



Little Hearts Matter

Membership of Little Hearts Matter

Little Hearts Matter is a charity and a not for profit registered company.

All financial data on the organisation can be found on both the Charity Commission and Companies House websites and is updated annually in accordance with the company or charity policy.

Little Hearts Matter is a national charity which has been established to:

- **promote the relief of and support for persons affected by a single ventricle heart condition;**
- **support families of children and young people affected by a single ventricle heart condition; and**
- **Advance the education of the general public and the medical profession on the subject of single ventricle heart conditions and their implications for the family.**

The activities to support these objectives include to:

- Offer a range of support to the families of children and young people with single ventricle conditions at all times, but particularly from the time of diagnosis, through treatments and times of stress – including bereavement – and ongoing challenges faced by the children and their families as they become young adults
- Provide a source of information on diagnosis, care, treatment and ongoing lifestyle issues affecting children and young people with single ventricle heart conditions for use by children and young people, their families, professionals and others involved in their care.
- Provide peer to peer support for the children, their families and their siblings, who are impacted by living with and supporting children with these conditions
- Heighten the awareness of single ventricle heart conditions and their treatments and implications with the charity membership, within health, education and social care arenas and the general public.
- Initiate and assist in fundraising activities to aid the advancement of any of the powers of the charity.
- Liaise with other organisations working in the field of congenital cardiology services, disability and statutory services, including adult services for young people in transition from child to adult care.
- Promote and assist in research work in relation to single ventricle conditions, and keeping the membership up to date with new medical and surgical treatments as they evolve.
- Give affected children and young people and their parents the tools to enable them to live as full a life as possible.

A full copy of the charity's governance and membership liability is set out in the Articles of Association which can be seen in full in the governance section of the website.

MEMBERSHIP:

- **Full membership** of the charity is open to parents, grandparents, legal guardians, siblings or step siblings (once they have reached the age of 18 years old) of a child or young person diagnosed with a single ventricle heart condition and anybody with single ventricle conditions once they reach 18 based in the UK and Ireland.
The trustees have the discretion to admit anyone to full membership provided their reasons for inviting someone to do this are documented and transparent, and the Board is in agreement.
- **Associate Membership:**
 - Child Membership is open to any child or sibling of a child who has a single ventricle condition under the age of 18 living in the UK or Ireland.
 - Families from outside the UK and Ireland affected by a diagnosis of single ventricle heart disease.
 - Open to any person interested in furthering the objects of the charity and who has made commitment on an annual basis. This includes advocates and fundraisers.
- **Professional Membership**
Is open to all health, educational and social support professionals involved in the treatment and care of children and adults with single ventricle heart conditions.

Membership entitles full members to:

- Invitations to free national and regional events.
- Use of the LHM support-line and access to LHM team and volunteer support.
- Access to one to one, remote, support for advice and information relating to single ventricle heart disease and single ventricle heart lifestyle information.
- Access to closed social media groups.
- Access to free written information on all aspects of single ventricle heart disease.
- Access to all child and youth focussed activity.
- To have access to and vote on all aspects of the charity's work and the charity accounts presented every year at the annual AGM.
- To vote for the Trustees and for the named positions on the Board.
- To put themselves forward to explore a position on the Board.

Responsibilities of membership

There are no costs relating to membership of the charity but there is an ongoing responsibility for members to work with the Board of Trustees and staff to ensure that:

- the charity can maintain its core functions,
- Income raised for support and information activity is always adequate to maintain the service for all users and growth to ensure that the service remains available for users in the future.
- Maintain the reputation of the charity and the voice of its membership.

In the unfortunate event that LHM has to be wound up, the liability of each member is limited to £1.

The use and protection of member's data

To ensure that Little Hearts Matter can offer the most appropriate support and information members are asked to submit information about themselves and their children, some of which is sensitive. Little Hearts Matter takes the responsibility of protecting member's personal information very seriously.

A number of safeguards have been put in place to ensure that the Little Hearts Matter data base and any written membership files or individual information is kept locked away or encrypted and password protected.

Data within Social Media

All open internet and social media sites are not protected by Little Hearts Matter but personal member's details and contacts used within the closed membership groups or the youth forum will follow the code of conduct set out within the Social Media membership pages.

The use of photographs or films of any child under the age of 18 will follow the clear consent process circulated to all members before any publication or event. Children over the age of 13 will have to consent in partnership with their parents.

Member's data will never be sold on for use by other companies.

Data will only be used by Little Hearts Matter to:

- Offer support
- Offer and disseminate charity information
- Keep members up to date with charity news and the charity's focus.
- Ensure that members are aware of any national or regional issues or consultations that they might like to take part in.
- Provide access to all of the charity's financial and annual reports.
- Update the members on fundraising opportunities and income targets.