



# SOFT UK ANNUAL REPORT

**2020 - 2021**

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ANNUAL REPORT AND FINANCIAL  
STATEMENTS

**FOR YEAR ENDING APRIL 2021**

## Report of the trustees for the year ending 30<sup>th</sup> April 2021

The Trustees of SOFT UK present their annual report and financial accounts for the year ended April 2021 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 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.

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, events and conferences. 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. 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 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 is now complimented by a closed Families Facebook group where families can obtain peer support empathy from others who have the lived experience of trisomy. A regular programme of themed virtual calls has been introduced in 2021.

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

### Engagement:

**Podcast – Series 1 – Family Stories** Successfully launched our first podcast series which is available across multiple platforms. This series focuses on lived experiences of our community across multiple different scenarios.

**Podcast – Series 2 – Against All Odds** Our second series of podcast stories focuses on families who defied the odds and experienced something they were told would never happen. We have spoken with a range of families, authors, and other support organisations.

**Podcast – Series 3 – The Right Choice For You** Due to be launched in 2022, we have begun recording these episodes. After recognising an imbalance in the stories we have, and a lack of ended pregnancy stories, we reached out to our community to find these stories.

This series will focus on the difficult decision families have made to end their pregnancy, giving a voice to those who can often feel silenced.

**Virtual Family Event** Due to the ongoing pandemic we made the decision to host our family event virtually. This was held via our Facebook page and YouTube channel. We averaged 99 attendees during the live event, and the content is still hosted on both platforms.

**Trisomy Awareness Month** During TAM we held our very first live event, a hosted welcome in which we introduced the month, interacted with the community, and held a small remembrance service. Throughout the rest of the month we published resources and had some of our best social media interaction.

**Expectant Family Calls** We now host a monthly call for expectant families. During these calls we have seen families attend throughout their journey, helping to build relations with them and other families, and also ourselves.

This has helped families get even more information and support, and is widely used by new expectant parents who get in touch with us.

**Themed Calls** We have begun hosting themed calls to help include other groups we support. So far we have hosted calls for dads, siblings, Scottish families, and grandparents.

**Same but Different – You're not Alone** The exhibition, 'You're not Alone', launched in line with Baby Loss Awareness Week 2021. The exhibition showcases incredible stories in a beautiful series of films and written stories.

The exhibition has been seen by a huge audience and very well received.

**Support Phone Line Opened** To further our support reach, the support phone line was opened at the start of 2021. This gives families another option to get in contact with us, and helps build those early relations with those who need it.

**New Blog Options** As part of our engagement drive we have created a new blog section on the website. Here, families will have the option to write a blog for us, detailing their journey for other families to read.

Currently we have two blogs online, with other options currently being explored.

#### Health Professional Awareness:

**NHS Digital** We have been involved with Public Health England, alongside the Downs Syndrome Association, to help create a series of videos that will be available to families in the future regarding a Trisomy journey. We were involved in the recruitment of participants and interviews.

The video will be made available soon and help families receiving a diagnosis of Trisomy. A longer film is being put together that will give more detail and focus on the different family journeys.

**Healthcare Professionals Training** We have responded to a number of requests for training during the course of this year. Delivering presentations at a London NHS Trust and an online conference organised by the British Midwifery Journal. This presentation is now being recorded to be made available online for future events and requests.

We also contributed articles for 2 professional journals

#### Staffing:

**Engagement Officer** In January we recruited a new Engagement Officer on an initial six month trial basis. The aim was to have someone focused on the community and drive projects such as podcasts and video offerings.

#### Governance:

**Rebranding** During 2021 we rebranded all of our information and materials, incorporating bespoke designs. The new design language has now been implemented across our website and social media channels, giving us a consistent, professional image.

**Security Policy Implemented** A new security policy has been implemented to ensure our systems and email are kept safe. This is now an automated service that will automatically prompt and enforce a password change every 90 days.

## 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. 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:

**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.

**Support Service Evaluation** This is in the early stages and offers a huge opportunity to explore what our community and volunteers feel SOFT UK offers in terms of support. We are working to understand areas for opportunities within our current support process, and what is already working well.

The next stage of this will be to explore, with our community through 1-2-1 calls and focus groups, where we can add support, and what they feel helps.

**Face to Face Events** Pandemic dependent, SOFT UK would like to arrange and facilitate local meetings for our community. These meetings would give families an opportunity to meet other Trisomy families and build relationships and support.

**Website Overhaul** In 2022 we will explore the website with the aim of making it more user friendly for our audience. The navigation tree and layout will be changed to help people find the resources they need when they need them.

**Working With Professionals** Linked with the training we will offer professionals; our aim is to also build a network with them. An information pack will help to enable this, which will be sent to new families coming onboard that they can then share with their professional team.

**London Science Museum** We have been approached by the London Science Museum to help them balance an exhibition piece they currently have on show. The exhibition aimed to prompt a discussion around diagnosis in pregnancy, however it had very little context and no stories. We have spoken with them to help source family stories that will help add context. The exhibition will now have an online section that goes into the history of pre-natal testing and the different outcomes. It will also link to stories, and organisations that can help and support.

**Collaboration with NHS** We will continue to support the evaluation of NIPT in NHS screening services, participating in the evaluation forums for NHS Public Health England, Public Health Scotland and Public Health Wales. We have been invited join the CARDRISS Expert Advisory Group which is developing the national Scottish register for congenital abnormalities.

## 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 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 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 two permanent members of staff – an Operations Manager, who works on a part time basis, and a part time Communications Officer, to support the communications of the charity. During the latter part of 2021 we also employed a part time temporary Engagement Officer. The Trustee Board delegates operational responsibilities for the charity to the Operations Manager, who works under the supervision of the Trustees. The Operations Manager and Communications Officer are supported by a small group of volunteers.

## **Trustees**

Mrs C Rose, Founder

Mrs J Fowler, Chair

Dr D Rees

Mrs L Petrie (appointed in December 2020)

Mrs E Egan Treasurer

Mrs A Pearson

Mr Gareth Glendinning

Mrs Marlene Graham

Mrs Rosalind Hill (resigned in October 2021)

Ms Vanessa Monroy

Mrs Juliette Bradley

Mrs Becky Wirth (appointed in March 2021)

**Registered Address**            48 Froggatts Ride  
Walmley  
Sutton Coldfield  
B76 2TQ

**Charity Commission  
Registration Number  
OSCR**                            1002918  
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.

## ANNUAL ACCOUNTS 2020 - 2021

### SOFT UK TRUST Profit & Loss For Period 01/05/2020 to 30/04/2021

	£	£
<b>Income</b>		
Bank Interest		35.85
Gifts and donations		0.00
Restricted	31488.00	
Unrestricted	31016.85	62504.85
Miscellaneous Income		408.00
<b>Total Revenue</b>		<u>62948.70</u>
<b>Expensee</b>		
Computer and Internet		4502.53
Dues and Subscriptions		496.00
Insurance		229.60
Miscellaneous		24.95
Office Expenses		
Consumables	0.00	
Stationery	0.00	
Supplies	81.60	81.60
Payroll Expenses		
Employers NI	0.00	
Employers Pension	174.77	
Salaries	20262.26	
SMP	0.00	20437.03
Postage and Delivery		573.78
PR		977.90
Printing and Copying		249.43
Professional Fees		2921.40
Promotional Material		354.48
Telephone		0.00
Travel and Meetings		
Conference, Meetings	2049.35	
Travel	0.00	2049.35
<b>Total Expenses</b>		<u>32898.05</u>
<b>Net Profit/ -Loss for period</b>		<u>30050.65</u>

Note	Unrestricted funds £	Restricted funds £	Total 2021 £
Income and Endowments from:			
	31,424	31,488	62,912
	35		35
Total Income	<u>31,459</u>	<u>31,488</u>	<u>62,947</u>
Expenditure on:			
	-1,580		-1,580
	-29,269	-2,048	-31,317
Total Expenditure	<u>-30,849</u>	<u>-2,048</u>	<u>-32,897</u>
Net Movement in Funds	<u>610</u>	<u>29,440</u>	<u>30,050</u>
Reconciliation of Funds			
Total Funds brought forward	95,972	0	95,972
Total funds carried forward	<u>96,582</u>	<u>29,440</u>	<u>126,022</u>

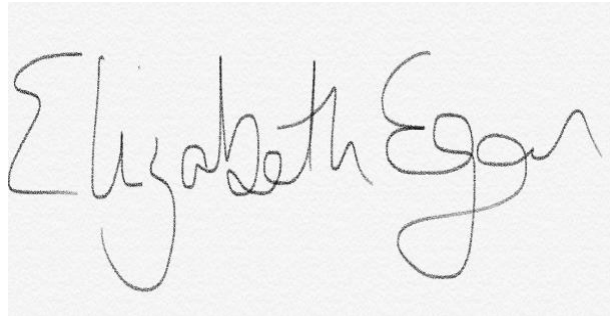
Note	Unrestricted funds £	Restricted funds £	Total 2020 £
Income and Endowments from:			
	60,013	0	60,013
	141		141
Total Income	<u>60,154</u>	<u>0</u>	<u>60,154</u>
Expenditure on:			
	-1,345		-1,345
	-17,477	-12,307	-29,784
Total Expenditure	<u>-18,822</u>	<u>-12,307</u>	<u>-31,129</u>
Net Movement in Funds	<u>41,332</u>	<u>-12,307</u>	<u>29,025</u>
Reconciliation of Funds			
Total Funds brought forward	54,640	12,307	66,947
Total funds carried forward	<u>95,972</u>	<u>0</u>	<u>95,972</u>

	2020	2019
Note	£	£
Current Assets		
Debtors	114	0
Cash at bank and in hand	96,122	66,983
	<u>96,236</u>	<u>66,983</u>
Creditors: Amounts falling due within one year	-264	-36
Net Assets	<u>95,972</u>	<u>66,947</u>
Funds of the charity		
Restricted funds	0	12,307
Unrestricted income funds		
Unrestricted funds	95,972	54,640
Total Funds	<u>95,972</u>	<u>66,947</u>

Accounts signed by:

Mrs Jan Fowler, Chair of Trustees:

Mrs Liz Egan, Treasurer:



## 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 2021, which are set out on pages 10-11 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

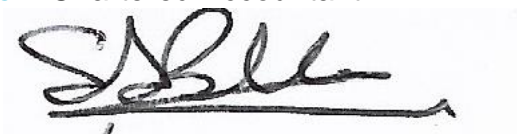
- to prepare accounts which accords with the accounting records and comply with the accounting requirements of the 2011 Act., have not been met;

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: 4<sup>th</sup> January 2022

## 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.

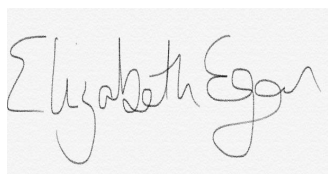
Annual Report signed on behalf of the Trustees by:

Signed:



Chair Trustees

Signed:



Treasurer

Date: 5<sup>th</sup> January 2022

