



# The BC Inherited Arrhythmia Program (BCIAP): A New Provincial Initiative to Understand and Prevent Familial Sudden Death



The BC Inherited Arrhythmia Program was established in April 2013 under the leadership of three provincial experts:

- Dr. Laura Arbour, *Medical Geneticist*
- Dr. Andrew Krahn, *Cardiac Electrophysiologist*
- Dr. Shubhayan Sanatani, *Pediatric Electrophysiologist*

This multidisciplinary health care initiative provides state of the art-care to families affected by inherited heart rhythm conditions and at risk for sudden death through partnerships, innovation and advocacy.



**PROGRAM SITES**

- St. Paul's Hospital and BC Children's Hospital in Vancouver
- Royal Jubilee Hospital in Victoria
- Northern BC\* (Terrace, Hazelton and New Aiyansh)
- Telehealth in development

\* There is a high rate of LQTS in Northern BC First Nations based on 2 different mutations in the gene causing LQTS1 (Jackson et al, CMAJ 2011. DOI:10.1503/cmaj.100138)



## One Family's Tragic Story...

Jenny was a healthy and active teenager. Two days before her 14th birthday, she goes to sleep and never wakes up. When her parents hear that a genetic heart problem could be to blame, they fear for their two other children. Mom and Dad are filled with the guilt that one of them may have contributed to their daughter's death.

## THE BCIAP MODEL PROVIDES QUALITY CARE

### Enhanced Patient Care and Access

- Streamlined and improved access to clinical evaluations and genetic counselling for all BC patients and families at risk through a centralized referral network
- Expert care team of adult and pediatric heart rhythm specialists, medical geneticists genetic counsellors, nurses, research staff delivers state-of-the art care to families
- Best practice and management strategies developed by the team ensure a consistent clinical approach
- Improved education, support and family resources
- Family centered appointments facilitate continuity of care

### Health Care Provider Education and Awareness

- Provincial Inherited Arrhythmia case-based videoconference rounds for trainees and established clinicians (specialists and GPs) throughout BC, and ultimately to optimize care
- Educational avenues for primary health care providers to be explored

### Monitoring Outcomes and Program Evaluation

- Provincial database to track referrals, clinical and genetic tests, treatment plans and cardiac surveillance
- Patient satisfaction to be evaluated by surveys

Every year, 50 apparently healthy British Columbians will die suddenly and unexpectedly. Inherited arrhythmias explain nearly one third of these sudden unexpected deaths and overall, affect 1 in 500 British Columbians.

Affected or at risk individuals can be difficult to identify. Inherited arrhythmias may be misdiagnosed or missed all together. Expert evaluation is needed.

Genomic advances have given us the ability to recognize those at risk for premature sudden cardiac death and to put in place prevention strategies.

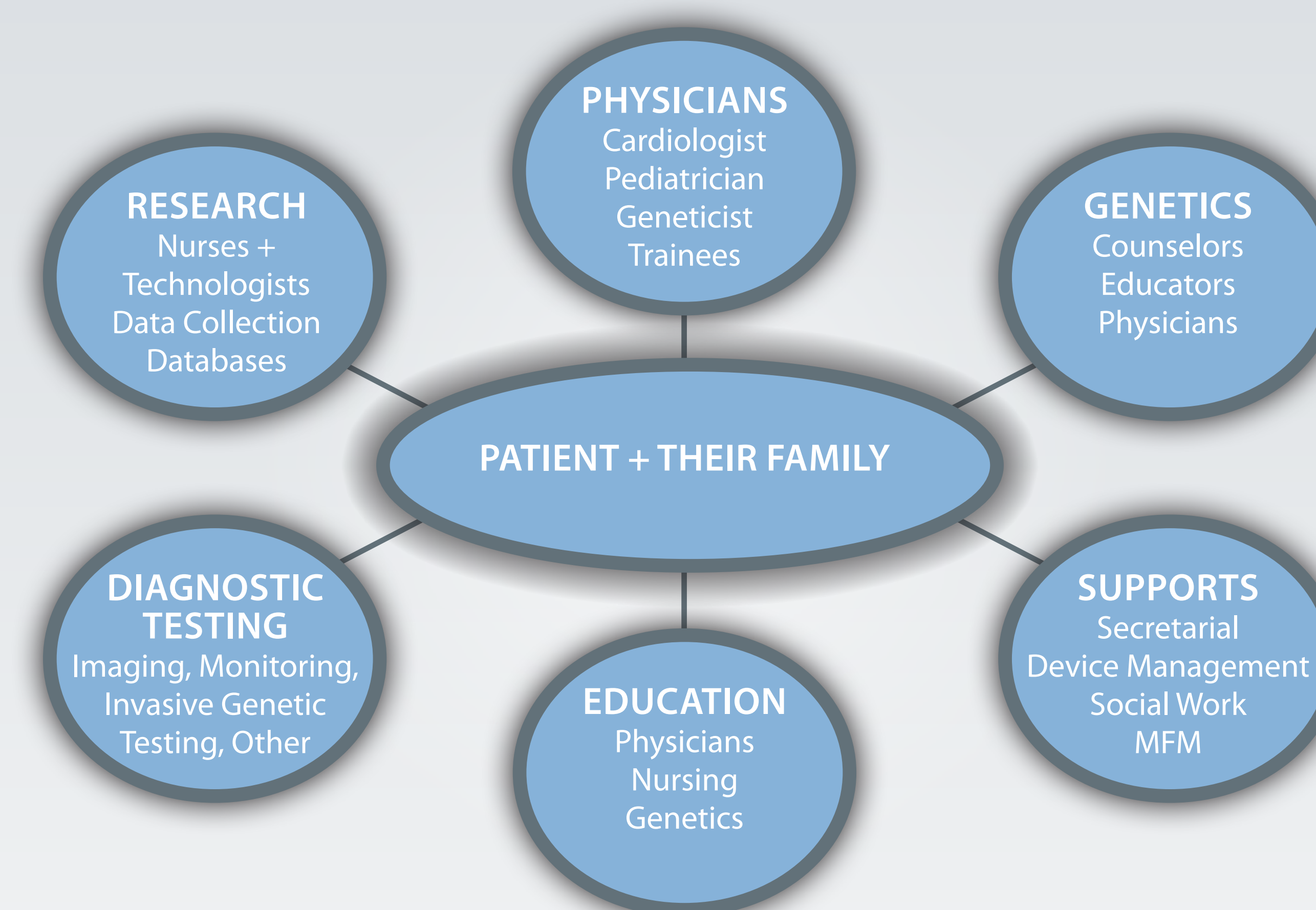
A multidisciplinary approach to between heart rhythm specialists and medical genetics is essential.

### An Opportunity to Prevent Sudden Death

- Prevention of sudden death caused by inherited arrhythmias can happen if risk is recognized and management is implemented
- An expert, multidisciplinary team is needed to diagnose, screen and manage patients and at risk family members
- Primary care awareness of familial risk will promote referrals to the expert team
- Management strategies are developed and care returns to the primary provider

**All BC patients and families at risk need expert care and improved access to cardiogenetic services**

## THE MULTIDISCIPLINARY TEAM



### Research and Innovation

- BCIAP physicians are leaders in investigator-driven inherited arrhythmia research
- Families are invited to participate in Provincial and National registries as well as bio-banking
- Clinical, basic science, population and health services research will improve diagnostics and patient outcomes

## COST CONSIDERATIONS AND IMPACT ON RESOURCES

### Treatment Options

- Low cost medical therapy for at risk individuals (daily beta-blocker)
- Targeted use of more expensive therapies
- Genetic Testing and Family Member Surveillance
- Genetic testing protocols identify the most cost-efficient approach to family evaluations, such as the most appropriate person to offer testing, and excluding individuals who are not at risk
- Provincial database to monitor impact of cardiac surveillance in cases where genetic test results are uninformative (30-75% of families)

### Challenges Encountered

- Greater number of patient referrals than expected required increased health care provider resources
- Implementation of a provincial, privacy-protected database, which involved significant engagement from teams across various health authorities
- Limited availability of specialized testing in certain areas, which required patients to travel to BCIAP sites for initial assessments. Partnerships with specialists in other health authorities

### Funding Source and Sustainability

This project received \$500,000 from the Specialist Services Committee (SSC), a joint collaborative committee of the Ministry of Health and the Doctors of BC (formerly the BCMA). Cardiac Services BC supports the ongoing sustainability of the program in collaboration with the regional health authorities