FRIENDS OF THE SCOTSMAN /

We're saving more babies with heart defects thanks to pioneering work

James Cant explains how putting money into research is paying back big dividends for parents and children

One of the most important parts of my role at British Heart Foundation Scotland is meeting the people whose lives we're trying to improve – those directly affected by heart disease and their families.

It's particularly moving to spend time with families whose children have been affected by congenital heart disease. Their bravery and determination is both inspiring and humbling.

Congenital heart disease is an abnormality of the heart that develops in the womb and there is a range of different conditions.

Sometimes a congenital heart condition is picked up during pregnancy, but often it's not discovered until after birth. Some children don't need any treatment, while others may need medication, heart surgery or other procedures.

What should be the happiest time of their lives can become frightening and upsetting for new parents. Imagine you've just met your long-awaited baby, only to discover that they have a potentially life-threatening heart condition that could require major surgery.

It's not surprising that parents tell us they can feel overwhelmed by a range of emotions, including anger, disappointment, fear and guilt.

Each year, 300 babies in Scotland are diagnosed with a heart defect. Behind every statistic is a child and a family facing the unknown. Last summer, this was the situation the Taylor family found themselves in. When their son Cohen was born, he seemed perfectly healthy. But at his eight week check-up, their GP detected a heart murmur.

Doctors at the Sick Kids Hospital in Edinburgh found Cohen had coarctation of the aorta (narrowing of the aorta which stops the blood from circulating normally in the lower half of the body) and two holes in his heart.

Cohen had open heart surgery a week later in Glasgow to remove the narrowed part of the aorta and repair the holes in his heart. It was a hugely worrying time for his parents, but he recovered well and should grow up to lead a normal adult life.

The ground-breaking surgery that helps children like Cohen has only come about in recent times. In the 1950s, around eight out of ten babies born with a complex congenital heart condition died before their first birthday.

Today, thanks to advances in treatment and care, eight out of ten babies with congenital heart disease grow up to be adults. That's a remarkable turnaround.

That's why the BHF is committed to funding more research into congenital heart disease. We're currently investing over £11 million in 23 research projects across the UK.

In the 1970s, the pioneering heart surgeon, BHF Professor Sir Magdi Yacoub, developed a revolutionary surgical technique to correct a defect where a baby's major blood vessels are attached to the wrong chambers of the heart – his 'switch' technique is still used by surgeons worldwide.

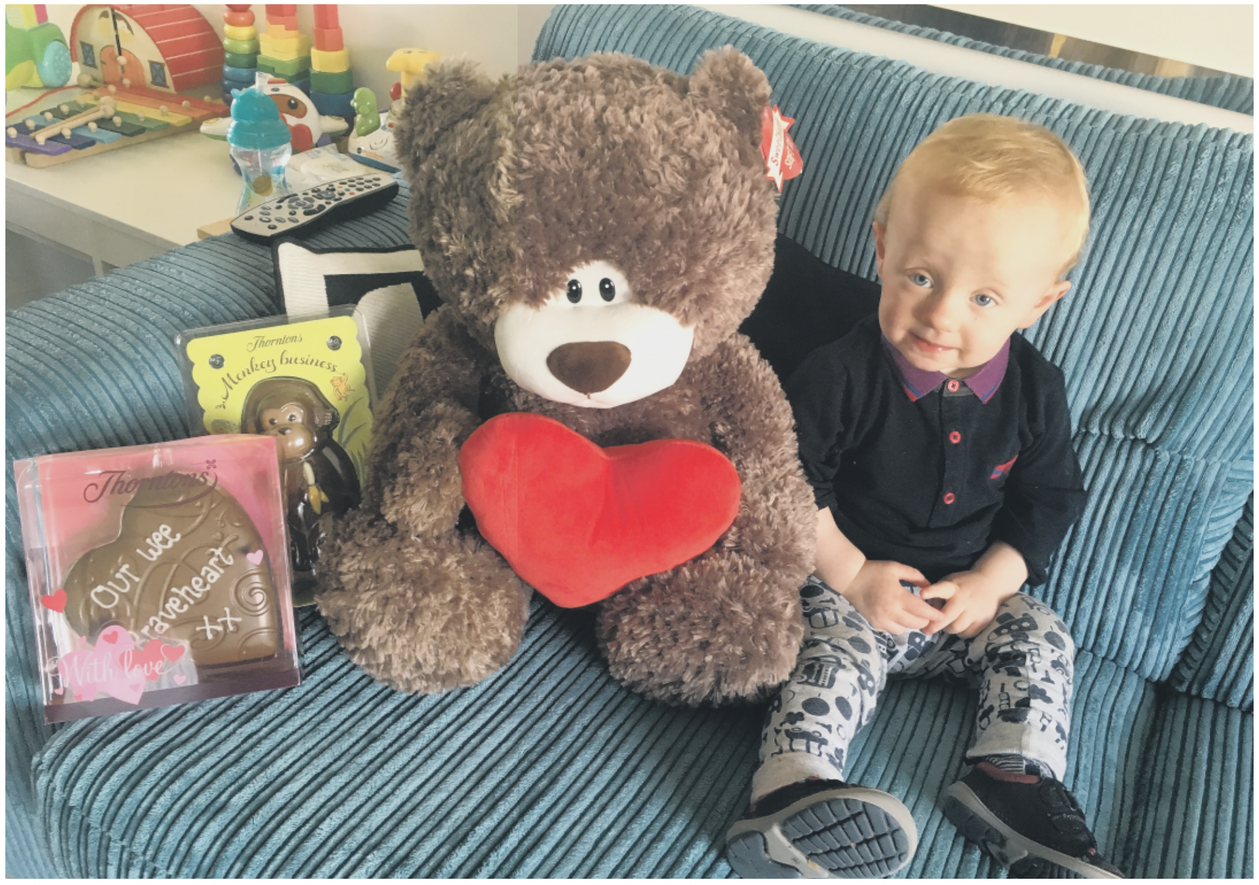
BHF Professor Robert Anderson helped to improve treatment by carefully mapping the anatomy of heart defects. BHF-funded research transformed the replacement of faulty heart valves in children. Instead of traumatic open heart surgery, a much quicker and less stressful technique was developed.

This track record gives us confidence that BHF-funded research can continue to drive forward new discoveries in congenital heart disease. We have scientists investigating how the heart develops in the embryo, others working to identify genes that could cause some heart defects, and studying stem cell development to understand how heart cells form. Computer simulations are being used to help plan personalised treatments for children, and new ways to protect their heart muscle during open heart surgery are being developed. We're also looking at what we need to do for adults who have grown up with congenital heart disease.

This is a fairly new and growing area of research – what future challenges might child heart patients face as adults, how can we predict them and what support will they need? After his treatment, Cohen's dad Martin told us, "we were delighted with the support we got from the BHF and we'd like to do whatever we can to raise awareness of the need for more research".

While there are still families like the Taylors facing this situation, and while we have the support of donors across Scotland who fund our work, we'll keep fighting to improve the lives of children born with heart disease. Find out more at www.bhf.org.uk/congenital

James Cant, director, BHF Scotland.



In the 1950s around 80 per cent of babies born with a complex congenital heart condition died before they were one – now children like Cohen Taylor are being saved by new discoveries

British Heart Foundation SCOTLAND

Equality and fairness? People with disability are being judged before they are even born

Uuganaa Ramsay is concerned about new tests for Down's syndrome

I work with young people with learning difficulties and disabilities as part of my job as a career coach, advising and supporting them through career planning.

From applying to college and any employment opportunities, it is clear that many applicants feel discrimination. That is even before the interview stage, before coming face to face with the interviewer, and not having been given the chance to show how capable they are, how wonderful their personalities are.

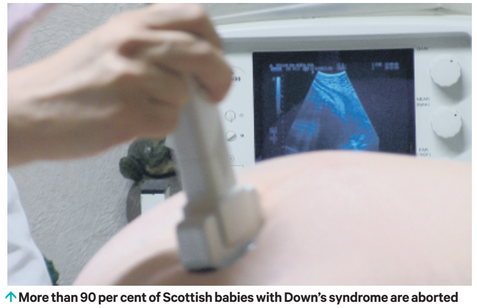
More organisations should seek to access the support available to increase diversity and develop inclusive working environments, helping to bridge skills gaps and harness different experiences, backgrounds and approaches. A diverse workforce is a more creative and innovative workforce.

In this context, I feel that the proposed, new Non-Invasive Prenatal Tests for Down's syndrome mirrors existing discrimination in society. People with an extra chromosome are already written off.

As we discuss this new screening test I have concerns, not only as a career coach, but also as a mother and also as someone who campaigns for equality, human rights and justice.

With the existing tests, more than 90 per cent of babies with Down's syndrome are aborted before birth in Scotland.

But how can we make things equal and fair when society already accepts that before birth we are not equal? This attitude is programming individuals in society to see disabled people differently and influencing decisions about equal opportunities, and thereby screening takes place with respect to college, training and job applications.



More than 90 per cent of Scottish babies with Down's syndrome are aborted

At a time when we want to be seen to value diversity, we seem to be ignoring it in antenatal clinics, where a social model of Downs syndrome is being overshadowed by the medical one.

With the new screening tests the decisions to abort are likely to increase. I am not saying people should not have the tests. We chose to have a test for our youngest child, who was born after our late son Billy. We needed to know and be prepared.

What is important is that parents should be given balanced information about life with a child with Down's syndrome. Information that is in line with UK and international disability guidelines and legislation while reminding us that we are more than the sum of our parts.

Surely, employers, training and opportunity providers need to know what incentives, funding and support is out there before closing their doors to disabled people and people with additional support needs.

When introducing new scientific tests, we need to be aware that they are carrying many messages to society.

This is the issue which concerns the Don't Screen Us out campaign, which is campaigning to ensure that any future screening for Down's syndrome conforms to the ethics with which a country is bound.

The consequences of screening remaining unfettered by ethics will have a profound long-term effect on the population of the Down's syndrome community and how society accepts disability.

Uuganaa Ramsay is a guest writer for the Scottish Council on Human Bioethics and an award-winning author, campaigner and advocate.

Scottish Council on Human Bioethics

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