Supplementary Appendix 1: National HiRO Registry Participant Consent Form

Participant Information and Consent Form

Title: Hearts in Rhythm Organization (HiRO) National Registry and Bio bank:

Improving Detection and Treatment of Inherited Heart Rhythm Disorders to Prevent Sudden Death

Short Title: National HiRO Registry and Bio bank

Principal Investigator: Dr. Andrew Krahn MD, FRCPC FHRS
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Vancouver BC V6E 1M7

Dr. Krahn is a member of the Department of Medicine at the University of British Columbia.

Inherited Heart Rhythm Research Office: XXX-XXXX

Note: If you are a parent or legal guardian of a child who may take part in this study, permission from you and the assent (agreement) of your child may be required. When we say "you" or "your" in this consent form, we mean you and/or your child.

Funding Source: This project is being financially supported by a grant from the Canadian Institutes of Health Research.

INVITATION
You are being invited to consider participating in this research registry because you or a first-degree (blood-related mother, father, sister, brother or child) family member are being investigated for or have been diagnosed with an inherited heart rhythm condition.

YOUR PARTICIPATION IS VOLUNTARY
Your participation is voluntary. You have the right to refuse to participate in this study. If you decide to participate, you may still choose to withdraw from the registry at any time without any negative consequences to the medical care, education, or other services to which you are entitled or are presently receiving.

When you participate in research, the main goal is to learn things to help improve healthcare for patients in the future. Outside of research, your doctor's sole goal is to care for your health. Researchers as well have a "duty of care" to all their research participants.

Before you decide whether you will participate, it is important for you to understand what the research project involves. This consent form will tell you about the research registry, why it is being done, what will happen to you during your participation and the possible benefits, risks and discomforts. Please review this consent document carefully when deciding whether or not you wish to be part of the registry and sign this consent only if you agree to participate. You might like to discuss this with your family, friends, and doctor before deciding.

WHO IS CONDUCTING THE STUDY?
Dr. Andrew Krahn, is leading the registry from the University of British Columbia, at St. Paul's Hospital in Vancouver, BC. He will partner with other Canadian Inherited Heart Rhythm clinics to recruit participants, in Halifax, Hamilton, Ottawa, Toronto, Montreal, Quebec, Kingston, London On., Calgary, Edmonton, Winnipeg and Victoria.

BACKGROUND
Inherited (meaning passed from parent to child) heart rhythm conditions can cause fainting, cardiac arrest and in some cases sudden death and affect thousands of Canadians under the age of 60. The conditions vary in severity of the signs and symptoms, so they are poorly understood by most healthcare providers.

Inherited conditions usually affect more than one family member. These conditions are rare, difficult to diagnose and require a wide range of cardiac diagnostic testing. Sometimes all the testing does not provide a clear diagnosis or treatment plan. Occasionally the first sign of the condition can be a cardiac arrest or sudden death of a child or a young adult.

The National HiRO research team believes that patients and their families are interested in learning more about these complicated conditions. This research registry and permission to contact for future research will assist the researchers/clinicians in improving their understanding of these conditions and will also help them to contact inherited heart rhythm families for future research projects.

This registry is a collection of healthcare information into a computerized data system designed to reflect current patterns of practice without influencing the treatments or interventions described. In

its purest form, a registry is intended to include all cases of a particular disease, or condition, in a given region or country. Registries often go on for years or even decades, increasing our understanding of a disease or condition and it's progression over an extended period for a large group of individuals. Your participation in the HiRO Registry is expected to last for the duration of the project which is most likely to be indefinite.

The National HiRO research team hopes to gather data on 10,000 participants across Canada by June 2025. This registry has been designed to provide an accurate picture of the Canadian inherited heart rhythm patient population and to help determine who might be at risk for a life threatening cardiac event.

WHAT IS THE PURPOSE OF THE STUDY?

Inherited heart rhythm conditions are rare and complex. Cardiologists have many questions about how best to diagnose and treat these patients and the families who may also be affected. Gathering the healthcare information from individuals and their first degree family members with inherited heart rhythm conditions and sudden unexplained cardiac arrest will lead cardiologists and other healthcare providers to a better understanding of these conditions and hopefully lead to improved care.

The information gathered with this registry may lead to other research projects. The data may also be shared or pooled with other researchers in Canada or internationally.

WHO CAN PARTICIPATE IN THIS STUDY?

You are able to participate in this study if you:

- Are willing and able to provide informed consent for this study or have a parent or guardian who will consent on your behalf
- Have been investigated for or diagnosed with an inherited heart rhythm

Or

- Are a first-degree family member of someone diagnosed with an inherited heart rhythm condition or an unexplained cardiac arrest

WHO SHOULD NOT PARTICIPATE IN THIS REGISTRY?

You should not participate in this registry if you:

- Do not want to share your healthcare information for research
- Have not received care or testing for an unexplained cardiac arrest or an inherited heart rhythm condition

  Or
- Are not a first-degree family member of someone with an inherited heart rhythm condition or an unexplained cardiac arrest

WHAT DOES THE REGISTRY INVOLVE?

This study is designed to collect all of your healthcare information that relates to your inherited heart rhythm diagnosis, or unexplained cardiac arrest. If you are a family member participating, we will collect all the tests and results that you will have to help determine whether you too are at risk. You will not be required to do anything out of your standard medical care for someone examined or treated for an inherited heart rhythm condition or an unexplained cardiac arrest. If you are not seen

in the heart rhythm clinic regularly we may telephone you just to stay updated with your heart health. Once you have signed this consent form your healthcare information will be collected. It will include your:

- Healthcare history
- Race
- Sex
- Height, weight, age, blood pressure
- Medications
- Family cardiac history
- Results from all of your cardiac tests such as Magnetic Resonance Imaging (MRI), Echocardiogram, Electrocardiograph (ECG), stress test, Electrophysiology study with voltage mapping and genetic testing results
- A family tree/pedigree will be constructed by your research staff (doctor or coordinator)
- Any other testing done that may be related to your heart health will also be collected

Your healthcare information will be given a unique study code that will identify your research information. All of your personal information will be removed such as your name, healthcare number, date of birth, address and social insurance number. This data will be copied into a research data base housed on the Amazon Virtual Private Network (IP Address:XXXXX), and will be backed up on University of British Columbia Research Server (2405 Wesbrook Mall, Vancouver, BC V6T1Z3).

Follow Up
Most patients with inherited heart rhythm conditions or sudden unexplained cardiac arrest are seen at least once a year by their heart rhythm specialist. When you see your heart rhythm specialist your healthcare information will be collected and entered into the registry.

Your healthcare information will be collected indefinitely or at least until 2025. It is important for you to understand that the information gathered into the registry will be governed by the study investigators, and Dr. Krahn will have the ultimate responsibility for the data. In the future there may be other researchers at other institutions in Canada and internationally that may ask to share the data that is gathered. Sharing information amongst researchers is important for improving understanding and medical treatment of rare conditions. No information that could identify you will be shared with anyone outside of Dr. Krahn's research team. You will not be contacted for future use of the coded information in the registry with other researchers. Your research information will not be sold for profit.

Optional Studies
You do not have to participate in research to be cared for by the doctors and other healthcare professionals in the University of British Columbia/Vancouver Inherited Arrhythmia Clinic.

1. Bio Bank:
   You are also eligible to participate in an optional bio bank arm of this registry, which means that we will ask you to donate a blood sample to store for research testing in the future. If you would like to participate in this optional study, we will give you a separate Participant Information and

Consent Form that describes the research and any associated risks and benefits so that you can decide if you would like to participate.

2. Next of Kin Consent: Post-Mortem (after death) Specimens for Research

The researchers would like also to collect healthcare information and bio specimens (materials taken from the human body, such as tissue, blood, plasma) from patients who have died from an unexplained cardiac arrest or inherited heart rhythm condition. This is being done to learn more about these rare complex cases in order to help prevent unexplained cardiac arrest. To be able to use the deceased's healthcare information and bio specimens for research, it is necessary for us to obtain the permission of the next of kin (NOK).

Future Research

By signing this consent form, you authorize the research team to enter your health information in the HiRO Registry and use your HiRO Registry data for approved research studies, currently and in the future. Any subsequent research studies looking to access the data system for research purposes related to the core goals for which the data was originally collected will require review and approval by the Research Ethics Board that the primary researcher is affiliated with.

Future Contact

If you agree to participate in the HiRO Registry, Dr. Andrew Krahn or a member of his research team may use your health information for future research on inherited heart rhythm conditions.

Studies involving genetics now routinely collect information on race and ethnic origin because of the inherited nature of the conditions being studied. Providing information on your race or ethnic origin is voluntary. The HiRO Registry may also be used to identify potentially eligible research participants based on their genetic testing information if the participant has agreed to future contact for research participation.

The information that we are collecting during this research will help to identify those who may be eligible to participate in future research projects that involve more than just an analysis of existing data. In that case you will be contacted by Dr. Krahn or his research staff (in clinic, by phone or by email) to see if you are interested and to be given detailed information describing the research, so that you can decide whether or not you want to participate.

In rare cases there may be future findings about your heart health that are important to report to you. In this case Dr. Krahn will meet with you to explain the findings and how it might affect your care and lifestyle.

The information that we find from the research must first be checked carefully by the doctors who take care of you, to make sure it is relevant to you, before they use it for your care.

WHAT ARE THE POTENTIAL RISKS OF PARTICIPATING?

Taking part in this registry will not put you at any physical risk. The only known risk to your participation would be that your research information may be linked to your healthcare records that may identify you. However the research information is secured with the same consideration as your clinical records and access is limited to research personnel only. As public bodies, University of

British Columbia and Providence Health Care must follow the rules of BC Freedom of Information and Protection of Privacy Act.

In addition to the risks of physical harms outlined in this consent form, there are also possible non-physical risks associated with taking part in this study. For example, disclosure of genetic or tissue marker research data could result in discrimination by employers or insurance providers toward you or your biological (blood) relatives. The chance that research data would be released is estimated to be small.

When you donate your blood or tissue for genetic testing or research, you are sharing genetic information, not only about yourself, but also about biological (blood) relatives who share your genes or DNA. The risk of your information being accidentally released in this study is estimated to be low. A recently passed Federal (Canada-wide) law now prohibits anyone such as an employer or an insurer from requiring you to disclose the results of a genetic test or to take a genetic test as condition of providing services. You should be aware that this law is likely to be challenged on the basis of whether or not the Canadian government had the legal ability to approve it. If the challenge is successful, it might be possible in the future for an organization to require you to reveal your genetic results and / or to discriminate against you based upon your genetic characteristics.

WHAT ARE THE POTENTIAL BENEFITS OF PARTICIPATING?
There may be no direct benefits to you as a result of your participation in this study. However, information obtained during this study may benefit other patients who have a clinical condition similar to yours. Similarly, data from other participants in the study may shed light on cases such as yours. You will be helping to advance the knowledge and understanding of inherited heart rhythm conditions.

WHAT ARE THE ALTERNATIVES TO PARTICIPATING?
If you choose not to participate in this registry, your information will not be collected. Your decision not to participate will not affect any treatment that you receive. There will be no disadvantages should you decide not to participate in this study.

WHAT IF NEW INFORMATION BECOMES AVAILABLE THAT MAY AFFECT MY DECISION TO PARTICIPATE?
If you choose to participate and at a later date new information becomes available that may affect your willingness to continue your participation, you will be notified.

WHAT HAPPENS IF I DECIDE TO WITHDRAW MY CONSENT TO PARTICIPATE?
You may withdraw from this study at any time without giving reasons. If you choose to enter the study and then decide to withdraw at a later time, the study team will have a discussion with you about what will happen to the information about you [and/or your samples] already collected. You have the right to request the destruction of your information [and/or samples] collected during the study, or you may choose to leave the study and allow the investigators to keep the information already collected about you until that point.

If you choose to have the data collected about you destroyed, this request will be respected to the extent possible. Please note however that there may be exceptions where the data [and/or samples] will not be able to be withdrawn for example where the data [and/or sample] is no longer

identifiable (meaning it cannot be linked in any way back to your identity) or where the data has been merged with other data. If you would like to request the withdrawal of your data [and/or samples], please let your study doctor know. If your participation in this study includes enrolling in any optional studies, or long term follow-up, you will be asked whether you wish to withdraw from these as well.

CAN I BE ASKED TO LEAVE THE STUDY?
At any time during your participation, the research doctor (investigator) may wish to take you out of the registry or may discontinue the registry. If this happens, the reasons will be explained to you and you will have the opportunity to ask questions about this decision.

HOW WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?
Your confidentiality will be respected. However, research records and health or other source records identifying you may be inspected in the presence of the Investigator or designate by representatives of the University of British Columbia Providence Health Care Research Ethics Board for the purpose of monitoring the research. No information or records that disclose your identity will be published without your consent, nor will any information or records that disclose your identity be removed or released without your consent unless required by law.

You will be assigned a unique study number (code) as a participant in this registry. This number will not include any personal information that could identify you (e.g., it will not include your Personal Health Number, social insurance number, your initials, day of birth etc.). Only the study code number will be used on any research-related information collected, so that your identity will be kept confidential.

Information that contains your identity will remain only with Dr. Krahn and/or a designate and kept in a secure location in the research office of Dr. Krahn and his research staff. The list that matches your name to the unique study code number will not be removed or released without your consent unless required by law.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you the right of access to the information about you that has been entered in this research registry and if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request to your study doctor.

In the future the researchers may want to share the information collected about you with other doctors and scientists outside of Canadian borders. This may increase the risk of disclosure of information because the laws in those countries (for example the Patriot Act in the United States) dealing with protection of information may not be as strict as in Canada. However, all study related data [and samples], that might be transferred outside of Canada will be coded (this means it will not contain your name or personal identifying information) before leaving the study site. By signing this consent form, you are consenting to the future possibility that your coded information might be transferred to research organizations located outside of Canada.

Your de-identified research data may be published or deposited into a publicly accessible location at the time of publication. This data could include your age, sex, genetic testing results and clinical diagnostic testing results. At no time will identifying information, such as your name, birth date or

street address be included in such data. This enhances the transparency of the research, but also allows others to access the data. This should not increase risks to you, but it does mean that other researchers may analyze the data for different reasons other than those described in this consent form. Once data is made publicly available, you will not be able to withdraw your data. The extent of the risk of you being identified through public data is unknown, but currently appears to be low.

WHAT HAPPENS IF SOMETHING GOES WRONG?
By signing this form, you do not give up any of your legal rights and you do not release the study doctor, participating institutions or anyone else from their legal and professional duties.

WHAT WILL MY PARTICPATION COST ME?
Your participation will not cost you anything. You will not be paid for your participation. In the long term, the results from this project may be valuable for commercial and/or intellectual (for example patent) purposes. It is important that you realize that you will not have any claim on or receive any money from products that may result from this long term investment.

WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING MY PARTICIPATION?
If you have any questions or desire further information about this study before or during participation, you can contact Dr. Andrew Krahn or the research coordinator at XXX-XXXX.

A description of this registry and bio bank will be available on http://www.ClinicalTrials.gov, as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT MY RIGHTS AS A PARTICIPANT?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at XXXX or by phone at XXX-XXXX. Please reference study number XXXX so that the Complaint Line staff can better assist you.

If you want to participate in this study, please sign the consent form and return it to us in one of the following ways:
In person to: Dr. Andrew Krahn or the research coordinator,
By mail : Dr. Andrew Krahn, HiRO research office, room 220, 1033 Davie St. Vancouver BC V6E 1M7
By fax: XXX-XXXX
By email XXXXXXX
NOTE: Personal information that you send in email could be at risk if an email account is compromised. It is your responsibility to protect your accounts from inappropriate access and/or loss."

Title: Hearts in Rhythm Organization (HiRO) National Registry and Bio bank: Improving Detection and Treatment of Inherited Heart Rhythm Disorders to Prevent Sudden Death

PARTICIPANT CONSENT

My signature on this form means:

- I have read and understood the information in this consent form.
- I have had enough time to think about the information provided. I have been able to ask for advice if needed.
- I have been able to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific purposes.
- I understand that my participation in this study is voluntary.
- I understand that I am completely free at any time to refuse to participate or to withdraw from this study at any time, and that this will not change the quality of care that I receive.
- I authorize access to my health records as described in this consent form.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to me.

The parent(s)/guardian(s)/substitute decision maker (legally authorized representative) and the Investigator are satisfied that the information contained in this consent form was explained to the child/participant to the extent that he/she is able to understand it, that all questions have been answered, and that the child/participant assents to participating in the research.

- I will receive a signed copy of this consent form for my own records.
- I consent to participate in this registry.

Participant's Signature	Printed Name	Date
Parent/Legal Guardian/Substitute Decision Maker Signature	Printed Name	Date

Signature of Person Obtaining Consent	Printed Name	Study Role	Date

If this consent process has been done in a language other than that on this written form, with the assistance of an interpreter/translator, indicate:

Language: _____

Signature of Translator_____ Printed Name _____Date_____

Was the participant assisted during the consent process in one of the ways listed below:

Yes ____ No _____
If yes check the relevant box and complete the signature space below:

_____ The consent form was read to the participant, and the person signing below attests that the study was accurately explained to, and apparently understood by, the participant (please check if participant is unable to read)

_____ The person signing below acted as an interpreter/translator for the participant during the consent process (please check if an interpreter/translator assisted during the consent process).

Signature of Person Assisting Printed Name

_____ _____

Role in the consent discussion _____

Consent to be Contacted for Research in the Future

We would also like to ask that you consider providing consent to be contacted about future research studies. The information that you should consider before agreeing to this is outlined below.

Dr. Krahn or his research team will contact you, your name and contact information will be stored on a computerized, password protected computer file that only Dr. Krahn and his team will have access to.

You may be contacted by mail, telephone, or email.

You are not obligated to participate in any research studies that you are contacted about.

You can remove your name from this recontact list at any time that you do not wish further contact by letting Dr. Krahn or his research team know either in person or by phoning: XXX-XXXX

It will be your responsibility to keep your contact information up to date so that you can be contacted.

Statement of Consent – Future Contact for Research Purposes

I have read the above information, and I agree to be contacted for future research as described above.

_____	_____	_____
Participant Name (print)	Participant Signature	Date

Supplementary Appendix 2: HiRO National Registry Core Data Variables & Definitions

Variable:	Options: (Definition)
Patient:	
Date of Birth	15-mm-yyyy
Ethnicity	Aboriginal (e.g. Inuit, Métis, North American Indian) Arab/West Asian (e.g. .Armenian, Egyptian, Iranian, Lebanese, Moroccan) Black (e.g. African, Haitian, Jamaican, Somali) Chinese Filipino Japanese Korean Latin American South Asian South East Asian White (Caucasian) Other Unknown
Sex	Male Female
Referral:	
Date 1st Assessment	dd-mm-yyyy **Note:** Refers to date the patient was first evaluated/seen by the inherited arrhythmia team. This may be the same date as the registry date of enrollment, or prior. For example, if the patient was first seen in clinic in 2014 but not consented to research until 2016, the date of first assessment will be in 2014.
Baseline Consult Upload:	Please upload an anonymized consult letter corresponding with the date above.
Referral Reason	**Symptomatic Patient:** The patient is being evaluated because of symptoms *attributed to IA/ICM conditions.* **Asymptomatic Family Member:** The patient was referred for evaluation because a family member has (or is suspected of having) an inherited arrhythmia. But, the patient DOES NOT have any symptoms *attributed to IA/ICM conditions.* **Symptomatic Family Member:** The patient was referred for evaluation because a family member has (or is suspected of having) an inherited arrhythmia. The patient has had symptoms *attributed to IA/ICM conditions.*

	Asymptomatic Primary Referral: The patient is being evaluated due to incidental findings of a possible IA/ICM, but has no symptoms *attributed to* an IA/ICM condition
Symptoms at Baseline	Pre-syncope (suspected arrhythmic) Syncope (suspected arrhythmic) Palpitations Chest Pain Cardiac Arrest Death Other **Note**: Only included symptoms the patient had **before** enrolling in research; symptoms experienced after enrollment will be entered under 'follow-up'. Multiple symptoms can be selected. Other refers only to symptoms relevant to IA/ICM conditions. Example is congenital deafness
Cardiac Arrest Date	dd-mm-yyyy **Note:** If the patient had more than one cardiac arrest prior to enrollment, please enter the date of the first cardiac arrest
Circumstances of Symptoms	Rest Mild Activity Exercise Swimming Auditory Stimulus Sleep Other **Note:** Should a patient have symptoms under multiple circumstances (ex. syncope both at rest and mild activity) select the option where symptoms occur most frequently
Circumstances of Sudden Death	Rest Mild Activity Exercise Swimming Auditory Stimulus Sleep Other
Family History:	
Sudden Death in Family?	Yes No
Actual Age of Death	Numerical
Estimated Age of Death if actual age not known	Numerical
Sudden Death Under 40?	Yes – Age <40

	Yes – Age = 40 No
Circumstances of Sudden Death	Rest Mild Activity Exercise Swimming Auditory Stimulus Sleep Other
Relationship of Patient to Sudden Death Family Member: **Note:** The patient is the _____ of the sudden death victim.	Sibling Child Parent Second Degree Relative *(e.g. grandparent, aunt/uncle, niece/nephew, grand-child, half-siblings)* Third Degree Relative *(e.g. first cousins, great-grandparents, great aunt/uncle, great niece/nephew)* **Note:** If a *patient's child* had a sudden unexpected death, the relationship of the patient to the sudden death victim is "parent" since the patient is the parent of the sudden death victim.
Working Diagnosis in Sudden Death Family Member [1]	ARVC (*includes PLN*) Brugada Syndrome CPVT DCM (*includes Lamin and other Mendelian causes*) Short Coupled VF ERS HCM LQTS Myocarditis SQTS Polymorphic VT Unaffected/Normal Acquired LQTS LVNC UCM Malignant Mitral Valve Prolapse Syndrome Pause Dependent VT/VF Unclassified Genetic Variant Carrier Sudden Arrhythmogenic Death Syndrome (SADS)[2] Sudden Unexplained Death Syndrome (SUDS)[3] [1] Please see appendix 1 for diagnosis definitions [2] SADS refers to deaths with a negative autopsy [3] SUDS refers to deaths with no autopsy performed
Living Relatives with an UCA/IA/ICM?	Yes No

	Unknown
If Yes: **Note:** For families with a complex family history, please upload a pedigree	Family History of UCA Family History of Brugada Family History of CPVT Family History of HCM Family History of LVNC Family History of DCM Family History of LQTS Family History of ARVC Family History of Other:____
Please select which family member(s) have been diagnosed:	Mother Father Sibling(s) Children Second Degree Relatives *(e.g. grandparent, aunt/uncle, niece/nephew, grandchild, half-siblings)* Third Degree Relatives *(e.g. first cousins, great-grandparents, great aunt/uncle, great niece/nephew)*
Total Number of Affected Relatives:	Numerical Value
Pedigree Upload	*Optional*
Diagnosis:	
Date of Diagnosis:	dd-mm-yyyy **Note:** This may be prior to enrollment or prior to first IA clinic visit. If only year of diagnosis is known, please enter "01-01-yyyy".
Working Diagnosis:	ARVC (*includes PLN*) Brugada Syndrome CPVT DCM (*includes Lamin and other Mendelian causes*) Short Coupled VF ERS HCM LQTS Myocarditis SQTS UCA/IVF Polymorphic VT Unaffected/Normal Acquired LQTS LVNC UCM Malignant Mitral Valve Prolapse Syndrome Pause Dependent VT/VF Unclassified Genetic Variant Carrier Sudden Arrhythmogenic Death Syndrome

	Note: The working diagnosis is the most likely current diagnosis as determined by symptoms, clinical and genetic testing, and family history. Should be assigned by local investigator according to diagnosis definition guidelines.
Basis of Diagnosis	**Phenotype:** Clinical testing and/or patient symptoms suggest a diagnosis **Genetic Testing:** Genetic testing suggests a diagnosis **Phenotype & Genotype:** A combination of clinical testing, patient symptoms and genetic testing suggest a particular diagnosis **Other:** Ex. Patient is an asymptomatic obligate carrier of a pathogenic mutation
Strength of Diagnosis[1]:	Consult appendix 1 for disease-specific definitions.
If Unaffected/Normal with no family history: Reason for Evaluation	Possible ARVC Possible LQTS Possible Brugada Possible Cardiomyopathy History of Syncope
Co-Morbidities	Previous Atrial Fibrillation: Age of Onset: Hypertension Heart Failure (HFREF)
Genetics:	
Genetic Testing Performed?	Yes No
Indication for Testing	**Family Specific:** Testing done to determine whether a patient has a variant previously identified in a family member. Family specific testing refers to a single variant or mutation being tested (i.e. testing only one location on one gene) **Comprehensive:** Testing done in an attempt to find a genetic variant explanatory for the patients phenotype (i.e. testing the entire sequence of one or more genes)
If Comprehensive: Test Type	Single Gene Gene Panel *(Sequencing Only or Sequencing + Del/Dup)* Whole Exome Sequencing Whole Genome Sequencing

Genetic Testing Result:	Negative (No P/LP/VUS identified) Positive (At least 1 P/LP identified) Uncertain (No P/LP, with at least 1 VUS)
If Result Positive or Uncertain: Mutation Type	Pathogenic Likely Pathogenic Variant of Uncertain Significance Likely Benign Benign **Note:** Definitions are according to the ACMG 2015 criteria. If entering a genetic test result from a report in which the variant has since been re-classified, please enter the **current** classification.
Gene:	Select from the list of genes tested **Note**: If gene is not included in the list above, please enter the gene name in the "test notes" section
Test Notes:	Any additional variant details
Genetic Document Uploads:	Genetic Testing Report (PDF) Clinical VCF/BAM Files Research VCF/BAM Files
Devices:	
ICD	Yes No
History of appropriate shocks prior to time of enrollment?	Yes No
Biobank	
Study:	CASPER (stored in Montreal) ARVC (stored in Hamilton) LQTS (stored at UBC Vancouver) HiRO Sample (stored at UBC Vancouver) Local Sample Available Sequencing Data Available (VCF/BAM/FASTQ Files)
If Local Sample: Type:	Whole Blood Serum Isolated DNA
Sample Shipped?	Yes No
Location where sample sent	Center for HLI (Vancouver) Montreal HI Population HRI (Hamilton) Other: _____
Research Sequencing Data Type Available:	VCF – Panel VCF - WES BAM – WES/WGS FASTQ – WES/WGS
Tests:	

Please select tests performed as part of baseline evaluation:	Adrenaline Coronary Angiogram Cardiac CT ECG [*Prompt to Upload]* Echo EP Study High Lead ECG Monitoring MRI Procainamide RV Angio RV Bio SAECG Exercise test
HiRO Registry:	
Date Enrolled:	dd-mm-yyyy **Note:** Date patient signed consent form
Uploads:	Optional

Supplementary Appendix 3: Example of Documents in HiRO Clinical Care Toolkit*: LQTS Family Letter – Mutation Found Template*

Title of PROGRAM

_____Hospital
Address
Tel:
Fax:

Adult Electrophysiology

John Doe, MD

Jane Doe, MD

https://heartsinrhythm.ca

DATE

Dear family member:

We are writing as we have seen your relative [patient name] in our Inherited Arrhythmia Program at (hospital or city). As you may know, [patient name] has a diagnosis of Long QT syndrome (LQTS). During our appointment with your [patient name] we discussed the importance of his/her relatives being screened for Long QT syndrome and we asked him/her to share this letter with you.

What is Long QT Syndrome (LQTS):
LQTS is a genetic condition which affects the heart's electrical system. People who inherit LQTS may experience heart dizzy spells, fainting episodes or no symptoms at all. A small number of people with this condition suffer a sudden cardiac arrest. Knowing if you have LQTS is important because there are lifesaving treatment options available and lifestyle changes which can be made. People who have LQTS should avoid certain medications which are listed on www.crediblemeds.org (and associate smartphone app), and www.qtdrugs.org.

Genetics of LQTS in Your Family:
Your relative underwent genetic testing (by sequencing) for XX genes associated with LQTS at xx laboratories on (date). A variant in the XX gene was found; XXXX. Based on what is known about this variant at this time, we expect it to be the explanation for [patient's name] diagnosis of LQTS.

As a Family Member, What Do I Need to Know?
Each of [patient name]'s first degree relatives (parents, and brothers/sisters) have an up to 50% chance of inheriting the XXX gene variant. Genetic testing for the XXX gene variant is available

to these relatives by means of a blood or salvia test and after an appointment in an inherited heart rhythm clinic or with a genetic counsellor. We recommend that genetic testing be arranged after a clinical evaluation in a heart rhythm clinic. The blood test cannot usually be arranged by a family doctor.

What Should I do Next?
If you would like to have genetic testing, please bring this letter to your family doctor (or other health care provider) and ask for a referral to the Inherited Arrhythmia Program by faxing it to XXX-XXX-XXXX. You can also call our clinic for referral information. A list of Canadian centers with experience in inherited heart rhythm conditions such as LQTS can be found at https://hiro.heartsinrhythm.ca/find_a_clinic

The heart tests that are typically recommended for a first degree relative of a person with LQTS are:

- a 12 lead resting ECG

While you are waiting for an appointment, your family doctor can arrange for a resting 12 lead ECG and clinical exam. Most patients will have a stress test arranged by the heart rhythm clinic.

Also, you and your family members are invited to participate in research projects developed to better understand these conditions. We are part of a national network of clinics that focus on inherited heart rhythm conditions.

We strongly recommend that all first degree relatives speak to their family doctors about this history as simple, life-saving treatment is available.

Please do not hesitate to contact us if you have any questions or concerns at XXX-XXX-XXXX ext. XXXX

Sincerely

, MSc., CCGC or CGC
Genetic Counsellor

, MD, FRCPC

Supplementary Appendix 3: Example of Documents in HiRO Clinical Care Toolkit:
Template Outline of Appointment Letter

Dear Patient/Family:

Welcome to the XXXXXXXXXXXXX. As you may know, we are a health care program that coordinates the care of patients and their families who have have an unexplained cardiac arrest, are suspected to have an inherited heart rhythm condition or have a family history of sudden unexpected death. Arriving at a diagnosis and a treatment plan (if necessary) for you and your family is very important, but can sometimes be challenging. For this reason, we work as a team, with health care providers from cardiology, medical genetics and research. Below, you'll find an outline of your appointment, including all the team members that you will meet, and their roles within the program.

*Clinic Team Member	Role
Booking Clerk	Registration
ECG/Cardiology Technician	Performs electrocardiograms (ECG) • All patients undergo at least one ECG prior to meeting with the team
Genetic Counsellor	Provides genetic counselling; • Review of family history • Information about the condition and how it is passed on in families • Genetic testing options (if it applies)
Heart Rhythm Specialist (specialized cardiologist)	Reviews your medical history and the results of your heart tests • Explains what these mean for you and your family Provides information about the inherited heart rhythm condition As needed, discusses treatment options and follow up plan
Inherited Heart Rhythm Research Team	Invites all patients and families to: • Enroll in registries • Provide a blood sample for biobanking Participation is voluntary

*** It's possible that you will meet team members in an order that is different than what is outlined above.**

There may also be a medical resident or genetic counselling student working with the team. If you have any questions or concerns, or if you have feedback about your appointment, please do not hesitate to contact us.