



SPLIT

SUPPORTING PAEDIATRIC LIVER & INTESTINAL TRANSPLANTATION

Trustees Annual Report

for the period 01/11/2018 – 31/10/2019

Administrative information

Charity name: SPLIT Supporting Paediatric Liver and Intestinal Transplantation

Other name the charity uses: SPLIT

Registered charity number: 1111945

Charity's principal address: Box No: 8
51 Pinfold Street
Birmingham
B2 4AY

Names of Trustees who manage the charity

Mrs Monica Smith Joint Chair of Trustees (from June 2019 for 2 yrs)
Appointed Trustee 2016

Mrs Sally Jerome Joint Chair of Trustees (from June 2019 for 2 yrs)
Appointed Trustee October 2016

Mrs Rachel Tobey Treasurer
Appointed Trustee 2017

Dr Sue Beath Trustee
Appointed Trustee November 2018

Dr Girish Gupte Appointed Trustee June 2018

Lorraine O'Reilly Trustee with liaison role with the specialist nursing team
and ward 8 (Appointed Trustee February 2019)

Professor D Mirza Trustee and Medical Advisor
Appointed Trustee May 2019

Charity's Medical Advisor Prof DA Kelly CBE resigned May 2019
Charity's administrator Ms Julie Taylor

Resignations

Ms Cherry Clifford resigned as Trustee in December 2019, The Trustees noted that her years of service and professional insights will be a loss to the charity and she will be greatly missed.

Professor Deirdre Kelly resigned as Medical Advisor in May 19. The trustees recognized her as the founding member of SPLIT and expressed gratitude to her for her work which has benefited families and children with liver diseases, and her dedication over many years in furthering the aims of 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.

The Charity aims to achieve this in four key ways:

1. Small cash grants to families experiencing hardship as a result 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.
2. SPLIT will also consider providing grants for specific medical equipment for individual children and their families in order to enable them to receive treatment in their local area and on the advice of their medical team. Consideration is also given to the provision of equipment in order to enable children to manage their difficult and invasive procedures.
3. Specialist Staff working with children who undergo Liver and or intestinal transplantation are encouraged to apply for Educational grants which SPLIT can award to enable them to further their skills and knowledge and to share information with colleagues working in the same field. These education grants are mainly awarded to those working within the specialist liver units but not exclusively.
4. The Charity is committed to supporting research into liver and liver related Intestinal failure, by the provision of grants to enable small research projects.

SPLIT prides itself that it differs from other charities, in that it will consider grants for young adults up to the age of twenty five provided their treatment started at a Paediatric Centre. Transition to Adult Services can be a very difficult time both for the young person and their family. Many of the resources available in Paediatric Services are not available in Adult hospitals, this at a time when increased support is paramount for an effective transition. Providing financial support and advice to young adults and their families at this time can lead to improved medical outcomes.

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 are administered as follows:

1. The Family Fund:

Applications up to £300.00 will be awarded when endorsed by a health professional who knows the applicant and agreed by two named trustees.

2. Equipment, Educational and Research Grant (categories 2, 3 and 4) will be considered at a quorate meeting of trustees usually at 2 to 3 monthly intervals and awards made according to merit and financial resources of the charity.

3. The Charity has continued to provide a lump sum grant to the Liver Unit at Birmingham Children's Hospital. The purpose of the grant has been to provide individual and immediate grants of up to £50.00 for families attending the unit. Grants are given directly to families by the specialist nurses and family support staff at what is a time of crisis for that family. It is the immediacy of this support which is so helpful to families, at a time of financial crisis often precipitated by a sudden hospital admission to a specialist unit. The provision of the crisis fund better enables medical teams to provide

care for children as it enables parents to focus on health needs without worry about immediate living costs.

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.

Structure Governance and Management

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.

The Charity has a Chair of Trustees who ensures that regular Trustee meetings take place (at least 4 times per year). The Chair also ensures that the following offices are filled or undertakes them him/herself until an appointment is made

1. Administrator
2. Secretary
3. Treasurer

Other Trustees work toward ensuring the charity functions efficiently and according to its main objective: to provide support to children and young people who have a serious liver disease or require/have had an Intestinal Transplant.

Recruitment of Trustees

SPLIT believes that its Board of Trustees should be comprised of individuals that possess a range of skills and experiences, 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. The trustees also seek to have at least one Board member 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.

Achievements and Performance October 2018 - November 2019

Family Fund

In February 2019, an eighteen year boy and his parents received £300.00 to mitigate financial hardship associated with having to make arrangements for an in-patient stay to prepare him for transition to adult services.

In July 2019, a Family Fund grant made to Velma Wright to a total of £500.00 on behalf of families with no transport of their own needing funded assistance with travel home after discharge.

Debbie Hartt Allied Health Professional Fund

1. In May, 2019 Monica Smith was awarded £500.00 to enable her to represent the Liver Unit and participate at the 10th International Paediatric Transplant Association meeting in Vancouver where she was a speaker in the Workshop "Interventions and Outcomes in Transition: Engaging Adolescents in Transition."

2. In June 2019, Laura Johnson was awarded £450.00 to fund travel costs to represent the Liver Unit and speak at session called A Multidisciplinary Approach to Evidence-Based Care in paediatric intestinal transplantation at the international conference in Paris (CIRTA). She also presented a poster at the same conference.

Research publications

Professor Joel Talcott published the results of a long term collaboration between Aston University and the Liver Unit in Birmingham. The award to support Dr T Patel in Long term neuro-cognitive outcomes in cholestatic liver disease was made in 2009-10 and the research was published in the Journal of Pediatric Gastroenterology 2019; volume 69; pages 145-151 – see Appendix 1.

Research projects funded

Dr Warner's application was reviewed for support for a project entitled "*The Role of Mucosal-associated Invariant T (MAIT) cells in Paediatric Autoimmune Liver Disease*" was reviewed. The Trustees agreed in September 2019 to make an award of 50% of the consumables budget described up to a limit of £3783.50, which would enable her to purchase laboratory reagents needed to measure activation patterns in T regulatory cells and other cellular components of the immune response in children with autoimmune liver disease.

Charles Tobey Fund – for rules of administration see Appendix 2

In March 2019, the Trustees approved the grant of up to £50000 to fund a Fibroscan machine for the Paediatric Liver Unit in Birmingham.

Medical Equipment. A request for purchase of a home coagulation monitor for a child requiring regular testing (£172.04) was granted in February 2019 to reduce the number of hospital visits and school time being missed.

Fund raising -

The Charity's principle source of funds has been from the fund raising efforts of families affected by childhood Liver 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.

Financial Review -

The annual financial report for the period 31st October 2017 to 31st October 2018 was submitted to the Charity commission on 14th May 2020.

As of 31st October 2019

The charity's total assets stood at	£33731
Unrestricted Income Funds	£7121
Restricted Income Funds	
Charles Tobey	£12079
Family Fund	£1662
Post Graduate Fund	£849
Debbie Hart Memorial Fund	£7020
Neurocognitive study	£3000
Equipment fund	£2000
Total Restricted Income Funds	£26610

The SPLIT General Fund is unrestricted and stands at £7121. This fund is used to support the administration costs of the Charity, Research Applications, Equipment grants and Education grants to individuals. This fund can also support other funds within the charity as is considered necessary by the trustees.

Restricted Funds

Charles Tobey Fund stands at £12079. It is primarily for research, education and equipment. Donors have stipulated that other requests for funding can be considered if trustees are all in agreement – see Appendix 2.

Family Fund stands at £1662. This fund provides financial support for families in need and supports the provision of medical equipment for individual children when this is advised by specialist medical and surgical advisors.

Post Graduate Fund stands at £849. It provides financial support to enable the organisation of Post Graduate courses in order to promote the sharing of knowledge and experience.

Debbie Hart Memorial Scholarship Fund stands at £7020. It provides financial support for Allied Health Professional to travel to National or International meetings or to undertake Educational visits to further their education or advance their research interests

Neurocognitive Study fund stands at £3000. To further neurocognitive research interests especially in young people aged 15-25 years.

Equipment Fund £2000. For the purchase of medical equipment.

Reserve Policy

The Charity does not hold any reserves. This is because the administrative costs of the Charity are small and the charity does not have pension or salary liabilities.

The Charity has no debts and is committed to using it's funds for the benefit of children with liver disease and those living with an organ transplant (liver and/or intestinal transplant).

The Charity's principle source of funds has been from donations and the fund raising efforts of families affected by childhood Liver 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.

Charity Management

Trustees hold at least four minuted meetings each year. No open meetings were held between 1st November 2018 and 31st October 2019, but the Trustees met on 13th November 2018; 28th March 2019; 18th July 2019; 26th September 2019 and a non-quorate meeting via telephone on 5th December 2019.

Appendix 1

Talcott JB et al abstract of research published in Journal of Pediatric Gastroenterology 2019; volume 69; pages 145-151

Objectives:

Children with liver disease have increased risk of long-term cognitive deficits. We differentiated between the effects of chronic liver disease from that associated with transplantation by recruiting children with cholestatic liver disease (CLD) with and without transplantation.

Methods:

Psychometric measures and magnetic resonance spectroscopy were obtained for 3 groups of children: stable liver disease without transplantation; CLD from birth with transplantation; and individuals healthy to 18 months of age, before transplantation for acute liver failure.

Results:

Cognitive outcomes between children with different disease histories were significantly associated with the duration of liver disease but not the effects of transplantation, including that of immunosuppression. Lower intellectual ability was most frequently observed in the CLD group, whereas all of the acute liver failure group scored within the normal range. Myoinositol and glutamate/glutamine concentrations in cortex were significantly associated with disease duration across the cohort. Neurometabolite profiles in stable liver disease were consistent with subclinical encephalopathy. Impaired growth in early childhood was associated with later cognitive performance.

Conclusion:

Children with prolonged liver disease had the poorest cognitive outcomes despite successful transplantation, suggesting that prolonged cholestasis before transplantation adversely affects neurodevelopment, and reinforces the need for timely interventions.

Appendix 2

Rules for administering the Charles Tobey Fund

CHARLES TOBEY FUND

Aim:

The Charles Tobey Fund is a grant making registered charity which was established to support research and education related to liver disease and liver transplantation in children and young adults.

We support research or education which is designed to prevent, diagnose or manage disease and improve outcomes and quality of life.

Our emphasis is on clinical research or research at the interface between clinical and basic science. We pride ourselves that our research is innovative and of a high standard as judged by rigorous peer review.

Split accepts applications for a wide range of projects, including social, psychological, clinical and laboratory based research which includes equipment and consumables.

1. Meetings for which bursaries are requested should be related to research or education and should be appropriate to the aims of the charity.
2. Bursaries for meetings may be granted up to a maximum of approximately £1000
3. Reimbursement will only be made on presentation of invoices/receipts plus.
4. Applications for research projects should be submitted using the appropriate form available from: splitUK@yahoo.co.uk
5. Applications for funding are determined by the Trustees of the SPLIT.
6. All successful applicants are asked to submit formal feedback on the research project.