

2020

Inherited Heart Disease (IHD) Clinic

Please bring the following to your appointments:

- Your medications in their original containers, or a list of your medications
- A list of the health care providers involved in your care
- Any family history info, such as family tree/genetic info or autopsy reports



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The Inherited Heart Disease (IHD) Clinic is for people with a suspected or diagnosed heart problem that may be inherited (be passed from parents to their children). The Clinic does genetic testing (blood tests) and helps people manage their condition. Inherited heart disease can be diagnosed at any age. You may have a wide range of symptoms, from no symptoms at all to sudden cardiac death (heart stops working).

It may take up to 12 months (1 year) to get an appointment at the Clinic. **You will need some tests before your Clinic visit, which may make your wait time longer. If you feel you need to be seen sooner, please talk with your referring health care provider.**

Clinic team members

Program Coordinator: Reviews new referrals to make sure we have enough info and that the info is accurate. Follows up on new and returning appointments, and tests.

Clinic nurse: Takes your blood pressure and heart rate, asks how you are feeling, and reviews your medications and family history.

Genetic counsellor: Reviews your family history, talks about possible genetic testing, and may give you info to share with your family.

Research coordinator: You may be invited to take part in research studies. This may include registries/databases (collection of patient info). It is up to you if you want to take part. Your choice will not affect your care.

Cardiologist (heart doctor): Reviews your medical history, gives you test results, and talks about any further tests, treatment options, or other followup.

How do I get referred to the Clinic?

- You must be referred by your primary health care provider or cardiologist.
- Once we receive your referral, we will mail you a family history questionnaire. **Your answers are very important to help us evaluate you.** You can return this form by email, fax, mail, or bring with you to your appointment.

How do I get ready for my appointment?

- We will mail you your appointment time and date. One week before your appointment, you will get an automated reminder phone call. **If your address or phone number changes after the date of your referral, please tell the IHD Clinic right away. If you cannot attend your scheduled appointment, let us know as soon as possible by calling 902-473-8517. This lets us book another patient in your timeslot.**
- We will schedule some tests for you to do before your appointment. These tests will depend on the reason for your referral.

Tests MAY include:

- **Electrocardiogram (ECG):** A recording of your heart rhythm for 10 to 20 seconds.
- **Echocardiogram (Echo):** An ultrasound is used to measure the size of the heart chambers and how well the heart is pumping.
- **Exercise stress test:** A recording of your heart rhythm and blood pressure while you exercise on a treadmill.
- **Holter monitor:** A recording of your heart rhythm for 24 hours (1 day).
- **Genetic testing:** A blood sample may be collected to try and determine if there is a specific genetic change in your DNA that has caused your heart condition.

- **Cardiac MRI:** A scan using magnets and radio waves. It can measure the size of the heart chambers, how well the heart is pumping, and give info about the type of disease affecting the heart muscle.


How do I register for my appointment?

Go to the kiosk on the 4th floor of the Halifax Infirmary building, Robie Street entrance. Cardiac tests are done on the 3rd floor. The Clinic is on the 6th floor.

What will happen during my appointment?

- You may meet with several Clinic team members. This will depend on the reason for your referral. **Your visit may take several hours.**
- **All of our team members work together to develop the plan of care that is best for you.**

What will happen after my appointment?

- We will send the health care providers involved in your care a letter about your appointment. We may also arrange for you to have further followup tests and Clinic appointments.
 - **If you are having genetic testing, the genetic counsellor will contact you directly to review your results.**
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Followup appointments

- Followup appointments will be different for each person. The average time before a followup visit is 1 to 2 years.
- We will schedule some tests for you to do before your appointment. These tests will depend on the reason for your referral.
- Your followup appointment will be much like your first visit, but you will not have to complete the family history questionnaire again.
- You may meet with several Clinic team members. This will depend on the reason for your referral. Your visit will take about 30 minutes.

Research

- The Clinic takes part in research studies and registries. If you would like more info, please call 902-473-5341.
- You can also find info on our research registries at Hearts in Rhythm Organization:
 - › www.heartsinrhythm.ca

FAQs

Why do I need to go to the Clinic if I'm feeling well?

Heart problems can be genetic. This means you may have an abnormal gene that could cause a heart problem to show up at any time. This is why we do new and followup visits to look for any changes in your test results.

What if my child/children (under 16 years old) needs to be seen?

Children under 16 years old are referred to the IWK Health Centre at 5850 University Avenue, Halifax, Nova Scotia, B3K 6R8.

What should I do if I can't make my test or Clinic appointment?

If you cannot attend your scheduled appointment, let us know as soon as possible by calling 902-473-8517. This lets us book another person in your timeslot.

Who can I call if I have questions?

Program Coordinator:

- › Vicki Newman-Burd
- › 902-473-5341

Looking for more health information?

Find this pamphlet and all our patient resources here:

<http://library.nshealth.ca/PatientGuides>

Contact your local public library for books, videos, magazines, and other resources. For more information, go to <http://library.novascotia.ca>

Connect with a registered nurse in Nova Scotia any time:

Call 811 or visit <https://811.novascotia.ca>

Learn about other programs and services in your community:

Call 211 or visit <http://ns.211.ca>

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The information in this pamphlet is to be updated every 3 years or as needed.