Somerville Heart Foundation

For young people and adults born with a heart condition

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www.sfhearts.org.uk

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Introduction…Our Why

Somerville Heart Foundation (SHF) was founded by Professor Jane Somerville in 1993 (originally named Grown Up Congenital Hearts Patient Association). Professor Somerville was able to extend their lives through her work and recognised that there was no support available to help them deal with everyday life.

SHF is the only UK-wide charity dedicated to supporting young people and adults born with all forms of heart conditions, known as Congenital Heart Disease (or CHD). We provide support, advocacy, communication, and a community. We also campaign for improvements to cardiac care and the right to receive excellent medical care delivered by appropriate specialists, and to enable them to lead happy, healthy, and longer lives.

We receive no government funding and rely on donations and fundraising to provide our services and support.

Professor Jane Somerville receiving the BCS Mackenzie Medal from HRH Princess Anne

Our How (cont'd).....

Advice on lifestyle choices;

- Can I get a tattoo? Is it safe for me to get piercings?
- A helpline
- Our website
- A range of leaflets
- Information on travelling with CHD
- Pregnancy and contraception advice
- A Personal Health Passport
- The risk of endocarditis
- Travel Information
- The importance of good dental care

We support young people transitioning to Adult Services –a difficult time for them regardless of their health concerns and a worrying time for parents too so we're supporting events across the UK for teens and their families – a parent said:

"Heartfest has been great, so much information and the chance to meet staff that will be involved in the future"

Outcomes (cont'd)....

Depending on condition and current health, some may see no imminent need for our support or may access it only when necessary. We're here for them (and their families) whenever they need us. A fear or concern may creep up over time and we're there for psychological support. Often people just need a listening ear or to speak with someone who really understands what they're going through.

The Heart Stories shared in our quarterly newsletter make for powerful reading. We often signpost to these - providing someone recently diagnosed the comfort of knowing they're not alone or giving a family member a better understanding of their loved one's condition.

We work closely with Specialist Hospitals and Healthcare Professionals to ensure the information we provide is accurate and up-to-date. These links are also valuable for ensuring we reach as many people as possible. Going forward, we anticipate a continued demand for psychological support. Covid-19 leaves a lasting impact, particularly on those with health concerns. The fear of going out can still be very real and the uncertainty of changes to appointments, different teams etc is often daunting.

Going Forward

Discussions, focus groups, and events all help shape our work – current and upcoming projects include:

- Advice on exercise – how much should I do? Can I lift weights? How much is too much?
- **Further focus groups with those growing older – using the 5 key points highlighted**
- Campaigning for better dental awareness and services – helping to prevent endocarditis through better oral health, information about removal of teeth prior to surgery/clean bill of dental health
- **Menopause – focus groups exploring the concerns and difficulties experienced such as medication and controlling symptoms alongside CHD**
- Expanding our Psychological Support services to include more Counsellors and additional types of therapy
- **Supporting young people with transition events - partnering with The Prince's Trust, including support for parents, and improving the process of transferring to Adult Services**

Our How

Our increasing Membership offers services and support plus information and resources including leaflets and our popular newsletter UPBEAT. We also facilitate the provision of Coaguchek machines – enabling a new level of independence and fewer hospital visits.

> *"Whilst congenital heart disease is obviously a physical disorder, it more often than not creates a greater mental impact...Needing regular specialist follow up means always thinking of yourself as a patient and living knowing you have a disease...is another burden on the mind."*
>
> The late Michael Cumper, CHD patient and former Somerville Heart Foundation President.

Whilst CHD is a physical condition, the impact on mental health can be much greater - we deliver around 700 hours of psychological support annually.

- In the Priority Setting Partnership Report (A national strategy to address the James Lind Alliance priorities for children and adults with CHD, released in August 2023), the impact of living with CHD on mental health in adults is third of 10 priorities.
- Our Counsellors, both of whom have CHD themselves, offer 1:1 sessions by phone or Zoom.
- We also facilitate peer support via closed Facebook groups and via Zoom. Members say: "I feel seen" and "I am not alone with my condition"
- We enable and encourage peer support for the 1,600+ members on our Closed Facebook Groups and share information, guidance and events to our 7,000+ followers across various social platforms.

Outcomes

There are huge proven benefits for those with CHD in meeting others, combatting loneliness and isolation, often making friends for life and going on to build relationships – over many years and huge distances!

Our recent Hearts Together event in Newcastle was the 18th annual patient gathering. Highly valued by members and Healthcare Professionals, it's a full day packed with presentations, a Q&A session and topical discussions.

It's also a great chance to meet others with CHD and build lasting friendships. In the words of one attendee:

"I found my tribe"

Because of the advances in medication and people living longer with CHD - we support those at the other end of the population. Focus Groups held with those growing older determined 5 key points which continue to shape our work :

•General health and lack of GP awareness
•Changes in patient care
•Loneliness and isolation
•Financial concerns
•The desire to give something back (altruism)

This growing population are pioneers - experiencing the usual co-morbidities of older age alongside complications brought about by their heart condition. We're listening and learning from their lived experiences and hope they can help to inform and support the younger generations by sharing their knowledge.

Research we have been part of includes…

- NHS Golden Jubilee SACCS Improvement Project
- (Champion) Congenital Heart Audit: Measuring Progress In Outcomes Nationally
- Exploring psychological trauma of adults with CHD during COVID-19 - Dr Liza Morton in collaboration with Strathclyde University Senior Lecturer Dr Nicola Cogan
- Congenital Cardiac Disease Review – Patient Experience – Scotland
- Congenital Heart Disease Priority Setting Partnership
- Cardiology 2022 Curriculum Survey
- The CHD draft standards are out for consultation. Feedback will inform the final standards in Scotland
- Heart Disease Lived Experience Network

Impact

> *"Learning more about my condition is powerful"*
> Somerville Heart Foundation Member

> Meeting others with CHD was life changing. It made me realise I could live well with CHD
> Somerville Heart Foundation Member

> I have found connection I didn't know I could have
> Somerville Heart Foundation Member

Images from Scarred FOR Life - our photo exhibition sharing the mental and physical problems and heartache that accompany living with a heart condition

> *These scars are real. They are battle scars. They bear witness to the greatest battle any of us will ever face, the fight for life itself.*

SCIENCEPOSTERS

Working with NHS England and Specialist Hospitals across the UK, a proud member of the Congenital and Children's Heart Forum plus Membership of:

OSCR Scottish Charity Regulator · Charity Commission for England and Wales · Fundraising Regulator · ECHDO European Congenital Heart Disease Organisation · Global ARCH Global Alliance for Rheumatic and Congenital Hearts · NCHO · Community Action Suffolk

Proud to be one of the organisations endorsing the Call to Action on Addressing the Global Burden of Pediatric and Congenital Heart Disease

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