

SOFT UK Annual Report

2018 - 2019

# Annual Report and financial statements

## FOR YEAR ENDING APRIL 2019

**Report of the trustees for the year ending 30th April 2019**

The Trustees of SOFT UK present their annual report and financial accounts for the year ended April 2019 and confirm they comply with the requirements of the Charities Act 2011, the SOFT UK trust deed and the Charities SORP (FRS 102).

AIMS AND OBJECTIVES

SOFT UK operates under a Trust Deed dated 26th April 1991, updated by means of a Deed of Variation in 2011 which includes the regulations for appointment of trustees.

The principle aims and objectives of SOFT UK are to provide support, assistance and information to families having a child with a chromosome abnormality, principally Edwards’ Syndrome (Trisomy 18) or Patau’s Syndrome (Trisomy 13) and their related disorders of partial Trisomy, Mosaicism and Deletions.

SOFT UK provides information and support at all stages following a prenatal higher chance or prenatal diagnosis (irrespective of the families’ decision making regarding their pregnancy), or post-natal diagnosis and care of a living child, or bereavement following the loss of a child. With the objective that families feel supported and connected at whatever point in their Trisomy journey.

Approximately 1 in 10 babies born alive will survive to their first birthday and SOFT UK supports those who are caring for a baby or child with these conditions, and who often live with a range of medical challenges and disabilities. Families can share their experiences through the SOFT UK website, newsletter and regular family days, events and conferences. Support is offered to all members of the family, including siblings of affected child, for as long as is required. This may be delivered via our trained support volunteers who offer a support and advice service, accessed via our Enquiries Line. All support services are provided free of charge.

For over 25 years, SOFT UK has built networks with many professionals, including healthcare professionals, geneticists, social care workers and hospice staff. Our information is evidence based and experiential. Developed in collaboration with our professional advisors and families, it is always given to enhance the advice of clinical teams who care for individual families. In line with our charitable mission, we do not offer medical advice. Through our association with, and membership of complimentary organisations, including Genetic Alliance UK, Together for Short Lives, Children’s Hospices, the Fetal Anomaly Screening Programmes of Public Health England, Wales and NHS Scotland, we seek to advocate on behalf of our families, improve services for all affected families and raise awareness of Patau’s and Edwards’ Syndromes and their consequences.

The SOFT UK website provides families and healthcare professionals access to our information and sources of support, including downloadable information resources, research and links to other relevant websites.

A key element of support is our support and advice service, provided by dedicated volunteers and accessed via an Enquiries function within the website. (SOFT UK operates virtually and has no manned office). Families can be referred to the service by healthcare professionals or they can self-refer. Our trained volunteers, all of whom are parents with experience of Trisomy themselves, offer support, empathy, evidence based information resources and signposting to sources of support appropriate to individual families.

SOFT UK has funded and developed a bespoke training package to support our volunteers, in conjunction with Erica Brown, Vice President of Acorn’s Children’s Hospice and Coventry University. The training package is copyrighted to SOFT UK and can be delivered via distance learning or volunteer training development days. Ensuring our volunteers are prepared and supported to fulfil their role.

Written information is provided via booklets available in print or electronic copy, developed with medical professional advisors, who use their expertise to support SOFT UK in its objectives.

E-Newsletters are produced twice per year. These newsletters provide an opportunity for our families to share their experiences and personal stories as well as being an additional source of information.

REVIEW OF ACTIVITIES AND ACHIEVEMENTS IN 2019

**Family Events.** A number of family days were held in 2019. The English family day was held in May 2019, the Scottish family day was held in September 2019, for our Scottish families and an event was held for Northern Ireland families in October 2019. A local family event was also held for families in the South West. This was a new event, designed to enable families who are unable to travel to national events, to meet together and gain local support. This opportunity is being offered for other local groups in 2020.

**SOFT UK Clinician of the Year.** An award scheme to recognize excellence in the provision of clinical care was launched in 2018. Nominated by families, awards were presented to 3 clinicians who had provided excellent care during 2019.

**Working with the NHS.** SOFT has worked continued its work with the NHS during 2019, specifically with Public Health Wales (PHW) and Public Health England (PHE) Fetal Anomaly Screening Programmes (FASP), to support the introduction of Non Invasive Prenatal Screening (NIPT) in England, and the evaluation of NIPT in Wales. During 2019 NHS Scotland have begun to prepare for the introduction of NIPT as part of the Scottish fetal anomaly prenatal screening programme in 2020. SOFT is part of the NHS Scotland planning group and is contributing to the production of parent information literature and will be involved in the delivery of a training programme, co produced with SOFT UK, to audiences of healthcare professionals across Scotland. Ultimately this work will result in hundreds of healthcare professionals having received the training and a greater awareness of Edwards’ and Patau’s syndromes across the UK.

SOFT parent members have contributed to a number of training programmes for NHS staff, which have raised the awareness of Patau’s and Edwards’ syndromes, particularly from a lived experience perspective and contributed to a number of NHS consultations as the recognized support organization for trisomy 13 & 18.

A SOFT Trustee also contributed to an article focused on the power of language when communicating with parents, which was published on the Public Health England website.

**Website Development.** The SOFT UK website continues to be developed to ensure it remains accessible and compliant with developments in technology. This now provides us with a platform for delivery of improved content, use of analytics and a source of enhanced communication with families and healthcare professionals. One of the major developments of content during 2019 was focused on the introduction of the Families Stories section. Further work is underway on Research, Professionals and Trisomy sections.

**Raising awareness.**  A number of activities have taken place during 2019 to raise the awareness of Trisomy 13 and 18. Attendance and participation in the national Rare Disease Day 2019 parliamentary receptions; contribution to an open letter to government, which ultimately led to the launch of a National Geonomic Healthcare Strategy by Baroness Blackwood; attendance at a Westminster Reception of photographic images of children with rare conditions by Samebutdifferent CiC.

**Commissioned research**. A research project delivered by a PhD Education researcher from University of Exeter, which considered the experiences of support SOFT families have received from clinicians, from SOFT UK, and any other support services was published in 2019.The research considered the gaps which exist and what support needs families identified as requiring to be met, or that they would wish other families in the same circumstances to have access to; and what impact might these support services have upon their lives. SOFT UK has already taken action in relation to the findings and will use the outcomes of the research to inform its future developments. The research was at no cost to SOFT UK.

**Appointment of Administrator.** A temporary, part time Administrator has been appointed to support the SOFT Project Manager in delivering the objectives of SOFT UK and optimising its offering to families.

FUTURE DEVELOPMENTS

The Trustees intend to continue their current strategy of maintaining and developing SOFT UK as the organisation of first contact for families and healthcare professionals working with families affected by Patau’s or Edwards’ syndromes. Directing families to the best information and support for them and their circumstance. And increasing awareness of Patau’s and Edwards’ syndromes within health professionals and the public.

Our future plans will be influenced by, and in line with the needs of families affected by Patau’s and Edwards’ syndromes, as expressed by family user feedback and research findings. Developments will be financed from grant income achieved for specific projects, fundraising and donation income and our reserves. The Trustees need to maintain an equitable balance ensuring our current families benefit whilst, at the same time, ensuring a sound infrastructure and financial base are preserved for future families needs.

**Future Planned Development Projects include:**

**Family support.** Utilising the University of Exeter research findings to develop our offering to families. Family events, including trialing local, family peer support meetings.

**Continued website development**. The SOFT UK website has undergone a complete redevelopment to ensure it remains accessible and compliant with development in technology. The next stage in this project involves reviewing, updating and further developing the site content as part of the Information Project.

**Information project**. This project has been scoped and will result in the development of a *Lived Experience Information Resource* for new parents of a child affected by Trisomy 13 or 18. To ensure the resource is derived from lived experience, we will co-design the information with a number of our existing families - drawing on their experience, identifying what they have found helpful and where they have found gaps in available information. We will call upon our medical /professional advisors, who are all experts in the care of these children, to ensure the information is evidence based and aligns with the best research available. Elements of the project include downloadable factsheets; video’s; podcasts; multimedia images available via our website.

**Volunteer development project.** A great deal of work has been done tocreate a community of volunteers who feel supported and empowered to deliver the objectives of SOFT UK during 2019. A comprehensive Volunteer Handbook will be developed to incorporate the policy and training elements, together with consideration of working towards an accreditation scheme in 2020.

**Collaboration with NHS (Fetal Anomaly Screening Programmes).** Building on previous work with the NHS in the development of training programmes to support the implementation of NIPT, supporting the introduction of this step in prenatal screening for Scotland; membership of the NHS Public Health Wales NIPT Evaluation Board and the Public Health England Fetal Anomaly Screening Programme Board.

Trustees of SOFT UK continue to be actively involved in a range of national professional forums. In supporting the work of these forums, SOFT UK seeks to advocate on behalf of families affected by Trisomy 13 and Trisomy 18, to improve services for all affected families and to raise awareness of these genetic conditions.

STRUCTURE, GOVERNANCE AND MANAGEMENT

The Charity is constituted by way of a Trust Deed dated 26th April 1991, updated by means of a Deed of Variation in 2011 and is registered with the Charity Commission under Number 1002918. The Trust Deed regularises the informal arrangements which had been in force since 22nd June 1990.

SOFT UK is a cross border charity and registered with OSCR the Scottish Charity Regulator under the Number SC043341. As a cross border charity SOFT UK operates under the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006.

SOFT UK is governed by it’s Trustee board, which is responsible for setting the strategic direction of the organisation and the policy of the charity. The Trustees carry the ultimate responsibility for the conduct of SOFT UK and for ensuring that the charity satisfies its legal and contractual obligations. Trustees meet quarterly as a minimum.

The Trustee Board requires breadth and depth of experience to carry out is duties effectively. New Trustees are appointed by the existing Board of Trustees, interview and selection being undertaken by a minimum of 3 Trustees, including the Chair. When recruiting new trustees the essential attribute is an empathy and understanding for families affected by Edwards’ and Patau’s syndromes. We advertise via our own networks and invite appropriate professionals to consider joining our Board. Where possible we consider that the skills of the Board should comprise the following:

* Parent trustees
* Business or financial accounting experience
* Health or social care experience
* Education experience

SOFT UK employs one permanent member of staff – a Project Manager, who works on a part time basis, and a temporary part time Administrator to support the delivery of projects. The Trustee Board delegates operational responsibilities for the charity to the Project Manager, who works under the supervision of the Trustees. The Project Manager is supported by a small group of volunteers.

**Trustees**

Mrs C Rose Founder

Mrs J Fowler Chair

Dr D Rees

Mrs L Petrie

Mr J Capper

Mrs E Egan Treasurer

Mrs A Pearson

Mr Gareth Glendinning (re-appointed January 2019)

**Registered Address** 48 Froggatts Ride

Walmley

Sutton Coldfield

B76 2TQ

**Charity Commission**

**Registration Number** 1002918

**OSCR** SC043341

**Solicitors** Anthony Collins Solicitors

Birmingham

**Bankers** HSBC

Ross-on-Wye

**Independent Examiner** Stephen Baker

FINANCES

SOFT UK receives the majority of its funds via fundraising activities, donations and grant funding. The charity’s activities expose it to a number of financial risks. The management of these risks is governed by the charity’s policies approved by the board of trustees, which provide written principles and practices of financial management of the charities finances.

**Statement of Trustees' Responsibilities**

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.

The law applicable to charities requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing these financial statements, the trustees are required to:

* select suitable accounting policies and then apply them consistently;
* observe the methods and principles in the Charities SORP;
* make judgements and estimates that are reasonable and prudent;
* state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
* prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations, and the provisions of the constitution. The trustees contract with a qualified book keeper to maintain its accounts and comply with its employer responsibilities, including HMRC. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

SOFT UK participated in a Customer Review Appointment with our banker – HSBC in 2019. As part of their commitment to fight fraud and financial crime, the appointment ensured HSBC held the right information about SOFT UK as a key part of their ability to detect and deter fraudulent transactions, money laundering, and tax evasion. The Customer Review appointment did not identify any issues of concern in relation to the financial management of the charity.

SOFT UK FINANCIAL ACCOUNTS FOR YEAR ENDING APRIL 2018

FINANCIAL ACCOUNTS

Year ending April 2019

|  |  |  |  |
| --- | --- | --- | --- |
| **Note** | **Unrestricted funds** | **Restricted funds** | **Total 2019** |
| **£** | **£** | **£** | **£** |

**Income and Endowments from:**

Donations and Legacies 29,942 18,097 48,039 Investment Income 73 73

Total Income 30,015 18,097 48,112

**Expenditure on:**

Raising Funds -1,911 -1,911 Charitable Activities -16,307 -5,790 -22,097

Total Expenditure -18,218 -5,790 -24,008

Net movement in Funds 11,797 12,307 24,104

**Reconciliation of Funds**

Total Funds brought forward 42,843 0 42,843 Total Funds carried forward 54,640 12,307 66,947

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  |  | **Note** | **Unrestricted funds** | **Restricted funds** | **Total 2018** |
|  |  | **£** | **£** | **£** | **£** |
|  |  |  |  |  |  |

**Income and Endowments from:**

Donations and Legacies 30,438 30,438 Investment income 16 16

Total Income 30,454 30,454

**Expenditure on:**

Raising Funds -1,810 -1,810 Charitable Activities -31,011 -31,011

Total Expenditure-32,821 0 -32,821

Net movement in Funds -2,367 0 -2,367

**Reconciliation of Funds**

Total Funds brought forward 45,210 0 45,210

Total Funds carried forward 42,843 0 42,843

Accounts signed by:

Mrs Jan Fowler, Chair of Trustees:

Mrs Chris Rose, Founder Trustee:

INDEPENDENT EXAMINER’S REPORT ON SOFT UK FINANCIAL ACCOUNTS 2018

I report on the Accounts of the charity (SOFT UK) for the year ended 30 April 2019, which are set out on pages 10 – 12 of this report.

**Respective responsibilities of trustees and examiner**

The trustees are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is my responsibility to:

* examine the accounts under section 145 of the 2011 Act;
* to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
* to state whether particular matters have come to my attention.

**Basis of Independent Examiner’s Report**

My examination was carried out in accordance with the general Directions given by the Charities Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a ‘true and fair view” and the report is limited to those matters set out in the next statement.

**Independent Examiner’s Statement**

In connection with my examination, no matter has come to my attention:

1. which gives me reasonable cause to believe that in any material respect the requirements:

* to keep accounting records in accordance with section 130 of the Charities Act 2011: and
* to prepare accounts which accords with the accounting records and comply with the accounting requirements of the 2011 Act.

have not been met; or

1. to which in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Name: Stephen Baker

Qualification: Chartered Accountant

Signed: 

Date: 4th October 2019

RESERVES POLICY

SOFT UK has a reserves policy which requires it to hold a minimum of 12 months running costs. This is to ensure that the charity has sufficient funds to meet employment responsibilities, pay outstanding creditors and ensure stakeholder commitments are dealt with in a managed way, should the charity cease to be viable going concern.

The Reserves Policy is reviewed annually by the Board of Trustees.

Annual Report signed on behalf of the Trustees by:

Signed: Chair Trustees

Signed: Founder Trustee

Date: