

Trustees Annual Report for SPLIT

for the period 01/11/2021 – 31/10/2022

agreed by Trustees 29th June 2023

SPLIT Supporting Paediatric Liver and Intestinal Transplantation

Charity No: 1111945

Administrative Information

Charity name: Supporting Paediatric Liver and Intestinal Transplantation (SPLIT)

Other name the charity uses: SPLIT (or the Charity)

Email: info@splituk.org ; Website: splituk.org.

Registered charity number: 1111945

Charity's principal address: 24 Springfield Rd, Kings Heath,
Birmingham West Midlands B14 7DS

Names of Trustees who manage the charity

Dr Girish Gupte	Chair of Trustees (from January 2020) Elected Trustee 2017; Elected Chair June 2022
Mrs Monica Smith	Deputy Chair of Trustees – resigned June 2022 Elected Trustee 2016
Dr Sue Beath	Elected Trustee October 2018 and Secretary (from April 2020 for 2 yrs)
Mrs Sally Jerome	Elected Trustee October 2016 with oversight of the Website (from April 2020 for 2 yrs)
Professor D Mirza	Elected Trustee June 2018 and Medical Advisor
Ms Evie Calcutt	Elected Trustee September 2021 With advisory role on Financial Risk Management
Mrs Jodie Rhodes	Elected Trustee March 2022 With advisory role of charity public profile
Charity's admin support	Pending

The Model Declaration of Trust for a Charitable Trust deeds were signed on 27th October 2005. A new Governance model was agreed in 2011 implementing the policy and procedures manual. The Charity is an unincorporated association.

Resignations

Mrs Monica Smith resigned in June 2022 after many years of service to the charity and to the children, adolescents, and families of the Liver Unit at Birmingham Children's Hospital. Her wonderful personality, compassion and insights will be missed enormously by all of us. We are all truly grateful for her contributions to the Charity.

Objectives and Activities

The vision and purpose of the Charity is to provide support to children and young people who have a serious liver disease or require/have had an intestinal transplant. Following the strategy meeting in July 2021 and interim meeting focused on how the charity could support post-graduate meetings, some change of emphasis in the Charity's objectives were agreed as follows:

- Financial support for families and crisis grants.
- Information on organ donation and liver / intestinal disease and transplantation, for families, professionals, and the public.
Research and education into the causes of liver / intestinal disease and transplantation, and treatments.

The Charity aims to achieve this in four ways:

1. **Family grants:** Small cash grants to families experiencing hardship because of prolonged hospitalisation of their child. This is especially important for families and children who are often far from home and without the support of extended family. The grants can be for in-patient and long-distance out-patient appointments. This objective continues and is unchanged.
2. **Education grants:** Education for NHS staff (new objective) which may take the form of a) grants for specialist staff to further their skills and knowledge and to share information with colleagues working in the same field, for example these can cover registration and travel expenses for national and international meetings (this aligns with previous objective 4) and b) sponsoring educational meetings for 10 to 150 individuals, with up to three meetings per year.
3. **Medical equipment grants:** Grants for specific medical equipment to enable children to receive treatment at home or in their local area, or for equipment to enable children to manage their difficult and invasive procedures. Such grants are subject to the advice of their medical team.
4. **Research grants:** Small grants medical research related to liver and liver related intestinal failure.

SPLIT's aim is to be flexible in its approach to grant applications and is always willing to consider any application from children and their families which will improve quality of life and support positive outcomes.

Grant applications and pay out as per the four categories above:

Family grant applications (category 1 above) with the approval of a family support worker or liaison nurse are considered by at least two trustees and normally paid out within two weeks. Grant awards for categories 2, 3 and 4 will be considered at a quorate meeting of trustees usually at 2 to 3 monthly intervals.

1. Family grants are for up to £300.00 per individual child up to twice a year, with the approval of a family support worker or liaison nurse (note upper limit has been adjusted

back to the original amount of £300.00 because the charity's income has stabilized following the pandemic).

2. For educational grants, £400 can be provided per applicant for National meetings, and £750 per applicant for international meetings. These are provided on a first come first serve basis, with up to three national and three international awards approved per year.
3. Medical equipment up to a maximum of £2,000.
4. Research grants are up to a maximum of £5,000.

The trustees have had due regard to the Charity Commission's Public Benefit Guidance when exercising powers and duties to which the guidance is relevant.

Financial Structure, Governance and Management

In June 2021 at a designated strategy day, the Trustees reviewed how the Charity interacted with fund raisers and recipients of grants and agreed that some changes were needed. This change in emphasis was agreed by all Trustees and confirmed at the next official Trustees meeting on July 19th 2021. The Trustees held further meeting on February 17th 2022 to focus on providing support for education and post graduate meetings. The Trustees agreed that the charity would allow unrestricted educational grants made by Pharmaceutical and other companies associated with medical science to be transferred to the SPLIT bank account to be spent on postgraduate, meetings which have received the approval of the Trustees. An example of this was the Paediatric Metabolic Study Day on 23rd September 2022 (<https://birminghampaedliver.org/index.php/paediatric-metabolic-study-day-23rd-sep/>).

It was agreed that the Charity's various named notional funds should be consolidated under two broad categories for ease of administration and to reflect the fact that SPLIT has always maintained a single bank account. Darius Mirza confirmed that Rachel Tobey (past Trustee and Treasurer of SPLIT) was content for the residual funds in the Charles Tobey Fund to be amalgamated under the general fund. The funds which had been ring fenced for the Neurocognitive Audit (£3,000) were used to cover the Publishers cost of handling the manuscript (\$1,900 which came out as £1,651.36), and the residual was amalgamated into the general fund and the audit was formally closed (participants notified by letter).

The two remaining notional funds are:

1. Family Fund – this will be used to fund the family grants and medical equipment grants.
2. Education Fund – this will be used to fund education grants and research grants (and it combines the previous Post Graduate Fund & Debbie Hart Memorial Fund).

The charity's annual budget for allocating funds will be set each year usually at the Trustees Meeting in March. The amount will vary because it will depend on the previous year's income.

The decision to suspend research grant awards in 2020-2021 was reviewed in July 2022 and agreed that the Charity would in future, consider supporting small research grants.

The previously agreed structures and administration were continued as follows:

1. The role of Secretary to be created and fulfilled by one of the Trustees – see Duties in Appendix 1.

2. The role of admin support (see Duties in Appendix 1) in future should attract a part time salary amounting to £100 per calendar month and this individual will support the work of the Chair of Trustees and Treasurer and Website Administrator.
3. The communication with the charity should primarily be via the website including applications for funds which could be downloaded from the website.
4. Trustees acknowledged that the cost of energy and transport means that future meetings will mainly be virtual.
5. Dr Girish Gupte continued to take the chairmanship role; Dr Sue Beath remained as Secretary and Mrs Sally Jerome retained responsibility for the SPLIT website. Ms Evie Calcutt will continue to advise on the charity's financial risk management. Ms Jodie Rhodes has developed her role as advisor on the Charity's public profile and as an advocate for the voice of the family and child with liver/intestinal disease within the charity. Prof Mirza continues to act as Medical Advisor and contributes to the Trustee meetings.

During 2021-2022 the board of Trustees met on the following occasions:

November 29th 2021. Via Zoom

January 24th 2022. Via Zoom

February 17th. 2022. Interim Trustees Meeting re postgraduate fund (via Zoom)

March 28th 2022. Via Zoom

May 23rd 2022. Via Zoom

July 25th 2022. Via Zoom

October 3rd 2022. Via Zoom

Recruitment of Trustees - also see Appendix 2

Girish Gupte nominated Ms Jodie Rhodes for consideration as a Trustee on the Board of SPLIT. Jodie is the mother of T R who has been a patient in the Liver Unit at Birmingham Children's Hospital. Jodie has firsthand knowledge of what it is like to spend many weeks/months on the Liver Unit whilst your child receives critical care. Jodie and her family have also been very active in fund raising for SPLIT (see Christmas letter December 2021). It was enthusiastically agreed that Jodie would provide valuable perspectives and original ideas for fund raising and her application to the board was warmly welcomed. Ms Rhodes was elected to the board in March 2023 and the Board of Trustees were delighted to welcome her to her first meeting as Trustee was on 23rd May 2022.

Achievements and Performance November 2021 - October 2022

- Transfer of monies from Prof Mirza's UHB surgeon's fund (from funds donated as a result of his providing his surgical skills for free to individuals in need, not otherwise eligible for NHS care).
- Transfer of monies from the 2018 NITE fund (Network Intestinal Transplantation Europe), which contained the left-over monies from registration, and institutional & pharmaceutical firm sponsorship after speaker and venue fees and catering costs had been paid. Because this meeting was organized and administered by Dr Gupte who gave his time for free, the residual is now available to be donated to SPLIT for the purpose of post-graduate education in future.
- Brockhampton Cricket Fixture. This regular fund-raising event brought about by the family of Charles Tobey. This year the match was played on 29th May: the cricket was good,

The charity's total assets stood £34,823

Reserve Policy

The Charity does not hold any reserves. This is because the administrative costs of the Charity are small and largely consist of the Administrator's salary of £100.00 per month (although the post is currently vacant).

The Charity has no debts and is committed to using its funds for the benefit of children and young people with liver disease and liver with transplanted organs (liver and/or intestine).

The Charity's principle source of funds has been from donations and the fund raising efforts of families affected by childhood Liver and Intestinal Disease. SPLIT particularly wish to thank families who as well as caring for their sick children have been able to support SPLIT through their fund raising and donations. The Trustees wish to acknowledge the Family of Mary Chan who continue to make generous donations four times a year.

Charity Management

Trustees hold at least four minuted meetings each year. An open meeting would normally be held yearly which members of the public are invited to attend (the pandemic has precluded this in 2020 and 2021). Additional meetings can be held according to the needs of the charity and any trustee may call a meeting.

The charity's annual budget for allocating funds will be set each year, usually at the Trustees Meeting in March. The amount will vary because it will depend on the previous year's income.

Appendix 1: Duties for admin support and other roles within SPLIT

Duties of the Admin support for SPLIT

To excel in this position, you should be self-motivated and familiar with working in multi-professional teams in a health care environment.

Liaison role

- Liaise with specialist nurse team and family support worker and keep records of family fund applications
- Support the Chairman of Trustees by ensuring requests for emergency family funding are correctly filled in

Annual reporting duties

- Assist the Chair of Trustees to ensure end of year accounts are completed and available in good time for the auditor to complete the accounts before year end
- Obtain annual report from SPLIT Secretary to be filed with audited accounts and deposited with the Charity Commission

Legalities

- Work with Chair of Trustees or deputy, to review and update any relevant policies

Meeting preparation

- If requested by Chair or Secretary of Trustees, the Administrator will book meeting dates & rooms

Payment

- part time role with a cap on the number of hours funded
- monthly fee which the Trustees of SPLIT have agreed is £100.00 for 5hrs at an hourly rate of £20.00, delivered each month.

Duties of the Chair of SPLIT Trustees

- Ensure Trustee meetings take place at least 4 times per year
- Ensure that accurate minutes are kept by the Secretary and sign them off.
- Ensure that monthly bank statements are seen by all Trustees
- Ensure that the record of all income & expenditure for SPLIT is discussed at Trustee meetings
- Ensure that the Treasurer (if appointed) has reconciled the bank statement's each month with the relevant SPLIT income/expenditure records – otherwise the Chair should do this
- Ensure that all trustees are issued with any new or updated policies
- Ensure the board of trustees meet its legal obligations
- Update the Charity Commission on any changes to trustees / trustee details
- Ensure that ALL updates from the Charity commission are forwarded to trustees

Duties of the Secretary of SPLIT

- Arrange meeting date and place and send meeting invite to all trustees / advisors in good time including information for teleconference
- Receive & process any agenda items from trustees
- Circulate agenda to all trustees at least 2 weeks prior to meeting

- Ensure all trustees are aware of the tasks they have been allocated from previous meetings
- Check that all action has been taken following decisions at previous meeting
- At the meeting, ensure the Chair signs previous meeting minutes if all agree that this is a true & accurate record
- Ensure accurate minutes are taken at the meeting
- Produce & circulate minutes within 1 week of the meeting ensuring that there is a clear record of who will do what & by when
- Undertake actions as directed by Trustees such as official responses; updates to job descriptions; adverts as required

Duties of the Treasurer of SPLIT (or Chair of Trustees if not Treasurer in post)

- Review the record of all income & expenditure for SPLIT in relevant account books kept by the Administrator at every Trustee meeting (at least quarterly)
- Review reconciled bank statement's each month with the Administrator for relevant SPLIT income/expenditure records
- Ensure that annual accounts are submitted to the Charity Commission

Appendix 2: Recruitment of Trustees

SPLIT believes that its Board of Trustees should be comprised of individuals that possess a range of skills and experience, and reflect the diversity of the patients it seeks to help. To that aim, the trustees have recruited individuals to serve on the Board who have experience and knowledge gained through working in specialist paediatric liver units as medical doctors or allied medical staff. In addition, individuals with knowledge or expertise in finance and/or accounting are actively encouraged to join the board of Trustees. The trustees also seek to have at least one Trustee who is a parent of a child who has had a liver transplant, although this is not always possible. Trustees may also have experience gained through previous Trusteeship and Board membership. In order to remain relevant, the Board of Trustees must continually seek to refresh policies and procedures and to keep pace with new ideas. New trustees can be recruited at anytime. New trustees are usually proposed and nominated by an existing trustee or Charity advisor. Proposed trustees are invited to present a CV and are asked to attend the next meeting. Decisions regarding trustee election are made at the meeting.

Re-Drafted by Sue Beath 18th February 2023,

Edited by Evie Calcutt 19th March 2023,

Final draft by Sue Beath 29th June 2023 (incorporating updated information from Accountant's report 2021-2022).