coverage for drugs in the **Ontario Drug Benefit list**.

You will pay an annual deductible and a copayment for each prescription drug based on your household income.

For application forms, income calculation tables and more information, please visit the **Ontario Drug Benefit Program webpage**.

Exceptional Access Program

The Exceptional Access Program (EAP) may provide coverage for a drug that is not listed in the Ontario Drug Benefit List. Your claim will be evaluated by pharmacists on a case-by-case basis, based on the standards set by the Committee to Evaluate Drugs (CED).

Provincial Programs

Your doctor or nurse must fill out the application form and fax it to the program. A decision will be made between 3 days and 6 weeks, depending on urgency and whether the request requires an external review.

For more information, please visit the [EAP webpage](#).

Medical Travel Benefits - Northern Ontario

Northern Health Travel Grant

The Northern Health Travel Grant (NHTG) may provide coverage to individuals who need to travel outside of their Northern Ontario community to visit a specialist.

Eligibility

- You must be a resident of Algoma, Cochrane, Kenora, Manitoulin, Nipissing, Parry Sound, Rainy River, Sudbury, Thunder Bay or Timiskaming
- Your Northern Ontario health provider must give you a referral to the specialist
- You must travel at least 100km to visit the closest specialist able to provide care
- You are not covered by any other program

Reimbursement

The NHTG provides the following kinds of reimbursement:

- Private vehicle travel: you will not be reimbursed for gas for the first 100km driven. After 100km, you will be reimbursed 41 cents/km driven.
- Air, train or bus travel: provide the original ticket, receipt or itinerary showing the fare paid, who is travelling, date of travel and the destination
- Accommodation: \$100 per night up to 2 nights, \$250 for 3 nights, \$500 for 4-7 nights, \$550 for 8 or more nights

Provincial Programs

To download an application form, please [click here](#).

For more information, please see the **NHTG webpage** or contact ServiceOntario directly.

ServiceOntario
P: 1-866-532-3161
E: OHIPplus@ontario.ca

Quebec

Public Prescription Drug Insurance Plan

The Public Prescription Drug Insurance Plan (PPDIP) is offered by the Régie de l'assurance maladie Québec (RAMQ). It provides coverage to eligible Quebec residents. You must pay an annual premium between \$0-616, calculated based on your income. There is also a monthly deductible of \$19.90. Finally, there is a copayment of 30.4% for each prescription you fill or refill, until you reach your monthly maximum contribution.

Eligibility

- To receive coverage through the PPDIP, you must be unable to access a private insurance plan. Individuals who are recipients of last-resort financial assistance are automatically covered by the program.
- For a list of eligible drugs, please see the **RAMQ List of Medications**.

Exceptional Medications

- The program may provide coverage for drugs listed in the "Exceptional Medications" section of the List of Medications. Your doctor will submit a payment authorization request to the program and you will hear back within 24-48 hours.
- For a list of eligible drugs, please see the Exceptional Medications section of the **RAMQ List of Medications**.

Provincial Programs

Exception Patient Measure

For serious medical conditions, the program may provide coverage for a drug that does not appear in the List of Medications. Your doctor must send a payment authorization to the RAMQ for approval.

You have the right to appeal within 6 months of receiving a denial. You or your doctor may submit an application for review, along with new information or evidence for the RAMQ to consider.

You can download an application for review by **clicking here**.

If you are still not satisfied, you can appeal the review decision to the secretariat of the Tribunal administratif du Québec within 60 days.

For more information on the PPDIP and its Exceptional Medications and Exception Patient Measures, please visit the **RAMQ Prescription Drug Insurance webpage** or contact the program directly.

Régie de l'assurance maladie Québec
Case postale 6600
Québec (Québec)
G1K 7T3
P: 1 800 561-9749

Newfoundland and Labrador

Pharmacy Benefits

Access Program

The Access Program provides coverage to single individuals with a net income of \$27,151 or less; couples with a net income of \$30,009 or less; and families (including single parents) with a total net income of \$42,870 or less. There is a copayment between 20-70% of the total cost of the prescription drug, calculated based on income.

Provincial Programs

Assurance Program

The Assurance Program provides coverage for individuals whose drug costs exceed 5% of net income of \$40,000/year or less, 7.5% of net income for \$75,000/year or less, or 10% of net income for \$150,000/year or less. The program will calculate a copayment dependent upon income and drug cost.

Eligible Drugs

Both the Access and Assurance Programs use the Newfoundland and Labrador Prescription Drug Program (NLPDP) Drug Product Database. Each drug within the database is either an Open Benefit or requires Special Authorization.

- Open Benefit: These drugs are available to any patient without restrictions
- Special Authorization: You must meet certain criteria to receive coverage for these drugs. Your doctor must submit a request for coverage. To view the criteria for each drug, please see the **Special Authorization Guide**.

You can download an application form for both the Access Program and Assurance Program by **clicking here**.

For more information on the Access and Assurance Programs, please visit the **Health and Community Services webpage** or contact the NLPDP directly.

Newfoundland and Labrador Prescription
Drug Program
P: 1-888-859-3535
E: LIDPinfo@gov.nl.ca

Provincial Programs

Medical Transportation Assistance Program

The Medical Transportation Assistance Program (MTAP) provides financial assistance to individuals who have high travel costs to access specialized medical services unavailable in their home community.

Eligible costs may include;

- Airfare and related eligible taxi fares
- Private vehicle usage
- Purchased registered accommodations and related meal allowances
- Busing and use of ferries based on program criteria (deductibles may apply)

For more information and to access reimbursement forms, please visit the **MTAP webpage** or contact the program directly.

Medical Transportation Assistance Program
P: 1-877-475-2412

New Brunswick

New Brunswick Drug Plan

The New Brunswick (NB) Drug Plan is available to residents who do not have existing drug coverage through a private plan or government program. It is also available to those who have a private plan that does not cover a specific drug, when that drug is included in the NB formulary.

Premiums and maximum copayments are calculated based on annual family income. There is a 30% copayment up to a maximum amount for each prescription drug that is filled or refilled.

For more information, please see the **Premiums and Copayments webpage**.

To download an application form, please **click here**.

Provincial Programs

Appeals

If you are denied coverage for a drug, you can appeal to the Insurance Services Appeals Committee. The Committee is made up of three members of the public who will make recommendations to the Minister of Health. The Minister makes the final decision. You need to include all background information about the claim - this would include information such as diagnostic testing and results, case notes from your doctor, previous drugs tried and the reason you are requesting this specific drug.

All appeals can be sent to the following address:

Insured Services Appeal Committee
c/o New Brunswick Medicare
Department of Health
P.O. Box 5100
Fredericton, NB E3B 5G8

Medical Travel

The New Brunswick Medicare Program may provide out-of-province medical travel funds for hostel accommodations and meals. The maximum coverage for a hostel, including meals, is \$110/day. If a doctor confirms a medical escort is required, the maximum coverage for an escort is \$46/day. Escorts must share a room with the patient.

For more information, please see the **Out-of-Province Travel webpage**.

For more information on the medical benefits offered by New Brunswick, please visit the **Medicare and Drug Plan webpage** or contact the program directly.

Medicare – Eligibility and Claims
New Brunswick Medicare
Department of Health
P.O. Box 5100
Fredericton, N.B., E3B 5G8
P: 1-888-762-8600
E: Medicare@gnb.ca

Provincial Programs

Nova Scotia

Family Pharmacare Plan

The Family Pharmacare Plan does not charge any premiums or fees to join. If you need prescription drugs, the plan charges an annual copayment and deductible based on income. The first 20% of the cost of the drug goes towards the maximum annual copayment. The remaining 80% goes towards the maximum annual deductible. When the deductible is paid, you will continue to pay 20% of the cost until the maximum copayment is reached. When both the deductible and copayment are paid in full, you will receive the drug for free until the end of the program year (March 31).

Exception Status Drugs

Some drugs are only eligible for coverage if certain criteria are met. Your doctor will need to fill out an Exception Status Drug Request Form and fax it to the program. For a list of Exception Status Drugs and their criteria, please see **Appendix 3** of the Nova Scotia drug formulary.

For more information, please see the **Nova Scotia Pharmacare webpage** or contact the program directly.

Nova Scotia Pharmacare Programs
P.O. Box 9322
Halifax, NS B3K 6A1
P: 1-800-544-6191

Medical Travel

Nova Scotia may provide coverage for out-of-province travel. A specialist must seek approval from Medical Services Insurance (MSI) - the treatment must be medically insured and not available within Nova Scotia. Coverage will be provided for an escort if medically necessary, or if the patient is under 19 years of age. Once approved, you will receive information from the Department of Health and Wellness, including an application form.

Provincial Programs

Please keep all receipts, including boarding passes, and submit them to the Department of Health and Wellness after travel is complete.

The program will pay a maximum of \$1000 towards travel round trip, and a maximum of \$125/night or \$1500/month in accommodation assistance.

For more information, please see the **Out-of-Province Travel and Accommodation Assistance Policy webpage** or contact the program directly.

Out-of-Province Travel and Accommodation
Assistance Policy
Department of Health and Wellness
P: 1-877-449-5476

Prince Edward Island

There are several drug programs under PEI Pharmacare. Most relevant to Indigenous people with rare disorders is the Catastrophic Drug Program.

Catastrophic Drug Program

The Catastrophic Drug Program provides coverage to individuals who have high prescription drug costs that make it difficult to pay for other life essentials. The amount you pay is calculated based on your annual income.

Eligibility

To qualify for the program, you must be a resident of PEI, have a valid PEI Health Card and have filed your most recent income tax.

To download an application form, please **click here**.

Provincial Programs

Special Authorization

Some drugs require Special Authorization to receive coverage under the Catastrophic Drug Program. Your doctor will need to submit a Standard Special Authorization Request form to the program to have a drug considered for coverage.

Unfortunately, if the drug is not listed in the PEI Pharmacare Formulary, it will not be covered by the program.

You can check if the drug you require is covered by **searching the formulary**.

For more information on the program and Special Authorization, please visit the **Catastrophic Drug Program webpage**.

For more information on other drug programs available through PEI Pharmacare, please visit the **Drug Programs webpage** or contact PEI Pharmacare directly.

PEI Pharmacare
16 Fitzroy Street
Sullivan Building
Charlottetown, PE C1A 7N8
P: (902) 368-4947

Medical Travel

Health PEI may provide coverage for out-of-province medical travel if the treatment you require is not available in PEI. Prior approval must be obtained before receiving financial assistance. There are four different programs that use household income to calculate whether you are eligible for assistance:

- Maritime Bus Program - if you require medical treatment in New Brunswick or Nova Scotia
- Hope Air Flights Program - for individuals who cannot afford the cost of a commercial plane ticket for travel to another province for medical treatment

Provincial Programs

- Hope Air Bridge Toll Program - subsidizes a Confederation Toll Bridge pass for eligible PEI residents who require transport via private vehicle for medical treatment
- Hope Air Ferry Pass Program - subsidizes the cost of a Northumberland Ferries Ltd. ferry pass for eligible PEI residents who require transport via private vehicle for medical treatment.

For more information on these programs, please visit the **Out-of-Province Travel Support Programs webpage** or contact the program directly.

Out-of-Province Travel Support Program
16 Garfield Street
Charlottetown, PE C1A 7N8
P: (902) 368-5918
E: ooptravelsupport@gov.pe.ca

Yukon

Chronic Disease Program

The Chronic Disease Program provides coverage for individuals with a chronic disease or a serious functional disability.

The program is a payor of last resort. If you have private or third party insurance, you must submit your claim to these insurers first before the program will provide coverage.

Eligibility

To receive coverage, you must be diagnosed with a qualifying chronic disease. The prescription drug must be medically required to treat the disease and a medical professional licensed to practice in the Yukon must recommend the drug. For a full list of eligible diseases, to access the drug formulary and for more information, please visit the **Yukon Chronic Disease webpage** or contact the program directly.

Provincial Programs

Chronic Disease Program
Health & Social Services, Government of Yukon
Box 2703
Whitehorse, Yukon Y1A 2C6
P: 867-667-5092 or 1-800-661-0408 ext. 5092

Northwest Territories

The Northwest Territories does not have a general drug benefit program. The territory offers the Métis Health Benefits Program, which you can read more about on page 21, or the Specified Disease Conditions program for non-registered Métis, which provides drug coverage for certain eligible diseases.

To see a full list of eligible diseases and learn more about the Specified Disease Conditions program, please visit the **Extended Health Benefits webpage** or contact the program directly.

Health Services Administration Office
Health and Social Services
Bag #9
Inuvik, NT X0E 0T0
P: 1-800-661-0830
E: healthcarecard@gov.nt.ca

Nunavut

Medical Travel Benefits

The Nunavut Health Care Plan may provide coverage if you are required to travel outside of your home community in order to visit a specialist.

Provincial Programs

Eligibility

- You must be a resident of Nunavut
- You must have exhausted all other available coverage such as third party insurance or NIHB

Eligible Expenses

- Flight co-payment specified under the Medical Travel Policy
- Taxi fare or ground transportation between your accommodation, health facilities and the airport
- Ambulatory charges for transferring from one facility to another
- Private or commercial accommodations
- Meals for stay in private accommodations
- Long-term care plan, indicated prior to or after start of medical trip

For more information, please see the **Medical Travel Support webpage**, read more about the **Medical Travel Policy** or contact the program directly.

Nunavut Health Insurance Programs Office
Department of Health
Box 889
Rankin Inlet, NU X0C 0G0
P: (867) 645-8029
Toll free: (800) 661-0833
E: ehb@gov.nu.ca

Resources

NIHB System Navigators

- BC: 1-800-317-7878
 - Alberta
 - Treaty 6: 1-780-944-0334
 - Treaty 7: 1-403-539-0361
 - Treaty 8: 1-780-444-9366
 - Saskatchewan: 1-866-956-6442
 - Manitoba: currently in negotiations to establish a navigator
 - Ontario:
 - Quebec: Contact your community health centre or nursing station. For any other information, you can contact the Health Care Liaison Agent at First Nations of Quebec and Labrador Health and Social Services Commission: 1-418-842-1540
 - Atlantic (NL, NB, NS, PEI): 1-877-667-4007
 - Yukon: 1-867-393-9205
 - NWT: currently in negotiations to establish a navigator
 - Nunavut: does not currently have a navigator. Contact the regional NIHB office at 1-866-606-9750 or your local Department of Health and Social Development for further assistance
-

Provincial Patient Navigator Programs

- **British Columbia**
 - Vancouver Island
 - Aboriginal Liaison Nurses
- **Alberta**
 - Indigenous Health Program (Edmonton and North Zones)
- **Saskatchewan**
 - Saskatoon region
 - First Nations and Metis Health Service
- **Manitoba**
 - Winnipeg
 - Assembly of Manitoba Chiefs/Winnipeg Regional Health Authority Patient Advocate Unit
- **Ontario**
 - Hamilton, Haldimand, Brant and Niagara regions
 - Aboriginal Patient Navigator Program

Resources

- **Newfoundland and Labrador**
 - St. John's
 - Eastern Health Aboriginal Patient Navigator Program
 - **New Brunswick**
 - Client Advocate Services (not Indigenous-specific)
 - **Nunavut**
 - System Navigator (not Indigenous-specific)
 - **Yukon**
 - Whitehorse, Dawson City and Watson Lake Hospitals
 - First Nations Patient Support Services
-

Additional Resources

NIHB

- NIHB Drug Benefit List (updated approximately every 3 months)
- NIHB Drug Exception Centre Client Line: 1-800-580-0950 ext. 3

Patient Advocacy Groups

- Canadian Organization for Rare Disorders (CORD)
- Rare Disease Foundation

Project Background and Acknowledgement

My Story

My name is Natalie Day, and I am from Oneida Nation of the Thames in Southern Ontario. I am currently completing my Juris Doctor at the University of Toronto, Faculty of Law.

I am diagnosed with Narcolepsy Type 2, a chronic, rare sleep disorder. While there are all kinds of rare disorders, people with rare disorders often share one thing in common - they must become their own health advocates and their own experts.



During my undergraduate degree, I experienced increasing daytime sleepiness, sleep paralysis episodes at night, excessive REM sleep during naps and difficulty concentrating. I took a nap every day, sometimes missed my early morning classes because I was so tired and if I did attend morning classes, I often struggled to stay awake.

I sought help through my family doctor, who ran the usual blood tests to check for common issues like hypothyroid, anemia or low Vitamin D. All tests came back normal.

I later saw a psychiatrist, as I was also struggling with depressive symptoms and anxiety. Once those symptoms were treated, I was still experiencing the symptoms that are hallmarks of narcolepsy. I was repeatedly told by my psychiatrist that it was my anxiety that was causing my sleepiness and fatigue. I insisted this was not the case and that this was a physical, not mental, issue.

I did my own research and suspected that narcolepsy could be the cause of my symptoms. I went back to my family doctor and asked for a referral to a sleep clinic. The sleep study results were conclusive - I did in fact have narcolepsy.

I strongly believe that self-advocacy and being unafraid to discuss personal health, both physical and mental, allows us to support one another and contributes to the transformation of ineffective health policies.

The Project

This project was borne out of my own experience as a "Status Indian" person with a rare disorder.

After receiving my diagnosis, I had great difficulty obtaining adequate health services and drug coverage from the NIHB program. I engaged in the appeals process, which took three months and resulted in a failure to fully evaluate my claim. I decided to abandon any further appeals and worked with the drug manufacturer.

There, I was successful in finding an alternative solution that even my sleep specialist was not aware existed. She was grateful for the work I did and told me that she would inform her colleagues about this solution.

I found the NIHB program to be extremely convoluted, confusing and lacking any transparency. I even went so far as to write a letter to the Minister of Health about my poor experience. I realized that if someone like myself - someone with privilege, with a post-secondary education and access to many resources - was having such difficulty navigating the NIHB program, I cannot imagine what it must be like for people who do not have access to these resources.

My frustration with NIHB and the perpetuation of colonial institutions creating barriers for Indigenous peoples informed my research as I prepared this guide. Ultimately, there needs to be systemic transformation of health policy for all Indigenous peoples. Until that happens, I wanted to provide a resource for Indigenous peoples with rare disorders on how to navigate the multiple healthcare systems as they currently exist.

I hope this guide can help ease the navigation process, and help Indigenous peoples maximize the resources currently available to them.

Acknowledgement

I would like to extend my sincere thanks to my fellowship supervisor, Ian Stedman, who provided invaluable feedback and support as I researched and created this Guide, and to CORD for providing a platform for the project. I would also like to express my gratitude for Grandmother Dorothy Peters' knowledge and guidance as I sought to ensure I was completing this project in a good way. Finally, many thanks to Amanda Carling, Manager of the Indigenous Initiatives Office at the University of Toronto, Faculty of Law for her endless encouragement and tireless work as the coordinator of the June Callwood Fellowship, without which this project would not have been possible.