



SOFT UK ANNUAL REPORT

2017 - 2018

ANNUAL REPORT AND FINANCIAL
STATEMENTS

FOR YEAR ENDING APRIL 2018

Report of the trustees for the year ending 30th April 2018

The Trustees of SOFT UK present their annual report and financial accounts for the year ended April 2018 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. As a membership organization, families can share their experiences through the SOFT UK website, member's 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 Befriending 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 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 Befriender service, provided via 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 Befriender 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.

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

REVIEW OF ACTIVITIES AND ACHIEVEMENTS IN 2018

Family Events. A number of family days were held in 2018. The English family day was held in June 2018 and the Scottish family day was held in September 2018, for our Scottish members.

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 2 clinicians who had provided excellent care.

Working with the NHS. SOFT has worked extensively with the NHS during 2018, 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 Wales and England. In particular this has involved the delivery of a training programme, co produced with SOFT UK, to audiences of healthcare professionals across England; participation in PHE and PHW NIPT Evaluation Boards; and contribution to development of NHS information for parents. Hundreds of healthcare professionals have received the training and report a greater awareness of Edwards' and Patau's syndromes and an impact on their practice, as a result.

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.

Website Development. The SOFT UK website has undergone a complete redesign and redevelopment 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.

Parent Blog. A new monthly blog by a trisomy mum is published on the SOFT UK website, and captures in her words what it has been like for her and her family living through a diagnosis of Trisomy 18 and beyond.

Commissioned research. SOFT UK has collaborated in a research project to be delivered by a PhD Education researcher from University of Exeter. The project will research what experiences of support SOFT families have received from clinicians, from SOFT UK, and any other support services; consider which gaps

exist and what support needs do these families identify 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 will use the research findings to inform its future developments. The research was at no cost to SOFT UK.

Appointment of Project Manager. A part time project manager, with skills and experience in charity and 3rd sector organisations, project management and personal experience of Trisomy, has been appointed to support SOFT UK in delivering its objectives 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 family membership 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.

Information review project. This will involve a wholesale review of our information resources. Co-producing resources with our families and professional advisors to ensure that information is both relevant, experiential and inclusive of the latest evidence base.

Volunteer development project. Creating a community of volunteers who feel supported and empowered to deliver the objectives of SOFT UK.

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 its 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 its 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 member of staff – a Project Manager, who works on a part time basis. 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 (resigned April 2018)	

Registered Address	48 Froggatts Ride Walmley Sutton Coldfield B76 2TQ
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Charity Commission Registration Number OSCR	1002918 SC043341
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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 FINANCIAL ACCOUNTS FOR YEAR ENDING APRIL 2018

FINANCIAL ACCOUNTS

Year ending April 2018

	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		-32,821
Net Movement in Funds		-2,367		-2,367
Reconciliation of Funds				
Total Funds brought forward		45,210		45,210
Total funds carried forward		42,843		42,843

	Note	Unrestricted funds	Restricted funds	Total 2017
		£	£	£
Income and Endowments from:				
Donations and Legacies		24,105		24,105
Investment Income		22		22

Total Income	24,127		24,127
Expenditure on:			
Raising Funds	-1,537	-386	-1,923
Charitable Activities	-44,872		-44,872
Total Expenditure	-46,409	-386	-46,795
Net Movement in Funds	-22,282	-386	-22,668
Reconciliation of Funds			
Total Funds brought forward	67,492	386	67,878
Total funds carried forward	45,210		45,210

	Note	2018 £	2017 £
Current Assets			
Debtors		592	982
Cash at bank and in hand		42,273	44,504
		<hr/>	<hr/>
		42,865	45,486
Creditors: Amounts falling due within one year		-22	-276
		<hr/>	<hr/>
Net Assets		42,843	45,210
Funds of the charity			
Restricted funds			
Unrestricted income funds			
Unrestricted funds		42,843	45,210
		<hr/>	<hr/>
Total Funds		42,843	45,210

Accounts signed by:

Mrs Jan Fowler, Chair of Trustees:



Mrs Chris Rose, Founder Trustee:

Chris Rose

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 2018, 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

2. 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:



13/02/19.

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:

Chris Rose

Founder Trustee

Date: 13.02.2019