

## Common medical tests for people with a Fontan circulation: *Patient and parent information*

As part of monitoring your heart and health, your doctor may request that you/your child complete medical tests. We have compiled a list of some of the tests which people with a Fontan circulation encounter most often on their health journey. If you have any concerns or questions about any test or procedure you/your child should talk to your doctor, nurse, and family support person.

### Blood tests

People with a Fontan circulation will have blood tests done. For adults this is usually yearly and in children this may be performed less frequently.

Some of the blood tests that you/your child might have are:

- *Full blood count and iron study* - many people with a Fontan circulation may have a slightly low oxygen level. A full blood count and iron studies is done to make sure the person has enough iron to match their red blood cell making needs (the red blood cells carry oxygen in the body, and iron is required to make red blood cells).
- *Liver function tests, urea and electrolytes* – these tests check how the liver and kidneys are working. Liver problems can arise in the Fontan circulation, and although why and how to monitor this is not well understood, blood tests form part of the regular checks. Although reduced kidney function has been noted in the Fontan population, it is unclear whether this is progressive. Testing the kidney function is a good screening and monitoring test.
- *Thyroid function and uric acid* - in the general population thyroid issues are relatively common and can be a cause for tiredness or palpitations, so they are often included in blood tests. Sometimes people who have low oxygen levels have a higher rate of cells in their bodies being made and destroyed. This causes uric acid levels in the body to rise - uric acid crystals sometimes form in the joints and cause a painful condition called gout. Gout can be well treated with medication (usually a preventer medication).

Blood tests are performed with a needle. If you/your child find having blood taken uncomfortable, have a chat to your doctor or laboratory about the possibility of having some numbing cream applied to the skin 1 hour before.

If you/your child are on warfarin (an anticoagulant) then the blood thinning level (INR) needs to be checked regularly (this can vary from a few times a week if it is unstable, to 4-6 weekly if the level is stable) with an INR test. People on warfarin will have an INR range to aim for – for most people this is between 2.0 and 3.0. It is essential you check

with your doctor what the INR range for you/your child needs to be, and that an INR test is done as frequently as advised. It is also important to know if you/your child are taking warfarin that the INR levels can be affected by foods, medications, and almost all antibiotics. When starting a new medication, make sure that the doctor and pharmacist know that you/your child are on warfarin and follow their advice on INR checking (usually INR is checked on day 3 of the new tablet). Sometimes, people on warfarin self-manage their INR checking at home with a finger prick test machine.

### Oxygen saturation (pulse oximeter)

Most people have an oxygen saturation  $\geq 96\%$ . Many people with a Fontan circulation will have a slightly lower reading – it is important for you or your parents/carers to know what the usual reading for you is.

The oxygen saturation (saturation of red blood cells with oxygen) is measured most often using a probe (pulse oximeter). The probe can either sit on a finger, a clip that goes on the ear, or a membrane that is taped onto the forehead (depending on the age or size of the person). The pulse oximeter makes a pinging sound (alarm) that lets doctors or nurses know of changes in oxygen levels. It is very useful particularly during surgery, and staff are trained to leave the alarm on, even if you are awake and well.

Sometimes, your doctor may want to know what happens to your oxygen saturation when you exercise. You may be asked to do an exercise test (usually using a treadmill or bicycle, or sometimes just walking) with a pulse oximeter on.

### Blood pressure

Monitoring the blood pressure is very important so that it can be maintained within a healthy range. Abnormal blood pressure readings, either high or low, may need to be addressed by your doctor. Blood pressure is measured using a special cuff that is inflated on the arm for a few seconds. The pressure of this cuff around the arm needs to be quite high to accurately measure the pressure in the blood vessels. Some people may find the pressure of the cuff uncomfortable. If you/your child finds blood pressure measurement distressing you should let your doctor know.

### Electrocardiography (ECG)

An electrocardiogram, usually abbreviated to ECG, records the electrical signals from the heart and whether the rhythm of the heartbeats is steady or irregular. It also gives some very basic information about the heart structure.

To record the ECG, twelve little sticky patches called 'electrodes' are put on the chest, arms and legs. Your skin may need to be shaved to help the electrodes stick. The stickers

are connected to an ECG recording machine that records your/your child's heart electricity into wavy lines which are printed onto paper. The test is safe and only takes a few minutes in total. The ECG records electricity and does not affect the heart in any way.

### Echocardiogram (Echo)

An echocardiogram, or “Echo”, can be used to provide a picture of the heart chambers and valves and check how well they are working. An Echo uses sound waves to form a moving picture of the heart and major blood vessels, the sound waves are converted to a picture by a computer on the Echo machine. The sound waves are recorded by a hand-held wand, known as a transducer that is placed on the chest.

The Echo may be performed by a technician who works with your doctor, known as a cardiac sonographer. Before the test you/your child may be asked to remove clothing from the waist up and wear a gown. To perform an Echo, a small amount of gel is placed on the end of the transducer to allow better contact with your/your child's skin and provide a clearer picture. Three ECG electrodes are often put on the chest in order to record the heart's electrical activity during the test. The technician will move the transducer to different parts of the chest to get a complete picture of the heart and blood vessels. You/your child may be asked to change positions several times during the test and briefly hold your breath to provide a clearer picture of your heart. The technician may take measurements of the size of different heart chambers, valves or blood vessels.

You/your child should not feel any pain or discomfort during an Echo, the gel may feel a little cold though and slight pressure may be felt from the transducer placed on the chest. The sound waves used in Echo are not known to lead to any long term harmful effects.

Your heart specialist will be able to talk to you/your child about the results of the echocardiogram.

### Transoesophageal Echocardiogram (TOE)

A transoesophageal echocardiogram, known as a TOE, may sometimes be recommended by your heart specialist when it is not possible to get a clear enough picture of your heart with an Echo. Your doctor may also recommend a TOE when looking for a blood clot in the heart chambers. In a TOE examination a flexible tube containing a transducer is guided down your/your child's throat and into the oesophagus, which connects the mouth to the stomach. The transducer can be positioned to obtain more detailed images of your/your child's heart. Your throat will be numbed, and you will have medications to help you relax during a TOE. A general anaesthetic may also be recommended to perform a TOE in some circumstances.