

Pioneering generation of young people with ‘half a heart’ saved by surgical advances only to be let down by society

- **A new survey revealed almost three quarters (70%) are living with mental anxiety as a result of struggling with their heart conditions.**
- **Nearly half (47%) feel isolated and left out of activities, preventing them from achieving the same as their peers.**
- **Three quarters (75%) say their lives are severely impacted due to their heart condition being invisible to others.**

A pioneering generation of young people living with ‘half a heart’ have been saved by state-of-the-art surgery only to be let down by society because awareness of their condition is so poor.

There are now 3,300 children and young adults in the UK with a single ventricle heart. They are a generation who would not exist without the wonders of modern medicine.

More babies born with these rare heart defects are surviving than ever before thanks to surgical advances to re-plumb their heart to function with a single pumping chamber. Yet these remarkable youngsters are often left isolated, struggling at school, suffering anxiety and other mental health issues because their needs are overlooked and misunderstood.

The widespread failings were exposed by a report launched today (**May 1**) by national children’s heart charity Little Hearts Matter to mark its 25th anniversary.

Suzie Hutchinson, CEO of Little Hearts Matter, said:

“Our survey reveals these pioneering young people and their families are being let down by society.

“An overwhelming majority are living with the anxiety and fear created when you have a life-limiting condition. This is compounded by a lack of understanding within the communities they rely on.

“Many of them look no different to their peers – the scars are hidden – but they are having to manage life with half a functioning heart and the many day-to-day limitations these bring.

“This generation need to be seen, understood, and supported so they have every opportunity to live as full life as their condition allows.”

The survey reveals that:

- Young people with a single ventricle heart have just half the energy of other children, making it harder to perform at school. A greater understanding of their individual needs would help create a better balance through the school week and lead to greater inclusion.
- More than a third (36%) have an educational deficit that requires extra help at school, but the current system makes it hard for them to obtain the Statutory Health Care Plan they are entitled to and often impossible for them to gain the added EHCP support that should be provided by the Local Education Authority.
- Nearly three quarters (70%) suffer anxiety. They are twice as likely to suffer from phobias, depression, night terrors and ADHD by the time they are 10 as children with a healthy heart. Some suffer PTSD. Yet their heart condition can make it harder to access mental health care

in the community because of a lack of understanding of their needs and very poor regional mental health provision.

- As adults they are not entitled to free prescriptions - which are available for diabetes and epilepsy patients - despite living with an incurable, life-limiting illness.
- Many find it harder to form long term relationships as they know their single ventricle hearts will not last as long as a healthy organ, leaving them facing a transplant or premature death.
- Three quarters say their lives are "severely impacted" because their heart is invisible to others and frequently overlooked, with some "not believed" about their illness.

A generation ago most children born with half a functioning heart did not survive. Parents faced an 80 per cent risk of losing their child during surgery to give them a chance of life. Surgical developments mean more than 70 per cent now survive their operations and more than 60 per cent reach their 5th birthday. However, their heart conditions remain uncured as the surgery is palliative. They face long term disability and many require a heart transplant before adulthood.

Mr William Brawn, world-renowned Consultant Cardiac Surgeon at Birmingham Children's Hospital, has operated on hundreds of babies and children with single ventricle heart conditions. He said:

"It's inspirational to see this group of pioneering teenagers and young adults who would not have survived without the developments of modern medicine. Little Hearts Matter has been a vital support to many of these families for the past twenty five years. However, their survival has uncovered a range of other issues that we see in these recent survey results. It's clear that there needs to be better awareness and understanding of the obstacles they face so they can receive the support they need to live fulfilled lives."

Quotes from young people involved in the survey include:

"I hate being referred to as a CHD (Congenital Heart Disease) hero or a heart warrior - because I am just me. My heart doesn't define me at all. I prefer to think about all the things I CAN do rather than the things I can't."

"I get angry when people lack understanding no matter how much I try to educate them they think I pretend."

"Not everyone believes me. If I'm blue they comment on it."

"Let me show you what I can do not just what I can't. Just ten minutes of PE is amazing instead of just watching."

"Teachers at school always say I lack concentration. They don't think about the tiredness."

"The issues would all be manageable if there was an end date to them or if there was a chance I would get better, but they're made harder when you realise that it's a reality of having a terminal condition."

- ENDS -

Notes to Editor:

Available for interview:

- Suzie Hutchinson, CEO of Little Hearts Matter (phone or broadcast)

- Mr William Brawn, Consultant Cardiac Surgeon.
- Case studies of children, teenagers and parents living with half a functioning heart.

Methodology

The findings in this report and press release are based upon evidence gathered in LHM's 2019 Membership Survey. The online survey collected responses from across the UK.

About Little Hearts Matter

Little Hearts Matter is a national UK charity offering help to anyone affected by the diagnosis of single ventricle heart condition. From initial antenatal diagnosis, through treatments and into life at home, the charity works with children, young adults and families to reduce the isolation, fear and lack of understanding created when a child is diagnosed as having half a working heart.

www.lhm.org.uk

What are single ventricle heart conditions?

A diagnosis of single ventricle heart disease is made in a child where only one of the two ventricles, heart pumps, has formed correctly. There are five main conditions:

Hypoplastic Left Heart Syndrome

A collection of malformations on the left side of the heart that affect the heart's ability to pump oxygen filled blood around the body. **This condition is incompatible with life if left untreated in the first days after birth.**

Tricuspid Atresia

A malformation in the formation of the Tricuspid Valve and the ventricle, heart pump, formation below it. This condition affects the heart's ability to pump blood to the lungs where it should pick up oxygen. **Long term this condition is incompatible with life and may be treated within days of birth.**

Complex Pulmonary Atresia

A complex malformation of the Pulmonary Valve and the right ventricle, pumping chamber, affecting the heart's ability to pump blood to the lungs thus restricting the body's ability to pick up and circulate oxygen. **This condition is incompatible with life and must be treated within the first few days of life.**

Hypoplastic Right Heart Syndrome

A combination of both Tricuspid Atresia and complex Pulmonary Atresia. **This condition is incompatible with life and may need treatment in the first day of life.**

Univentricular Heart, with Transposition and Double Inlet or Outlet Heart

Is a complex malformation within the pumping chamber of the heart and the valves and major blood vessels leading into the heart or out of the heart. **Long term this condition can be incompatible with life.** Children need surgery within the first year of their life.

Media enquiries:

Emma Pelling - 07958 558172

emma@pellingpr.co.uk