

The Jordan Boyd Inherited Heart Disease Clinic

Halifax Infirmary

Please bring these with you to your appointments:

- A list of all your medications (including prescription and over-the-counter products, inhalers, creams, eye drops, patches, herbal products, vitamins, and supplements)
- A list of the health care providers involved in your care
- Any family history information (like a family tree, genetic information, or autopsy reports)

The Jordan Boyd Inherited Heart Disease Clinic

- The Jordan Boyd Inherited Heart Disease Clinic is for people with a suspected or diagnosed heart problem that may be inherited (passed from parents to their children). The Clinic offers genetic testing (blood tests) and helps people manage their condition.
- You can be diagnosed with an inherited heart disease at any age. You may have a wide range of symptoms, from no symptoms at all to sudden cardiac death (your heart stops working).
- It may take up to 12 months (1 year) or more to get an appointment at the Clinic. You will need some tests before your Clinic visit. This may make your wait time longer. **If you feel you need to be seen sooner, talk to the health care provider who referred you to the Clinic.**

Clinic team members

Program coordinator: The program coordinator receives and follows up on new referrals. They may call you to check the information in your referral. They will also follow up with you about your appointments and tests.

Clinic nurse: The nurse will:

- › Take your blood pressure and heart rate
- › Ask you about your health and how you are feeling
- › Ask you about your medications and your family history

Genetic counsellor: The genetic counsellor will look at your family history. They will talk with you about genetic testing. They may give you information to share with your family.

Research coordinator: The research coordinator may ask if you would like to take part in a research study. This may include registries or databases (collections of patient information).

You are allowed to say no. You will have the same care whether or not you choose to take part in a research study.

Cardiologist (heart doctor): The cardiologist will:

- › Look at your medical history
- › Give you your test results
- › Talk with you about tests, treatments, or follow-up care that may help you

How do I get referred to the Clinic?

- You must be referred to the Clinic by your primary health care provider (family doctor or nurse practitioner) or cardiologist.

- When we get your referral, we will mail you a form with questions about your family history. **Your answers are very important to help us assess (check) you.**
- You can send the form by email, mail, fax, or bring it with you to your appointment. Information on where to send the form back is included on the form.

How do I get ready for my appointment?

- We will mail you your appointment time and date. You will get an automated reminder call **1 week before your appointment.**
- If your address or phone number changes after the date of your referral, **please call the Clinic right away.**

If you cannot come to your scheduled appointment:

Call to tell us **as soon as you can.** This lets us book another person in your timeslot.

› Phone: 902-473-8517

- We will schedule some tests for you before your appointment. What tests you have will depend on why you were referred to the Clinic.
- We will mail you your test appointment times and dates. You will get an automated reminder phone call **1 week before your appointments.**

Possible tests:

- › **Electrocardiogram (ECG/EKG):** A recording of your heart rhythm for 10 to 20 seconds.
- › **Echocardiogram (Echo):** An ultrasound that measures the size of your heart chambers and how well your 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 find 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 measures the size of your heart chambers, how well your heart pumps, and gives information about the type of disease affecting your heart.

How do I register for my appointment?

- Enter through, or go to, the Summer Street main floor entrance at the Halifax Infirmary Site of the QE II. Register at a kiosk.
- Then, go to the 3rd floor of the Halifax Infirmary. The Clinic and cardiac testing are both on the 3rd floor.

What will happen during my appointment?

- You may meet with several Clinic team members. This will depend on why you were referred to the Clinic.
- Your appointment may take several hours.
- **All of our team members work together to make a plan of care that is best for you.**

What will happen after my appointment?

- We will send your health care providers a letter about your appointment.
- We may arrange follow-up tests and Clinic appointments for you.

If you are having genetic testing:

- › The genetic counsellor will call you directly to review your results.

Follow-up appointments

- Follow-up appointments will be different for each person. Follow-up appointments are usually in 1 to 2 years.
- We will schedule some tests for you to do before your appointment. What tests you have will depend on why you were referred to the Clinic.

- Your follow-up appointment will be a lot like your 1st visit, but you will not have to fill out the family history form again.
- You may meet with several Clinic team members. This will depend on why you were referred to the Clinic. Your follow-up visit will take about 30 to 45 minutes.

Research

- The Clinic takes part in research studies and registries.
 - › For more information, call 902-473-5341
- For information about our research registries at Hearts in Rhythm Organization:
 - › www.heartsinrhythm.ca

Frequently Asked Questions (FAQs)

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

- Heart problems can be inherited (passed from parents to their children). This means you may have an abnormal gene that could cause a heart problem to show up at any time. This is why we:
 - › Take new referrals
 - › Do follow-up visits to look for any changes in your test results

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

- Children under 16 years old are referred to the IWK Health Centre.

What if I cannot attend my test or Clinic appointment?

- Call 902-473-8517 to tell us **as soon as possible**. This lets us book another person in your timeslot.

Who can I call if I have questions?

- You can call the Program Coordinator at:
 - › Phone: 902-473-5341

This pamphlet is for educational purposes only. It is not intended to replace the advice or professional judgment of a health care provider. The information may not apply to all situations. If you have any questions, please ask your health care provider.

Connect with a registered nurse in Nova Scotia any time:
Call 811 or visit: <https://811.novascotia.ca>

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