

# FACTSHEET

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## The Inherited Arrhythmia Clinic



The Inherited Arrhythmia Clinic (IAC) at the Heart Centre for Children, The Children's Hospital at Westmead, is a multi-disciplinary clinic that provides a range of services for families with children with arrhythmia conditions. The clinic is held once a month and offers access to a number of specialists relevant to your child's care. Components of the clinic include the following:

### Cardiologist appointment

Your family will meet with a cardiologist with expertise in heart rhythm problems (otherwise known as an "Electrophysiologist"). Given this clinic is held in a Sydney University associated teaching hospital, it is possible that your family may first be seen by a specialist in training, followed by the specialist Electrophysiologist.

### ECG & Holter Testing

Your child will have his or her routine testing performed on the day. The ECG provides a snapshot of your child's heart rate and rhythm at the time of the test. The Holter monitor provides heart rate information for a 24 hour

period and allows us to see the heart's electrical activity during normal daily activities. After 24 hours you can remove the Holter monitor and either drop it back to the Heart Centre or post it back in an Express Post envelope (available to be purchased from the front desk of the Heart Centre if needed).

### Genetics and Genetic Counseling

In the genetics appointment the genetics doctor (Clinical Geneticist) or genetic counsellor will discuss with you whether your child's arrhythmia could 'run' in the family. For some families, genetic testing may be offered to help better understand this. Genetic testing would usually involve a blood test from your child and other family members if needed. The genetic doctor or genetic counsellor will also talk with you what the test result may mean for other family members and can provide information about the likelihood of having another child with the same condition. The genetic counsellor may contact you in advance of the appointment to ask about your and your family's health history.

### Child Life Therapy

The child life therapy session provides an opportunity for patients and their siblings to come together and engage in a range of experiences while their parents are meeting with other health professionals at the clinic. A variety of open-ended craft materials are provided to encourage self-expression. The children are free to choose the subject of their artwork; however, we do notice that the creative process often allows children to share stories

and experiences associated with having an arrhythmia condition. A medical play area is also setup within the space to allow the children to role play their medical experiences and work through the feelings associated with this. A variety of other resources and toys, suited to a wide range of age groups, are provided on the day for children not wishing to engage in the activities above.



### Psychological Support

As part of our clinic, families have an opportunity to meet with one of our psychologists. Our psychologists are dedicated to supporting children with arrhythmia conditions and their families from the time of diagnosis and throughout all stages of their medical care.

Some of the ways our psychologists can assist include:

- Supporting you to talk with your child about his or her heart condition.
- Helping your child to cope with any worries or fears he or she may have about their heart condition or medical procedures.
- Supporting your child to understand and cope with any changes in their lifestyle, such as taking medicines or limiting their exercise.
- Providing an opportunity for you to talk about your experiences or concerns as a parent of a child with an inherited arrhythmia.
- Supporting siblings, grandparents, and other family members to adjust and make sense of the diagnosis and possible lifestyle changes.

### Cardiac Clinical Nurse Consultant

The Clinic Nurse Consultant (CNC) will provide basic life support training to family members who feel they would like to learn this skill. The training is performed away from younger children, although older children are invited to attend. Whilst training is generalised, this session offers an opportunity for you to ask specific questions about your child's condition and care in the

unfortunate event of collapse. The Clinical Nurse Consultant is also a good resource for you to access if you need help talking to your child's school about their condition.

### Frequently Asked Questions:

#### How long will the clinic take?

The clinic lasts for about 2-4 hours, depending on what services your child needs and which sessions your family would like to access. We recognise that this might be a long day for you and your family. We hope that overall this clinic will save your family time, as a number of different services are available, preventing multiple, separate trips to the hospital.

#### Do I need to attend all the sessions?

The clinic is designed to cover a range of supports and services that families have let us know are useful. Prior to the clinic, your cardiologist may make a recommendation that your family meet with the clinical geneticist and/or psychologist. It is not essential that you attend all the sessions, however we ask that you please advise the receptionist which sessions you would like to attend prior to the clinic.

#### How do I pay for the clinic?

The Inherited Arrhythmia Clinic is bulk-billed for Medicare cardholders. Please bring your Medicare card to all medical appointments. Overseas patients will need to pay for the service at the hospital cashier prior to the clinic.

#### What should I bring to the clinic?

We aim to schedule your sessions during the clinic as close together as possible. We recommend you bring drinks, lunch and snacks for both your child and yourself, as you may not have time to buy food. It is also important to bring your Medicare card.

### Contacts:

- For information regarding the clinic contact the Cardiac CNC or IAC coordinator on (02) 9845 2145
- To contact the Department of Clinical Genetics please phone (02) 9845 3273.
- To contact our Psychological Support team, please phone (02) 9845 0088.