

THE SANDCASTLE TRUST

ANNUAL REPORT AND ACCOUNTS
FOR THE YEAR ENDED 5 APRIL 2024

CONTENTS

	Page(s)
Reference and Administrative Information	1
Trustees' Report	2–10
Statement of Trustees' Responsibilities	11
Independent Examiner's Report to the Trustees	12
Financial statements	13- 14
Notes to the Financial Statements	15 -18

THE SANDCASTLE TRUST

REFERENCE AND ADMINISTRATION INFORMATION

P O Box 873, Haywards Heath, West Sussex, RH16 9QL
Registered Charity No. 1169523
OSCR No. SC051645

Committee of Trustees

Mrs D. Singleton (Chair until 12 July 2023)
D. Singleton
L. Dodd
C. Bateman (resigned 12 July 2023)
E. Bateman
I. Bateman
L Brooker
M. Holland
S. Eldridge (appointed 12 July 2023)
L. Skinner (appointed 7 February 2024)
J. Clatworthy (appointed 7 February 2024)

Independent Examiner

David Wheeler FCCA
Cheeld Wheeler & Co
Chartered Certified Accountants
Redhill Chambers
2D High Street
Redhill
Surrey, RH1 1RJ

Bankers

CAF Bank
25 Kings Hill Avenue
Kings Hill
West Malling
Kent, ME19 4JQ

THE SANDCASTLE TRUST **TRUSTEES' REPORT**

The Trustees present their report and the accounts for the year ended 5 April 2024.

STRUCTURE GOVERNANCE & MANAGEMENT

The Sandcastle Trust

The Sandcastle Trust was formed as a charitable incorporated organisation on 6 October 2016.

Trustees

Under its Constitution, the activities of the Sandcastle Trust are co-ordinated by a Committee of Trustees whose powers and responsibilities are defined in the Governing Document. The Trustees also decide on the general policy to be adopted in the pursuance of the objectives of the Trust. When the need arises, new trustees will be appointed with regard to their experience and background to further the activities of the Trust. The Committee of Trustees during the financial year being reported on are set out on page 1.

Public Benefit

The Trustees have complied with the duty to have regard to the public benefit guidance published by the Charities Commission.

AIMS, OBJECTIVES AND ACTIVITIES

The objects of the Sandcastle Trust as stated in our Articles of Association are for the public benefit, the relief of sickness of those with a rare genetic condition: to provide practical and emotional support to families living within the UK whereby a member or members of that family have been diagnosed with a rare genetic condition. Particular emphasis is placed on providing affected families with opportunities for family respite.

Mission: The Sandcastle Trust's mission is to reduce inequalities in emotional health and wellbeing outcomes for families living with a rare genetic condition. Our services help to build positive family memories, strengthen family relationships, reduce isolation and improve resilience.

We also increase public awareness of the inequalities and barriers to emotional health and wellbeing that families living with rare genetic conditions face and affect positive change through our work.

Beneficiaries: A family is eligible for The Sandcastle Trust's support when an individual(s) within it have been diagnosed with a rare genetic condition (single gene inheritance, mitochondrial inheritance or chromosome disorder). The Sandcastle Trust defines rare as a condition that affects less than 5 in 10,000 of the general population. The diagnosis must be clinically evidenced. At least one of the following must also apply:

- (i) The condition is degenerative;
- (ii) The condition is life threatening;
- (iii) The condition is life limiting;
- (iv) The condition results in complex health needs, physical disability and/or learning disabilities that have an enduring impact on their family's choices, ability to access social opportunities and enjoy family life; and/or
- (v) A family has suffered a bereavement as a result of a rare genetic condition.

The Sandcastle Trust supports families where a child, dependent young adult or parent has a diagnosis. In 2023/4 25% of the families we supported had parent with a rare genetic condition, 16% had an adult dependent child living with a rare genetic condition and 59% had a child under the age of 18 living with a rare genetic condition. Many of the families we support often have multiple family members with the same condition.

We work with a wide range of referral partners such as disorder specific charities, regional genetic centres, hospices, health, community and social care organisations. However, families can also self-refer to our services.

The Need: There are approximately 6,000 diagnosed genetic conditions. Each affects less than 0.1% of the UK's population, but together they are one of the greatest causes of disability and early death and affect the lives of 3 million people in the UK (source: National Human Genome Research Institute). Collectively, therefore, they are not rare at all. Symptoms of rare genetic conditions vary but can result in physical disabilities (for example, Spinal Muscular Atrophy) and/or severe learning disabilities (for example, Angelman Syndrome) and/or sensory disabilities (for example, Norrie Disease). Many of these conditions are life-limiting.

Living with or caring for a loved one with a rare genetic condition is emotionally demanding. It can involve feelings of anxiety, helplessness and emotional exhaustion, and may also lead to suicidal thoughts or intention.

Diagnosis, treatment, and management of rare genetic conditions are often challenging, and families have to navigate relentless hospital appointments and admissions. Limited awareness and inconsistent care across health, social care services and the education system further add to this burden. Additionally, fears about the future, concerns regarding the genetic inheritance implications for other family members and the impact on personal relationships all contribute to feelings of overwhelm and deteriorating emotional wellbeing.

81% of the families we supported in 2023/4 had experienced mental health issues, 87% felt isolated, 94% experienced anxiety, 92% experienced increased stress, 71% felt unsupported in their caring role and 70% were concerned about the impact on the emotional health of young people in their family acting as young carers. Unfortunately access to counselling via the NHS is limited and involves significant wait times.

In addition, the socio-economic challenges that often come into play following a diagnosis significantly contribute to emotional health and wellbeing disparities: 69% of families we support have a household income below the national average and 40% live in relative income poverty (i.e. have a household income of less than 60% of the UK average). For 98% caring responsibilities impact the number of hours they can work and for 95% disability benefits don't meet the additional costs their family incurs as a result of a rare genetic condition. This means that access private therapy services to support mental health is not financially feasible for our community and even less so since the cost of living crisis.

Whether you are the child or parent with a rare genetic condition, a sibling watching your brother or sister navigate life with a rare genetic condition, or a parent who is terrified of what the future might hold for your child and your family. Addressing the emotional needs of the whole family is of paramount importance

Our Support: Our services help to build positive family memories, strengthen family relationships, reduce isolation and improve resilience. Our work is delivered through our five Sandcastle Support Services:

1. Our Sandcastle Memories Family Respite Service is our largest support programme and provides family respite opportunities to families when a child, young dependent adult or parent is living with a rare genetic condition. We also offer respite support to families who have experienced bereavement as a result of a rare genetic condition.

This support programme gives families living with a rare genetic condition the opportunity to spend quality time together away from their daily routine to refresh and re-energise so that they are able to cope with the emotional and physical rigor of

caring in the long-term and support their emotional wellbeing and resilience.

2. Our Sandcastle Smiles Service provides fun, creative, sensory activities that can be enjoyed by a family together to foster and strengthen family relationships and create positive family memories. This category of support was developed as part of our Coronavirus response and now forms a permanent part of our offer.
3. Our Sandcastle Connections programme aims to alleviate social isolation by helping families build connections across the rare genetic condition community. Connecting with others in a similar situation can be a vital avenue of support for families living with a rare genetic condition and result in lasting friendships and peer support networks.
4. The Sandcastle Support Hub on our website contains lots of useful resources and signposting to reliable information for families who are affected by a rare genetic condition.
5. Our Sandcastle Counselling Service was launched in late February 2024, towards the end of this reporting period. This service is run in partnership with Rare Minds, an organisation that provides a team of experienced, registered therapists that are trained in both the psychological and emotional aspects of rare conditions, as well as in delivering video or telephone counselling. The aim of the service is to offer tailored, one-on-one emotional support to individuals living with rare genetic conditions and their family carers, helping to prevent them from reaching a crisis point. We also extend this service to couples and those who have been bereaved due to a rare genetic condition. The service provides a free, safe space for individuals and carers to discuss their feelings and concerns with a trained professional who understands their diagnosis and the anxieties related to the lifelong journey they face. Each individual or couple is offered a course of eight counselling sessions.

ACHIEVEMENTS AND PERFORMANCE

3. We supported 226 families with a *Sandcastle Memory family respite break, annual pass or day out* in 2023/24. This is just under a 10% increase in the number of families supported via this service in the previous year. This increase is due to the acquisition of our first accessible caravan on the Southview Holiday Park in Skegness at the end of the last reporting period.
4. We provided 38 families with a *Sandcastle Smile* in 2023/4.

5. 329 new families registered as *Sandcastle Families* to access our services during the reporting period and 184 indicated they were willing to provide peer support to other families as part of our *Sandcastle Connections* programme.
6. We provided 15 counselling sessions between the launch of the service in late February and the end of the reporting period. 100% of those who accessed the service this year reported feeling more able to manage the emotional impact of their / their family member's rare genetic condition following their counselling sessions. All reported they found the counselling 'very helpful' and felt it 'very important' to see a counsellor who had an awareness of the challenges of living with a rare condition.
7. Our *Sandcastle Support Hub* had 1800 unique page views in this reporting period.
8. This year we developed the Sandcastle Retreats area on our website – a product for our corporate supporters that are accessible property owners, as well as a useful tool to help families living with a rare genetic condition find accessible holiday accommodation. Run as a small social enterprise, *Sandcastle Retreats* raises funds for The Sandcastle Trust, supporting our family respite service. Properties can be listed for an annual fee of £50, which is reinvested into the charity to fund free respite holidays for families. Properties that donate a holiday to The Sandcastle Trust, providing a free break for one of our beneficiary families, receive a free lifetime listing on our website. This year, through this initiative, we raised £1,293.97 and received 9 donated holidays.
9. We recruited three new trustees in 2023/4 taking our board to 9 members, collectively offering a broad range of skills and lived experience of rare genetic conditions.

Our Impact: We carry out beneficiary surveys to monitor the impact of each of our support programmes in various outcome areas that we have identified as contributing to improved emotional wellbeing and resilience.

This, combined with qualitative feedback on our services, demonstrates they improve mental health outcomes, reduce isolation, help carers to maintain their quality of care and generally provide a positive focus which can empower families with a new enthusiasm and strength to deal with the ongoing daily struggles of illness, gruelling hospital treatment and sometimes a devastating loss.

2023-24

A snapshot of our impact this year!

SANDCASTLE MEMORIES FAMILY RESPITE SERVICE



Having a child with a rare genetic condition meant that going abroad on holiday was difficult; special insurance, doctors notes for injections and medication, having to transport heavy equipment and liquid feeding supplies proved stressful and expensive. Add to this that a lot of parents like me, have to give up work to become carers, puts a huge financial strain on things. Being gifted a caravan holiday was such a blessing to us. We were able to enjoy precious family time together and created memories that will last a lifetime. This proved to be extra special to us as unfortunately our beautiful son passed away a few months after our holiday. We are so grateful to The Sandcastle Trust."

82%
EXPERIENCED A
POSITIVE IMPACT ON
THEIR FAMILY
RELATIONSHIPS AFTER
ACCESSING ONE OF OUR
SERVICES

SANDCASTLE CONNECTIONS SERVICE

"Thank you so much for putting us in touch with X - we have never met anyone else with my daughter's condition before which has been a lonely and frightening experience. Me and X's mum are in regular contact via WhatsApp now. It's been lifechanging really."

100% reported feeling more able to manage the emotional impact of their and/or their family member's rare genetic condition following their counselling sessions.

41%
FELT BETTER
ABLE TO COPE
FOLLOWING THEIR
FAMILY RESPITE
BREAK

“My daughter's sudden and unexpected hospital admission and subsequent diagnosis was a very scary and lonely time for us, until we found other people through The Sandcastle Trust to connect with that also have the very rare gene change. The Sandcastle Trust made us realise that we aren't alone.”

83%
felt their quality of
life had improved
after engaging with
our services

“I feel more able to manage the emotional impact of my condition following the counselling sessions. Counselling also helped me to share my struggles with my family.”

64%
FELT LESS
ISOLATED

62%
Increased in
confidence

72%
REDUCED
STRESS

FINANCIAL REVIEW

The ongoing cost of living crisis and economic challenges that everyone has faced this year has had an impact on our fundraising efforts. Our team have had to work harder than ever before to raise funds

Our income reduced this year from £112,481 in the prior year to £92,999. During the year The Sandcastle Trust spent £68,827 on charitable activities, compared to £49,702 in the previous period. As at 5 April 2024, the Trust had accumulated funds of £74,310 (2023-£70,498).

FUTURE PLANS

In 2023/24, we will continue delivering our core services—Sandcastle Memories, Smiles, Connections, Counselling, and Support—while also focusing on a strategic review to develop a new five year strategy. This review will include an extensive survey to gather insights from the rare genetic condition community on how we can enhance our emotional health and wellbeing support services, as well as gain a deeper understanding of the needs of the families we support and impact of our services. Through this collaborative approach, we aim to co-produce a strategy that better serves our community and ensures lasting positive outcomes.

We also aim to extend our reach and connect with more members of the rare genetic condition community who may not be aware of The Sandcastle Trust and of the services we offer, so that they can also benefit from what we do. Our objective in 2024 is to increase the overall number of families registered to access our services by at least 5%

To achieve this, we will need to improve our fundraising performance. However, we anticipate that the UK fundraising environment will continue to be challenging due to the cost of living crisis and so we will be exploring other ways that we can diversify and develop new income streams for the charity, so that we are sustainable into the future.

RESERVES POLICY

The Trustees' policy is to maintain free reserves in unrestricted funds of a minimum of £5,000 in order to ensure that governance costs are covered and that sufficient funds are available to continue the charity's current activities in the short term while consideration is given to ways in which additional funds may be raised.

We are aiming to build on our reserves over the next few years to ensure long-term sustainability in delivering our vital services to families living with a rare genetic condition, as well as producing more opportunities for growth.

THANK YOU !

We would like to express our sincere thanks to everyone who has supported The Sandcastle Trust in 2023/4. Whether you donated, took on a fundraising challenge, shared your story to help raise awareness of rare genetic conditions, joined an event, played our lottery or volunteered for us, we couldn't have done it without you.

The majority of our income comes from grant making trusts and foundations and we are incredibly grateful to the following who supported our work this year:

The Rank Foundation Pebble Grant

The Albert Hunt Trust

The Charles S French Charitable Trust

The Bruce Wake Trust

National Lottery England Awards for All

Souter Charitable Trust

The Hull and East Riding Charitable Trust

The Pears Foundation

Leicestershire & Rutland Community Foundation

The Screwfix Foundation

The Sir John Middlemore Charitable Trust

The Hobson Charity

National Lottery Wales Awards for All

Kent Community Foundation

National Lottery Northern Ireland Awards for All

The Percy Bilton Charity

The Adamson Trust

Edward Gosling Foundation

The Masonic Charitable Foundation

THE SANDCASTLE TRUST
STATEMENT OF TRUSTEES' RESPONSIBILITIES

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

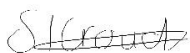
The law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing these financial statements, 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;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

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 Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They 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.

The trustees are responsible for the maintenance and integrity of the charity and financial information included on the charity's website in accordance with legislation in the United Kingdom, governing the preparation and dissemination of financial statements.

Approved by the Trustees on 23 December 2024 and signed on their behalf by:



.....
Samantha Crouch
Chair of Trustees



.....
Luke Brooker
Treasurer

THE SANDCASTLE TRUST CIO
INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES

I report to the trustees on my examination of the accounts of the Sandcastle Trust for the year ended 5 April 2024.

Responsibilities and basis of the report

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts as required under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. Accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. That accounts do not accord with those records; or
3. That accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than the requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



.....

Dated 24 December 2024

David Wheeler F.C.C.A– Independent Examiner

Cheeld Wheeler & Co,
Chartered Certified Accountants
Redhill Chambers,
2d High Street, Redhill,
Surrey, RH1 1RJ.

THE SANDCASTLE TRUST CIO
STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 5 APRIL 2024

	<u>Notes</u>	<u>2024</u>		<u>2023</u>
		<u>Unrestricted</u>	<u>Restricted</u>	<u>Total</u>
		<u>£</u>	<u>£</u>	<u>£</u>
INCOME				
Grants and donations	3	27,864	61,400	89,264
Other trading activities	4	3,609	-	3,609
Interest income		126	-	126
TOTAL INCOME		31,599	61,400	92,999
EXPENDITURE				
Costs of raising funds	5	7,973	-	7,973
Charitable activities		43,362	25,465	68,827
Governance costs	6	9,747	2,640	12,387
TOTAL EXPENDITURE		61,082	28,105	89,187
NET (LOSS)/INCOME FOR THE YEAR		(29,483)	33,295	3,812
TRANSFERS BETWEEN FUNDS		12,390	(12,390)	-
NET MOVEMENT IN FUNDS		£(17,093)	£20,905	£3,812
RECONCILIATION OF FUNDS				
Total funds brought forward		20,994	49,504	70,498
Total funds carried forward	7	£3,901	£70,409	£74,310


The charity had no recognised gains or losses for the year ended 5 April 2024 other than those included in the Statement of Financial Activities.

The notes on pages 15 to 18 form part of these accounts.

THE SANDCASTLE TRUST CIO
BALANCE SHEET AS AT 5 APRIL 2024

	<u>Notes</u>	<u>2024</u>		<u>2023</u>	
		£	£	£	£
FIXED ASSETS					
Tangible assets			38,452		33,212
CURRENT ASSETS					
Debtors		776		1,003	
Bank account		<u>36,882</u>		<u>38,083</u>	
TOTAL CURRENT ASSETS			37,658		39,086
Creditors – amounts falling due within one year			<u>1,800</u>		<u>1,800</u>
NET ASSETS			<u>£74,310</u>		<u>£70,498</u>
The funds of the charity:	7				
Unrestricted			3,901		16,550
Restricted			<u>70,409</u>		<u>53,948</u>
TOTAL CHARITY FUNDS			<u>£74,310</u>		<u>£70,498</u>

Approved by the Trustees on 23 December 2024 and signed on their behalf by:



.....
 Samantha Crouch
 Chair of Trustees



.....
 Luke Brooker
 Treasurer

The notes on pages 15 to 18 form part of these accounts.

THE SANDCASTLE TRUST CIO
NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2024

The charity is registered as a charitable incorporated organisation in England and Wales and its registered office is shown on page

1. ACCOUNTING POLICIES

1.1 Basis of Accounting

The statement of accounts has been prepared under the historical cost convention and is in accordance with applicable accounting standards and the Statement of Recommended Practice, Accounting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011. The charity constitutes a public benefit entity as defined by FRS102.

1.2 Income

Income is accounted for when received by the Trust.

1.3 Grants

Grant income is recognised when there is:

- a) entitlement to the grant,
- b) virtual certainty that it will be received and
- c) sufficient measurability of the amount. Unspent grants are shown on the balance sheet as restricted funds.

1.4 Gifts in Kind

The Charity receives the benefit of work carried out by volunteers and holidays donated by accessible holiday providers.

1.5 Taxation

As a registered Charity the Trust is exempt from Income Tax and Capital Gains Tax.

1.6 Tangible fixed assets

Depreciation is provided at the following annual rate in order to write off each asset over its estimated useful life:

Office equipment - 25% on cost.

Motor vehicles – 20% on cost.

THE SANDCASTLE TRUST CIO
NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2024 cont'd

2. Transactions with Trustees and Other Connected Persons

No remuneration is paid to the Trustees or expenses reimbursed to trustees (2022/23: £264).

3. Income from donations and grants

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2024</u> <u>Total</u>	<u>2023</u> <u>Total</u>
	£	£	£	£
Donations	14,464	-	14,464	30,288
Grants	13,400	61,400	74,800	80,790
	<u>£27,864</u>	<u>£61,400</u>	<u>£89,264</u>	<u>£111,078</u>

4. Income from other trading activities

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2024</u> <u>Total</u>	<u>2023</u> <u>Total</u>
	£	£	£	£
Fundraising & Organised Challenges	<u>£3,609</u>	<u>-</u>	<u>£3,609</u>	<u>£1,361</u>

5. Expenditure on Raising Funds

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2024</u> <u>Total</u>	<u>2023</u> <u>Total</u>
	£	£	£	£
Fundraising Materials	6,289	-	6,289	3,343
Advertising and marketing	1,684	-	1,684	1,947
	<u>£7,973</u>	<u>£ -</u>	<u>£7,973</u>	<u>£5,290</u>

THE SANDCASTLE TRUST CIO
NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2024 cont'd

6. Governance Costs

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2024</u> <u>Total</u>	<u>2023</u> <u>Total</u>
	£	£	£	£
Depreciation	169	-	169	-
Insurance	346	-	346	217
Bank charges	83	-	83	180
Postage and stationery	286	-	286	286
Storage costs	874	-	874	-
IT and software	924	-	924	-
Staff costs	352	-	352	-
Telephone and internet	634	-	634	-
Consultancy	4,200	2,400	6,600	-
Other costs	41	-	41	-
Independent examiner	1,756	240	1,996	1,320
	£9,747	£12,640	£12,387	£6,529

7. Movement in Funds

	<u>At 6</u> <u>April</u> <u>2023</u>	<u>Income</u>	<u>Expenditure</u>	<u>Transfers</u>	<u>At 5</u> <u>April</u> <u>2024</u>
	£	£	£	£	£
Unrestricted	20,994	31,599	(61,082)	12,390	3,901
Restricted	49,504	61,400	(28,105)	(12,390)	70,409
Total	£70,498	£92,999	£(89,187)	£ -	£74,310

THE SANDCASTLE TRUST CIO
NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2024 cont'd

8. Analysis in funds	<u>Unrestricted</u>	<u>Restricted</u>	<u>2024</u> <u>Total</u>
	£	£	£
Fixed assets	4,229	34,223	38,452
Debtors	776	-	776
Cash at bank	696	36,196	36,882
Creditors	(1,800)	-	(1,800)
	<u>£3,901</u>	<u>£70,409</u>	<u>£74,310</u>