



SOFT UK ANNUAL REPORT

2021 - 2022

ANNUAL REPORT AND FINANCIAL
STATEMENTS

FOR YEAR ENDING APRIL 2022

Report of the trustees for the year ending 30th April 2022

The Trustees of SOFT UK present their annual report and financial accounts for the year ended April 2022 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 and 2018 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, specifically 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 of the trisomy experience - following a prenatal higher chance screening result or prenatal diagnosis (irrespective of the families' decision making regarding their pregnancy), post-natal diagnosis, care of a living child, bereavement following the loss of a child or ending a pregnancy. With the objective that families feel supported and connected at whatever point they are in their Trisomy experience.

Around 7 in 10 pregnancies affected by Trisomy 13 or 18 end in miscarriage or stillbirth. Approximately 11 - 13% of 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, social media groups, podcasts, YouTube channel and other events. Support is offered to all members of the family, including siblings of the affected child, for as long as is required. This may be delivered via our trained support volunteers who offer a peer support service, accessed via our Support Service or via our virtual meetings and social media groups. All support services are provided free of charge.

For more than 30 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 our community of 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, Rare Disease networks, Antenatal Results and Choices, 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 associated consequences.

The SOFT UK website social media accounts and our YouTube channel provides families and healthcare professionals access to our information and sources of support, including downloadable information resources, films, podcasts, research and links to other relevant websites.

Key elements of support for families is provided via our Support Line Service, access via email or a dedicated helpline. The Support Line Service is provided by a team of dedicated, trained volunteers. Families can be referred to the service by healthcare professionals or can self-refer. Our 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.

Support can also be accessed via a range of closed Families Facebook groups where families can obtain peer support and shared experience from others who have the lived experience of trisomy. A regular programme of themed virtual calls is run via an online platform.

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 at least 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 2021-2

Engagement:

Remembrance Video Successful launch of a monthly video, shared on social media and remembering children on the anniversary their family was bereaved.

Podcast 'Our Sam' Contributed to the podcast series hosted by 'Our Sam'

SOFT UK Podcast Series Continue with our own podcast releases. Engaging with families and health professionals to share experience and create additional experiential resources

Family Event Two family events held in September and October. One in England and one in Scotland. Due to the impact of Covid 19, these were the first face to face events for over 2 years and were combined with a live streamed virtual event on the same date to enable families who continue to shield, to participate.

Facebook Support Groups Expanded our range of Facebook support groups by introducing specific groups for siblings and extended families looking for support

Short Form Video Content Introduced a new short term video content to appeal to a new audience

Collaboration with other organisations:

Presentation Delivered a presentation at the Genetic Alliance Conference on our guide to make a charity digital at no cost

Delegates Attended the Beacon Rare Disease Networking event in Cambridge

Media Partner Partnered with RASREfest 2022 sharing social media posts and information in support of the event

Health Professional Awareness:

NHS Pregnancy Screening Programmes Continue to work with Public Health England, NHS Scotland and NHS Wales in support of their evaluation of the NIPT addition to the prenatal screening programmes.

Healthcare Professionals Training Launched our first healthcare professional webinar Published our first webinar '*The Importance of Language*'. Further titles will be developed for 2023.

Staffing:

Engagement Officer Our Engagement Officer has been moved from a fixed term to permanent contract due to the success of this post and the importance of continuing effective engagement with our community.

New Appointment We were successful in achieving grant funding which has enabled us to create a Trisomy Advocate role. A 2-year fixed term post will provide specific support to families caring for a child affected by trisomy.

FUTURE DEVELOPMENTS

A Strategy Planning Event was held in September 2022, bringing together Trustees and Volunteers to contribute to the charities forward plan.

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. The primary focus of which will continue to be 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:

Trisomy Advocate Appoint into this grant funded post. Primary objective of the post to work with families caring for a child affected by trisomy, developing resources in support of this part of the SOFT UK community

Training To develop and maintain a series of training materials that will be made available to health professionals on request. This will be built upon depending on what training needs exist and more bespoke training will be made available.

Fundraising More focus to be placed on fundraising. We have just switched to Just Giving as our new platform, and when we have more capacity in March 2022, we will have a dedicated focus on fundraising.

We do currently have podcast stories taking place to promote the incredible work of our community and fundraisers, but there is further opportunity to explore this.

Website Overhaul In 2023 we will implement the developments agreed to develop our website, making it more user friendly for our audience.

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 2018, 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 three permanent members of staff, all of whom work on a part time basis. An Operations Manager, who is responsible for the day to day activities of the charity. A Communications Officer, to support the communications of the charity. An Engagement Officer, who is responsible for ensuring effective engagement with our community.

The Trustee Board delegates operational responsibilities for the charity to the Operations Manager, who works under the supervision of the Trustees. The Operations Manager, Engagement Officer and Communications Officer are supported by a small group of volunteers.

Trustees

Mrs C Rose, Founder (retired January 2022)

Mrs J Fowler, Chair

Dr D Rees

Mrs L Petrie

Mrs E Egan Treasurer

Mrs A Pearson

Mr Gareth Glendinning

Mrs Marlene Graham

Ms Vanessa Monroy (resigned June 2022)

Mrs Juliette Bradley (resigned December 2022)

Mrs Becky Wirth

Registered Address 11 Newlands Road
Uddington
Glasgow
G71 5QP

**Charity Commission
Registration Number
OSCR** 1002918
SC043341

Solicitors Anthony Collins Solicitors
Birmingham

Bankers HSBC
Ross-on-Wye

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 END OF YEAR ACCOUNTS 2021-2022

SOFT UK Profit & Loss for Period 01/05/2021 to 30/04/2022

Income	£	£
Bank Interest		20.01
Gifts and donations		
Restricted	25832.87	
Unrestricted	48407.97	
Miscellaneous Income		0.00
		<hr/>
Total Revenue		74260.85
		<hr/>
Expenses		
Computer and Internet		3718.18
Dues and Subscriptions		150.00
Insurance		229.60
Miscellaneous		49.00
Office Expenses		
Consumables	70.00	
Stationary	140.47	
Supplies	380.00	
		590.47
Payroll Expenses		
Employers NI	0.00	
Employers Pension con	230.52	
Salaries	23236.23	
SMP	0.00	
		23466.75
Postage & Delivery	173.60	
PR	0.00	
Printing & Copying	0.00	
Professional Fees	623.40	
Promotional materials	2750.00	
Telephone	0.00	
Travel & Meetings		
Conference meetings	27623.88	
Travel	0.00	
		<hr/>
Total Expenses		59374.88
		<hr/>
Net Profit/ -Loss for period		<hr/>
		14885.97
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SOFT UK Balance Sheet
As at 30th April 2022

Assets	£	£
Cash at Bank and in Hand		140933.68
HSBC – Business Money Manager Acc	140445.69	
HSBC – Community Acc	487.99	
Current Assets		
Accrued Revenue	0.00	
Prepayments	100.00	
Undeposited Funds	14.17	
Suspense	0.00	
Total Assets	_____	
		141047.85

Liabilities		
Current Liabilities		
Accrued Expenses	0.00	
Payroll Liabilities	105.99	
Accounts Payable	33.20	
Total Liabilities	_____	
		139.19

Charitable Funds		
Funds	126022.69	
Retained Profit/ Loss	14885.97	
Total Equity	_____	
		140908.66


Total Liabilities and Equity	_____	
		141047.85

Note: Restricted fund balance currently 10116.59

Signed by Chair:



Signed by Treasurer:
Date: 10th December 2022



INDEPENDENT EXAMINER'S REPORT ON SOFT UK FINANCIAL ACCOUNTS

I report on the Accounts of the charity (SOFT UK) for the year ended 30 April 2022, which are set out on pages 9 -10 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:

Date: 31st January 2023

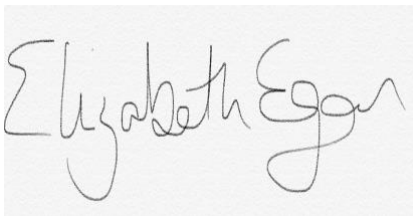
RESERVES POLICY

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:

Treasurer

Date: 10th December 2022