

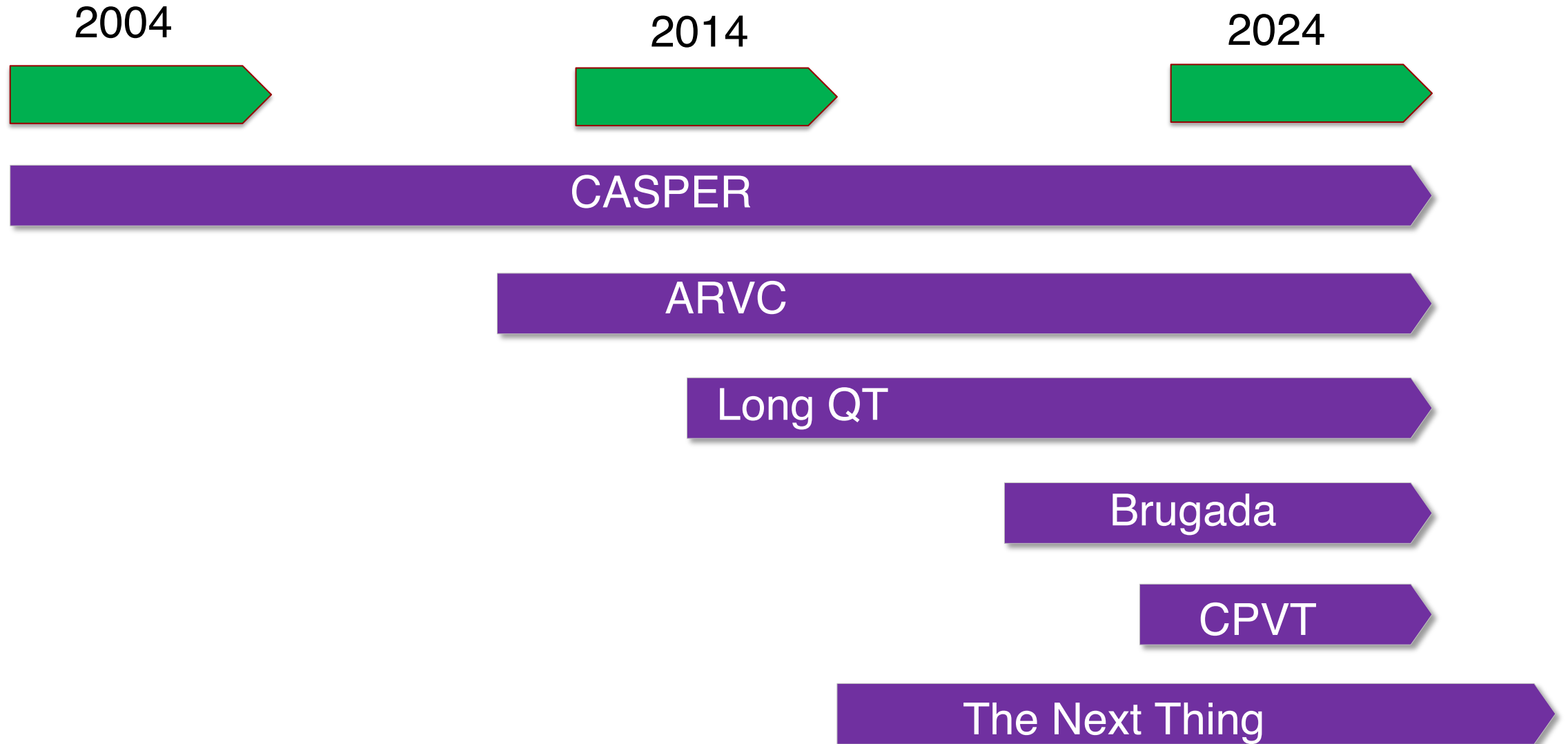
# THE HEARTS IN RHYTHM ORGANIZATION



<https://heartsinrhythm.ca>

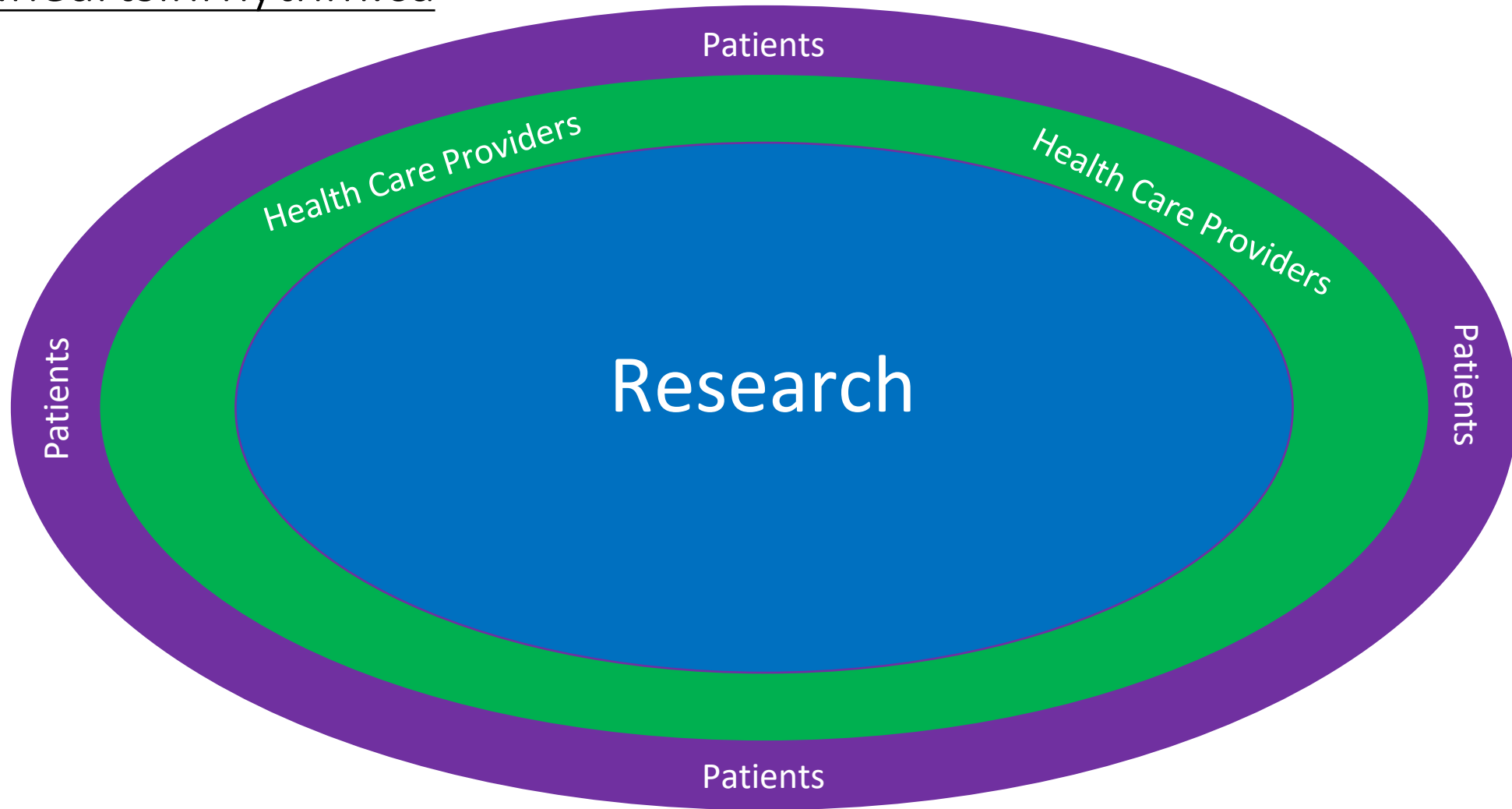


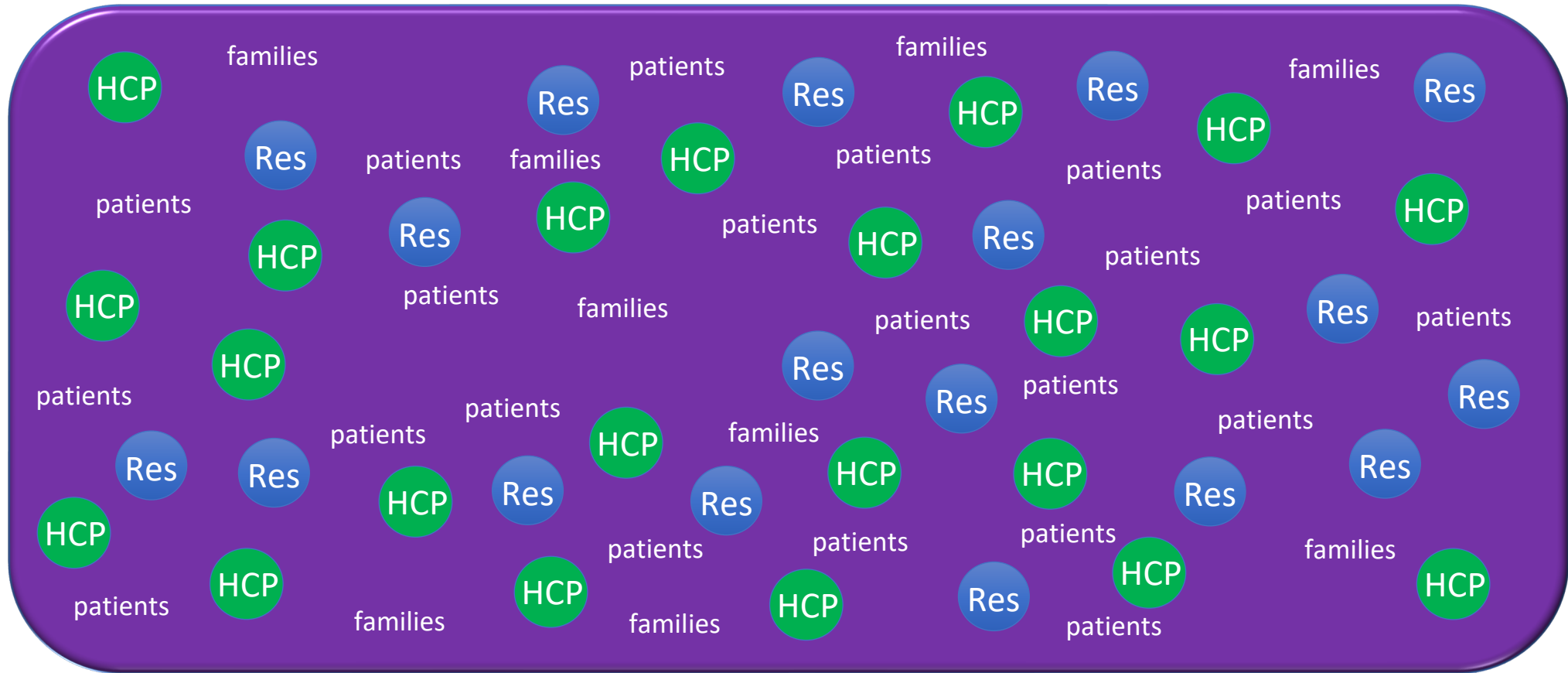
# Genetic Team Development Timeline



# Broadening the Scope: Hearts in Rhythm Organization (HIRO)

[www.heartsinrhythm.ca](http://www.heartsinrhythm.ca)





# *What is the Hearts in Rhythm Organization?*

Vision - Setting the standard for inherited heart rhythm excellence

Mission - We are a community committed to innovation and learning, focused on the detection of inherited heart rhythm conditions, provision of best treatments and protection from the tragedy of sudden cardiac arrest

Goals:

1. To ensure high quality, standardized care for inherited arrhythmia patients and families across Canada
2. To facilitate collaborative research, and engage patients and families in the process
3. To translate research to the health care system and the general public
4. To prevent sudden death from inherited arrhythmia



# HiRO Research Registries:

## National HiRO Registry & Biobank:



PI: Dr. Andrew Krahn  
Coordinating Centre: UBC

### One protocol with 5 funded sub-registries:

1. CASPER
2. Arrhythmogenic Cardiomyopathy
3. Long QT Syndrome
4. Brugada Syndrome
5. CPVT

All patients and families with an inherited heart rhythm or cardiomyopathy condition not otherwise meeting the above inclusion criteria are still eligible for enrolment & biobanking but site reimbursement is not available

**2031 enrolled locally | 6232 nationally**

## HiRO-HCM Registry & Biobank :



PI: Dr. Rafik Tadros  
Coordinating Centre: MHI  
**UBC Site PI: Dr. Zachary Laksman**

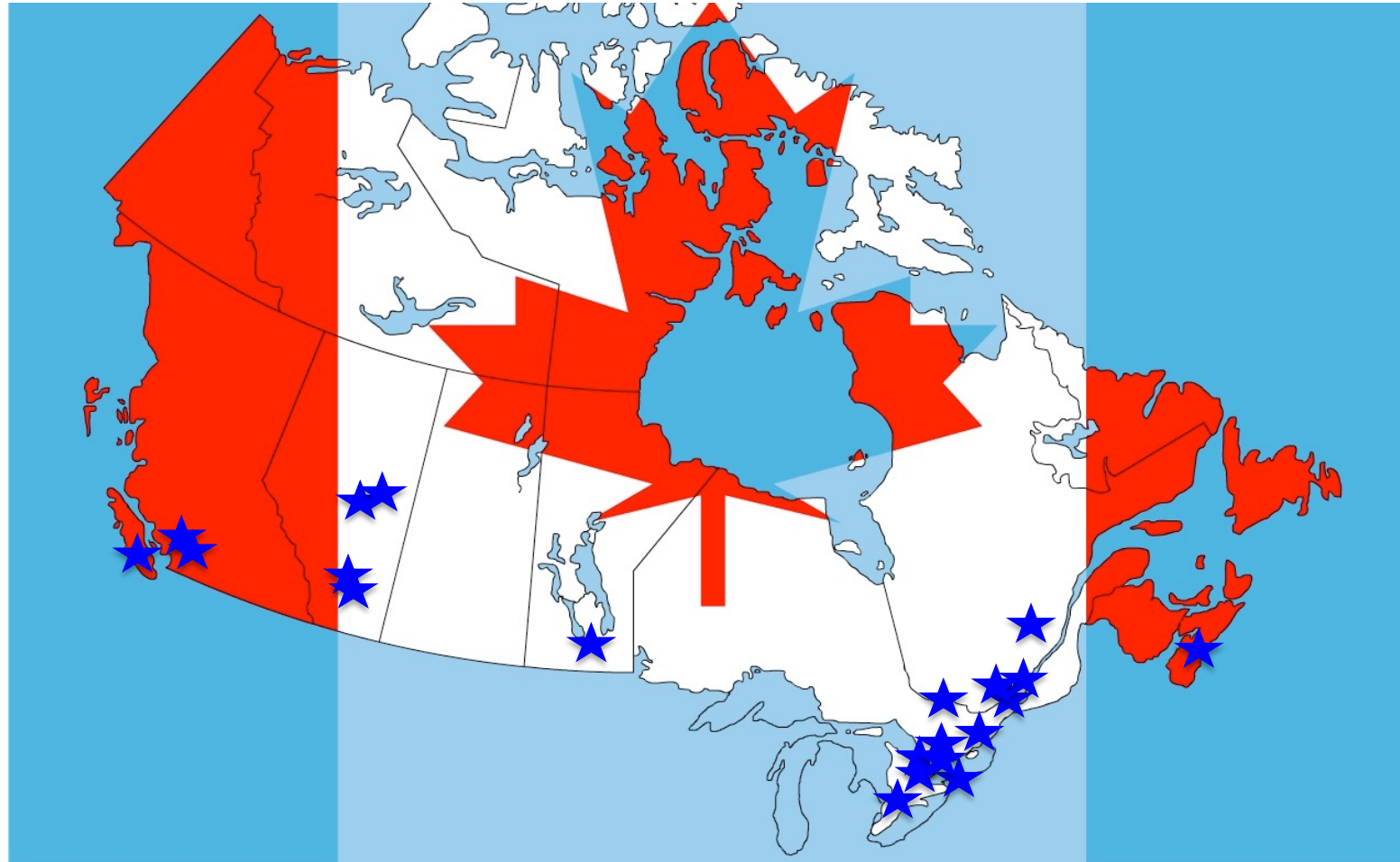
A spin-off registry launched in 2020, HiRO-HCM is overseen by Dr. Tadros and the MHI team. This is a different protocol, with aligned data variables. Data can be shared & combined between registries for national sub-studies.

Participants eligible & willing to consent for HiRO-HCM should be enrolled in this registry (instead of the National HiRO Registry).

**63 enrolled locally | 1217 nationally**



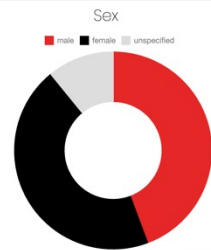
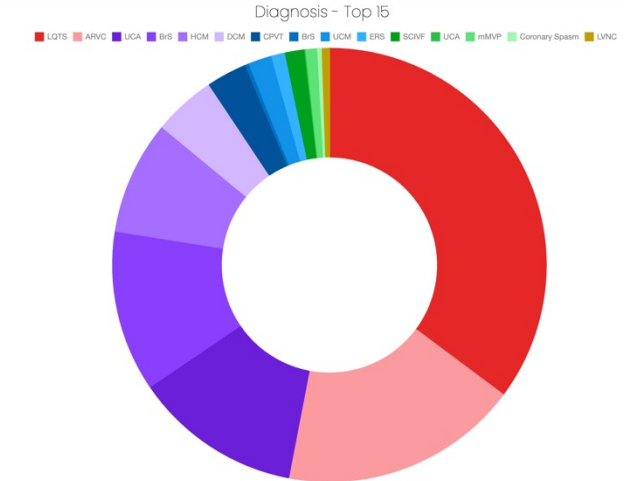
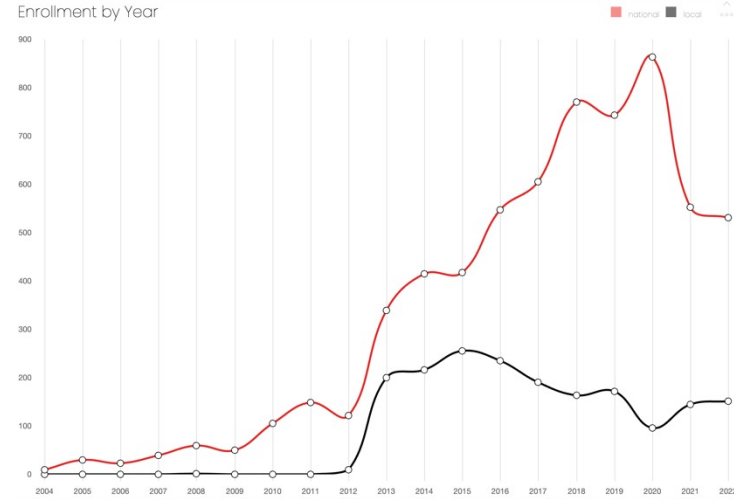
# *Canadian Enrolling Centers*



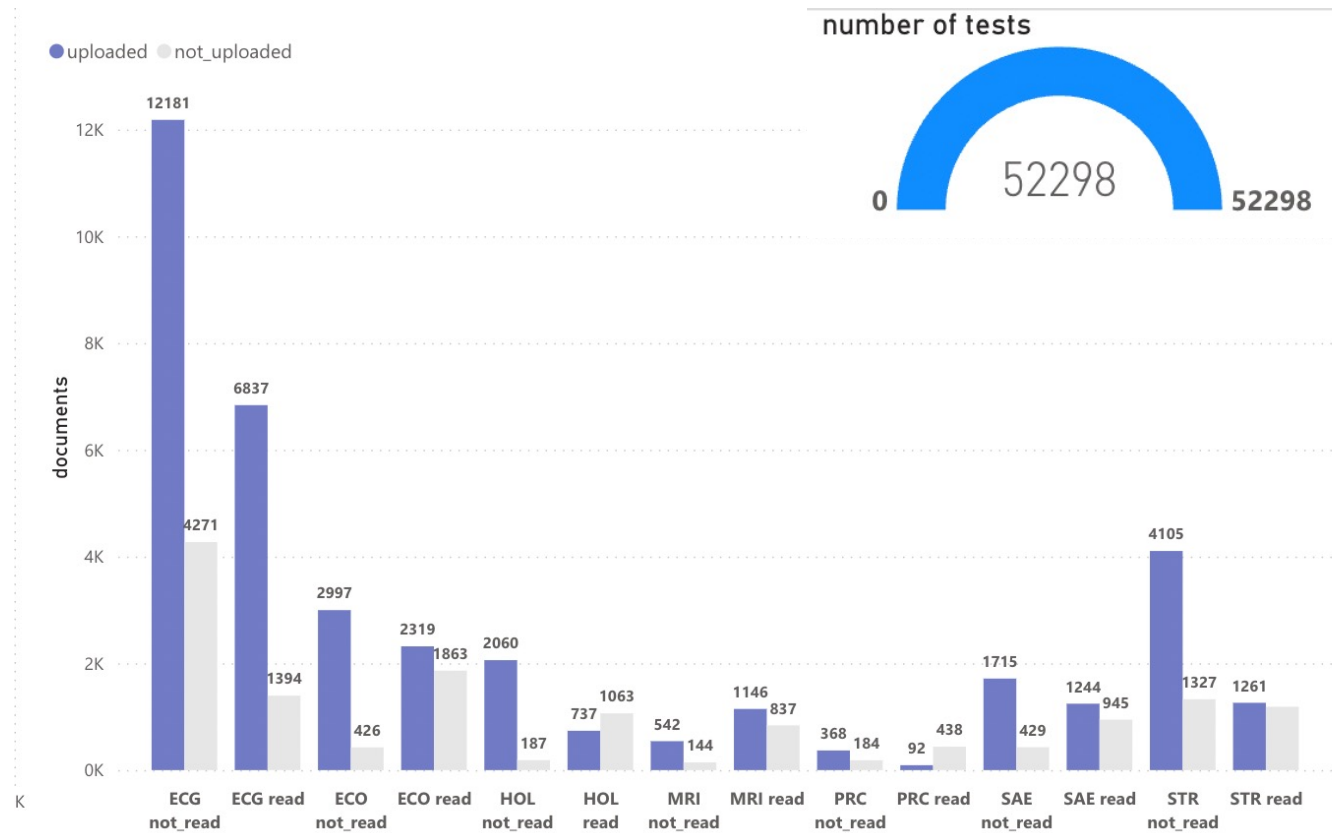


# National Registry Enrollment

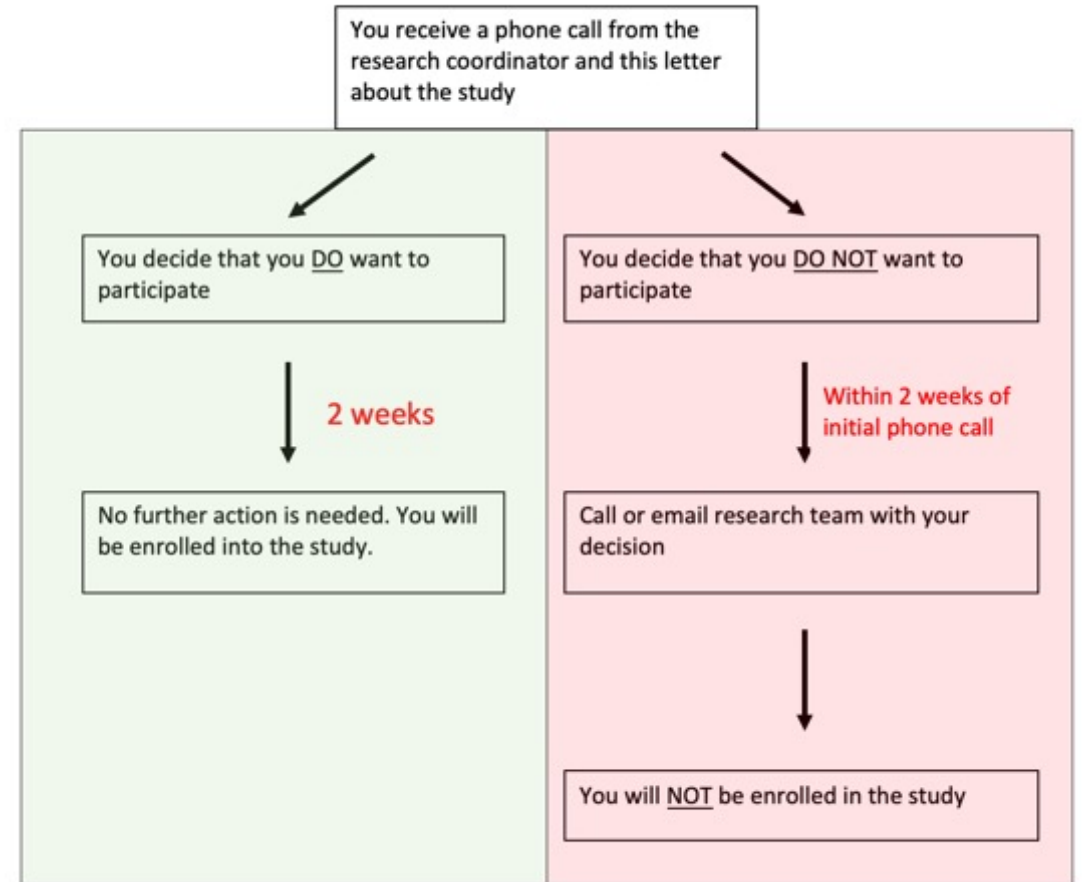
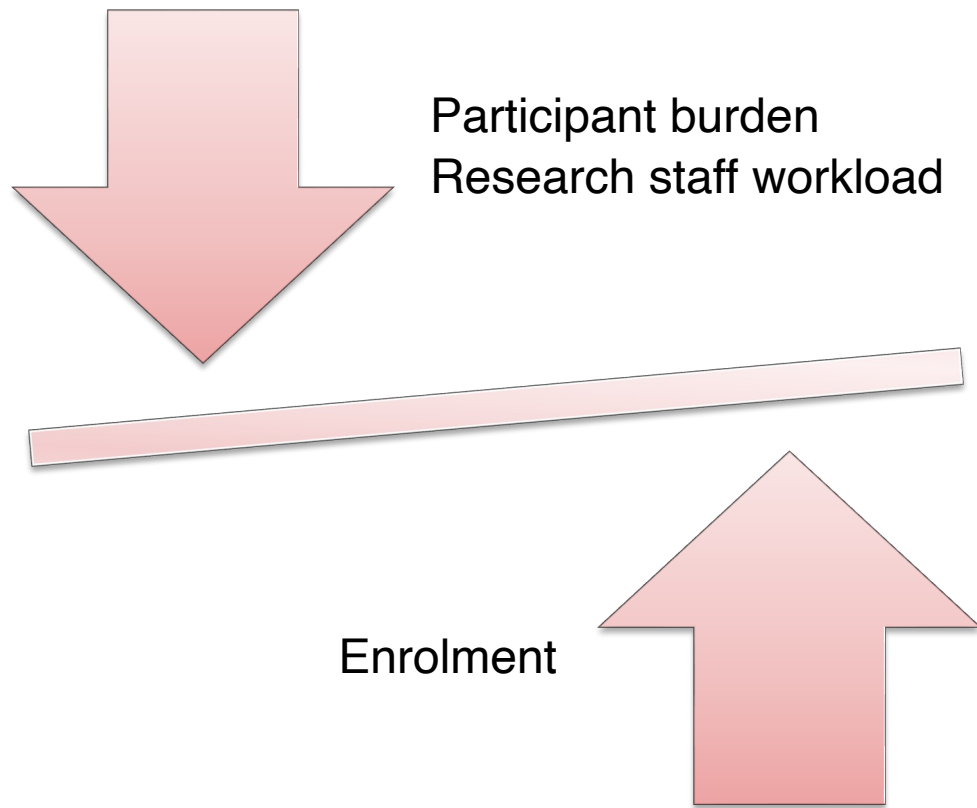
	enrolled	biobank
ARVC	1066	558
BRUGADA	450	248
CASPER	1709	681
HIRO	6232	2461
LQTS	1390	660



# Cardiac Testing Core Lab



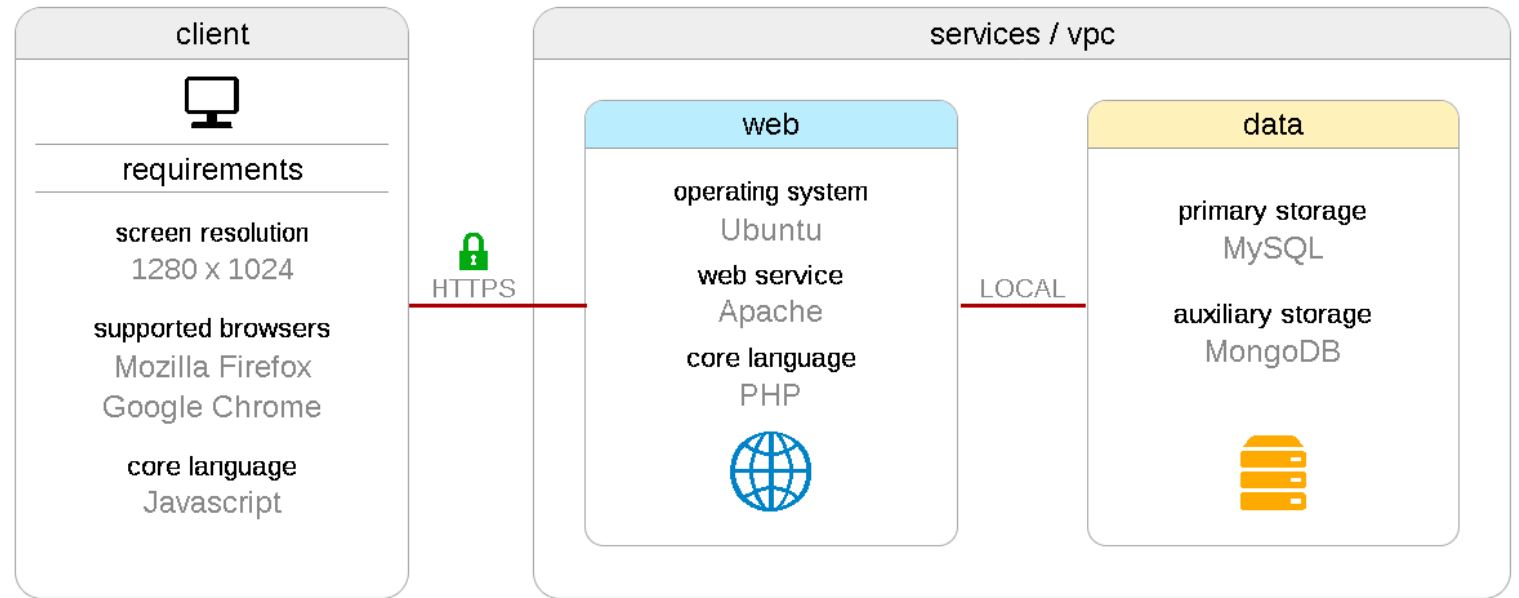
# HiRO Opt-Out Consenting Model (online consent started during COVID):



# Custom Database: Pedigree Pro



# Custom Database: Pedigree Pro



```
referral.referral [+]
referral.family [+]
referral.studies [+]
  r_arvc [+]
  r_brugada [+]
  r_casper [+]
  r_cpvt [+]
  r_hiro [+]
  r_ihrd [+]
  r_linq [+]
  r_lqts [+]
t_adrenaline [+]
t_angiogram [+]
  t_cct [+]
  t_ecg ▶ {
```

```
date of test
datex [+]
ix [+]
referral [+]

HR & intervals
HR [+]
QT [+]
PR [+]

QRS
qrs_axis [+]
qrs_duration [+]

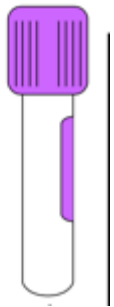
conduction
conduction [+]

abnormalities (NEW)
conduction_lbbb [+]
conduction_lafb [+]
conduction_lpfb [+]
```

- Javascript, JSON, R embedded
- Flexibility in modification and addition of fields

# BIOBANKING:

1 EDTA Tube



1 RedTop Serum



+



LifeLabs®



Participant receives kit in mail; takes to LifeLabs  
in their community

Ship to Vancouver  
(Samples stored at HLI)



**Biobanking is offered/optional for all HiRO Registry participants with separate consent**

# Active Projects: *HiRO-Initiated*

Active HiRO-Initiated Studies:	Project Lead(s):	Notes:
Brugada GWAS	Dr. Rafik Tadros	Study Design
DIAGNOSE-CRDS	Dr. Jason Robers	Study Design
TARGET-ARVC	Dr. Jason Roberts	Study Design
HiRO CardioSignal	Dr. Krahn & Dr. Tadros	Study Design
ARVC-ML ECG	Dr. Chris Cheung	Study Design
CASPER Yield of GT in UCA w. CAD	Dr. Thomas Roston	Study Design
HiRO LMNA	Dr. Zachary Laksman	Study Design
EPS Arrest	Dr. Roberts	Data Collection
QoL in SCA Survivors	Dr. Sanatani	Data Collection
Pediatric International Brugada Registry	Drs.Cecilia Gonzalez-Corcia (UK)	Data Collection
CPVT-BURST	Dr. Thomas Roston	Data Analysis
ARVC Clinical Predictors (Lexeo Collaboration)	Dr. Cadrin-Tourigny	Data Analysis
ARVC Penetrance by Age in FDRs	Dr. Arbour & Dr. Leather	Data Analysis
ST Depression Syndrome	Dr. Cadrin-Tourigny	Data Analysis
ARVC & Brugada Serum Biomarkers	Dr. Hamilton	Data Analysis
LQTS Stress Risk Prediction	Dr. Atallah	Data Analysis
CASPER Outcomes	Dr. Krahn & Dr. Cheung	Data Analysis
CASPER WES 2	Dr. Rafik Tadros	Data Analysis
LQTS Unusual Cases	Dr. Andrew Krahn & Dr. Zachary Laksman	Data Analysis
Brugada miRNA	Dr. Christian Steinberg	Data Analysis
ARVC 3D ECG	Dr. Christian Steinberg	Data Analysis
One, None & Done: Pediatric Cardiac Arrest	Dr. Sanatani	Manuscript under review
LQTS ECG Machine Learning	Dr. Krahn and Dr. Redfearn	Manuscript under review
CASPER MVP	Dr. Alqarawi	Manuscript under review

24 Projects

by

15 Investigators



# Active Projects: *International Collaborations:*

Active International Collaborations:			
International PLN Registry		The PLN Foundation (Netherlands)	Study Design
RIME-IVF		Dr. Jacob Tfelt-Hansen and Dr. Bo Winkel (Denmark)	Study Design
RASE-Brugada		Dr. Elijah Behr (UK)	Study Design
Pediatric International Brugada Registry		Drs.Cecilia Gonzalez-Corcia (UK)	Data Collection
Anderseon-Tawil Registry	<b>12 Cases Sent</b>	Dr. Melvin Scheinman (US)	Data Analysis
International SQTs Registry	<b>4 Cases Sent</b>	Dr. Ibrahim El-Battrawy (Germany)	Data Analysis
RBM20 International Cohort	<b>8 Cases Sent</b>	Dr. Victoria Parikh (US)	Data Analysis
ARVC GWAS	<b>235 Cases &amp; Samples Sent</b>	Dr. Proost/Dr. Bezzina (Netherlands)	Data Analysis
GWAS in IVF/ERS (GenUCA)	<b>135 Cases &amp; Samples Sent</b>	Dr. Behr (UK)	Data Analysis
THESIS (SCIVF)	<b>40 Cases</b>	Dr. Belhassen (Israel)	Data Analysis
LQTS-NEXT	<b>265 Cases &amp; Samples Sent</b>	Dr. Connie Bezzina (Netherlands)	Data Analysis

HiRO is currently contributing data and samples to **11** projects led by researchers in **6** other countries





# Recent Publications:

In the last 12 months, HiRO data has contributed to **6** publications

Recent HiRO Publications (Past 12 Months):		
ARVC SAECG	Dr. Krahn & Dr. Pearman	Heart Rhythm
HiRO Splice Site Variants	Dr. Laksman & Kaveh Rayani	European Journal of Human Genetics
LQTS Stress Test	Dr. Krahn & Lauren Yee	JAHA
Predictors of Perceived Self-Efficacy and Empowerment	Dr. Seifer and Dr. Fournier	Frontiers in Cardiovascular Medicine
ARVC Risk Calculator External Validation	Dr. Cadrin-Tourigny	European Heart Journal
HiRO Care Pathways	Dr. Andrew Krahn	CJCO



# HiRO Knowledge Translation:



1. Annual Meeting
2. National Case Rounds
3. Knowledge Translation Rounds



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[Heartsinrhythm](https://www.facebook.com/Heartsinrhythm)



[HeartsinRhythm](https://www.instagram.com/HeartsinRhythm)



[Hearts in Rhythm Organization](https://www.youtube.com/HeartsinRhythmOrganization)



<https://heartsinrhythm.ca>





**THANK YOU!**

