

# THE SANDCASTLE TRUST

England & Wales · Charity number 1169523

## Details

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**Status** Registered

**Legal form** CIO

**Registered** 2016-10-06

**Register** [View on the Charity Commission register](#)

## Contact

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**Address** The Sandcastle Trust  
c/o Anderida  
Beaconsfield Road  
Chelwood Gate  
East Sussex  
RH17 7LG

**Phone** 07540382724

**Email** [info@sandcastletrust.org](mailto:info@sandcastletrust.org)

**Website** [www.sandcastletrust.org](http://www.sandcastletrust.org)

## Activities

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**Objects:** FOR THE PUBLIC BENEFIT, THE RELIEF OF SICKNESS OF THOSE WITH A RARE GENETIC CONDITION AND IN PARTICULAR TO HELP AND SUPPORT 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 ENHANCING THEIR FAMILY LIFE BY(BUT WITHOUT LIMITATION):(A) THE PROVISION OF ACCESSIBLE HOLIDAYS;(B) THE PROVISION OF ACCESSIBLE DAY TRIPS;(C) THE PROVISION OF GRANTS TO ASSIST FAMILIES PLAN THEIR OWN ACCESSIBLE FAMILY HOLIDAY;(D) ASSISTING IN THE PROVISION OF CARE FOR THE INDIVIDUAL(S) WITH THE GENETIC CONDITION WHILST ON THEHOLIDAY/DAY TRIP IF REQUIRED;(E) RESPITE FOR CARERS EITHER BY WAY OF A GRANT, HOLIDAY OR DAY TRIP AWAY FROM THEIR CARING ROLE; AND(F) THE PROVISION OF SUPPORT AND INFORMATION ON ACCESSIBLE HOLIDAYS GENERALLY TO FAMILIES AFFECTED BY RAREGENETIC CONDITIONS.

**Activities:** The Sandcastle Trust walks alongside families living with a rare genetic condition to help build lasting positive family memories, strengthen family relationships, improve emotional wellbeing and resilience.

## Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Other Charitable Activities
- **What:** Disability
- **Who:** Children/young People, People With Disabilities, Other Defined Groups

## Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

## Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-05	£159,478	£104,868	-	-
2024-04-05	£92,999	£89,187	-	-
2023-04-05	£112,481	£61,521	-	-
2022-04-05	£64,392	£62,674	-	-
2021-04-05	£38,318	£30,998	-	-

## Trustees

Name	Role	Appointed
DAVID MICHAEL ROSS SINGLETON		2016-06-29
ELEANOR JANE BATEMAN		2016-06-29
IAN ANDREW BATEMAN		2016-06-29
Jessica Clatworthy		2024-02-07
LESLEY ANN DODD		2016-06-29
Laura Skinner		2024-02-07
Luke Brooker		2017-10-01
Mina Holland		2020-09-13
Samantha Louise Crouch		2023-07-12

**THE SANDCASTLE TRUST**

England & Wales - Charity number 1169523

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# Accounts

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**Sandcastle  
Trust**

Supporting rare families

**Annual Report &  
Financial Statements**  
For the year ended 5 April 2025

# Contents

## 2 Reference and Administrative Information

### 3 - 18 Trustees' Report

Structure, Governance and Management  
- Who we are

Aims, Objectives and Activities  
- Why we are needed  
- Our support  
- Our Strategic Plan 2025-30

Achievements and Performance  
- Our impact  
- Case study - Harry's Family Story

Future Plans

Financial Review

Thank you!

Reserves

Statement of Trustees' Responsibilities

### 19 Independent Examiner's Report to the Trustees

### 20 Financial Statements

### 21 Balance Sheet

### 22-23 Notes to the Financial Statements

## Reference and Administrative Information

### The Sandcastle Trust

Registered with The Charity Commission for England and Wales: 1169523  
and  
The Office of The Scottish Charity Regulator: SC051645

Principal office and registered address: c/o Anderida, Beaconsfield Road, Chelwood Gate, East Sussex, RH17 7LG

#### Committee of Trustees:

Samantha Crouch - Chair  
Luke Brooker - Treasurer  
David Singleton  
Lesley Dodd  
Eleanor Bateman  
Ian Bateman  
Mina Holland  
Laura Skinner  
Jessica Clatworthy

#### Staff Team:

Danielle Singleton - Head of Service Delivery and Operations  
Ali Bryant - Support Services Coordinator

#### Independent Examiner:

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

# Trustees Report

## Structure, Governance and Management

### Who we are

**The Sandcastle Trust's Mission is to reduce inequalities in emotional well-being outcomes for families living with a rare genetic condition. We walk alongside families providing a toolbox of emotional well-being services that build positive memories, strengthen family relationships, reduce isolation and improve resilience.**

**We also increase public awareness of the inequalities and barriers to emotional well-being that families impacted by rare genetic conditions face, and advocate for positive change.**

#### STRUCTURE GOVERNANCE & MANAGEMENT

The Trustees present their report and the accounts for the year ended 5 April 2025.

The Sandcastle Trust is a Charitable Incorporated Organisation which was registered 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.

**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. We support families where a child, dependent young adult or parent has a diagnosis and this contributes to significant emotional well-being challenges either for themselves or their immediate family members, for example due to:

- Degenerative progression
- A life-threatening prognosis
- A life-limiting diagnosis
- Complex health needs, physical disability and/or learning disabilities
- Bereavement as a result of a rare genetic condition

# Trustees Report

## Aims, Objectives and Activities

### Why we're needed

#### Rare Genetic Conditions - Facts and Stats



**There are more than 6,000 individual rare genetic conditions. Each affects less than 0.1% of the UK's population, but together they are a significant cause of disability and early death and affect the lives of 3 million people in the UK.[1]**



**Rare genetic conditions can be both life-limiting and life-threatening, and disproportionately affect children, Around 30,000 babies and children are newly diagnosed in the UK each year and more than 3 in 10 children with a rare genetic condition will die before their fifth birthday. [2]**



**Some rare genetic conditions are inherited, meaning the gene change is passed down from one or both parents. Alternatively, a condition may result from a de novo gene change - a new change in DNA that occurs spontaneously for the first time in that person, often during the formation of the egg or sperm, or very early in development; this kind of change is not present in either parent.**

**The Need:** Some rare genetic conditions are apparent at birth, while others are diagnosed throughout childhood and sometimes into adulthood.

Depending on the type of rare genetic condition, it can cause physical disabilities (e.g. Spinal Muscular Atrophy), severe learning disabilities (e.g. Angelman Syndrome) and/or sensory disabilities (e.g. Norrie Disease or Usher Syndrome which both cause severe eyesight and hearing impairment). It is also not uncommon for multiple family members to be affected by the same condition.

The complex challenges associated with rare genetic conditions have a profound impact on the emotional well-being of every member of the family, creating deep-rooted inequalities.

Throughout 2024, we undertook an extensive strategy consultation in which families generously shared their challenges.

Despite the wide range of rare genetic conditions and the varied symptoms they bring, families consistently described many of the same difficult experiences. Whether navigating limited awareness, delayed diagnosis, relentless hospital appointments, complex treatment decisions and unpredictable health crises, or trying to balance work, parenting and relationships - parents, children, siblings or adults living with a diagnosis all face emotional and psychological demands that can be overwhelming.

Our consultation also revealed that families face complex, intersecting barriers to accessing emotional wellbeing support. Together, these findings clearly show that families impacted by rare genetic conditions are at increased risk of poor emotional well-being and highlight the urgent need to address the emotional needs of the whole family.



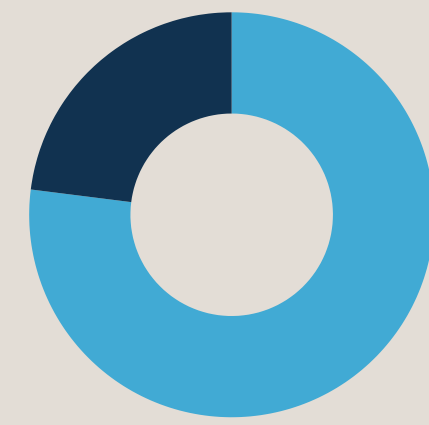
[1] National Human Genome Research Institute

[2] DHSC - UK Rare Diseases Framework

# What our community told us

Commonly occurring words and phrases in responses:

1. Trapped
2. Feeling useless
3. Burnt out
4. Lonely
5. Scared for the future
6. Excluded
7. Hopeless
8. Resentful
9. Frustrated
10. Unsupported



84%

have at least one family member experiencing mental health challenges.

69%

Have suffered anticipatory grief/loss

94%

regularly feel anxious

77%

would describe themselves as depressed

93%

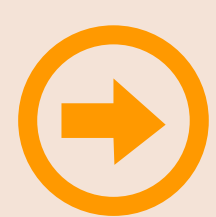
are chronically stressed

87%

are isolated

68%

have experienced relationship crisis or breakdown



We asked what aspects of living with a rare genetic condition were the largest contributors to poor emotional well-being within their family:

82%

Long hospital stays, painful procedures, traumatic medical events

61%

Concerns around genetic inheritance for other family members

91%

Impact on relationships

89%

Inaccessible environments

69%

Workplace or educational discrimination

84%

Having to be the "patient expert" and educating health professionals due to lack of awareness.

74%

Living with uncertainty around the condition's progression or life expectancy

70%

Lack of time or capacity for self-care, rest or personal identity outside caring.



## And what barriers they faced when accessing emotional well-being support:

### Financial

Financial challenges limit access to activities that can support mental health: 69% of the respondents had a household income below the national average, largely due to caring responsibilities impacting the number of hours in employment (98%) and disability benefits not meeting additional costs (94%).

### Systemic

Standard healthcare pathways tend to focus on physical symptoms rather than psychological impact - 75% of respondents were never asked about their emotional well-being in medical appointments relating to their condition or that of the person they care for. Unfortunately access to counselling via the NHS involves significant wait times. When families are provided with support, they often encounter mental health professionals with little awareness of rare conditions and generic support can fail to meet their highly specific needs.

### Practical and Logistic

Finding time away from caring responsibilities, frequent hospital appointments and unpredictable health crises can make it difficult to commit to counselling sessions or engaging in well-being/respice activities. Families with complex medical or accessibility needs who have had previous negative experiences with inaccessible venues or services, understandably can lack the confidence to try again.

### Emotional Overload

The idea of arranging support, attending appointments or taking time for respice can feel overwhelming, particularly when families are already operating in "survival mode". Some describe feeling they must "just keep going", leaving little space to process their emotions or prioritise their own well-being.

“When our youngest was born, we both had to significantly reduce our working hours to manage his care. A family holiday feels out of reach now, our income just can't stretch to it.”

“I was diagnosed 15 years ago and since then my condition has significantly progressed. I can no longer work and I have really struggled to come to terms with this. I probably need counselling, but the idea of fitting in another appointment when I'm already exhausted is overwhelming.”

# Our Strategic Plan 2025-30

At the end of this reporting period, The Sandcastle Trust launched its new five-year strategy, setting out a clear and ambitious direction for our work from 2025 to 2030. The development of this strategy was a significant piece of work undertaken throughout 2024, led by Trustees and staff and shaped by the voices and lived experiences of families in the rare genetic condition community.

Structured around four pillars, our new strategy articulates and builds on our long-term ambition, developed over the past few years, to move

from being primarily a provider of respite and memory-making opportunities, to a charity offering a broad, flexible 'toolbox' of emotional well-being support. While providing direct services to families will always be our primary focus, we recognise that breaking down the barriers to emotional well-being faced by families living with rare genetic conditions also requires greater awareness and broader systemic change. Our strategy therefore also commits to amplifying the voices of families impacted by rare genetic conditions to influence change.

## 1. SUPPORT

**GOAL:** Sustain our existing services, while developing new approaches to meet the complex and interconnected emotional well-being needs of families. We will:

- ➔ Grow the capacity of our existing services and broaden our support offer.
- ➔ Work with our community.
- ➔ Extend partnership working.
- ➔ Develop a volunteer programme.
- ➔ Improve the way we monitor and demonstrate the impact of our work.

## 2. SCALE

**GOAL:** Strive to ensure that every family affected by a rare genetic condition in the UK is aware that we are here to support them. We will:

- ➔ Ensure that the most marginalised in the rare genetic condition community are accessing our services.
- ➔ Work towards our service user database having a balanced representation from each UK nation.
- ➔ Raise our profile and get our messages to those who need to hear them, in a way that they can receive them.
- ➔ Strengthen our links with other organisations that work with families impacted by rare genetic conditions.

## 3. SPEAK UP

**GOAL:** Empower families to share the emotional well-being impact of living with rare genetic conditions and the barriers they face in accessing support. Amplify these voices to influence policy, practice and public understanding. We will:

- ➔ Plan campaigns, content, and communications that drive awareness and engagement.
- ➔ Increase our reputation as a 'trusted voice' on this subject and take an active role in disability coalitions and partnerships.
- ➔ Share more about The Sandcastle Trust and the impact of our services: Expanding our use of digital to bring people closer to our work.

## 4. STRENGTHEN

**GOAL:** The Sandcastle Trust is a sustainable charity that will be here to support families living with rare genetic conditions for many years to come. We will:

- ➔ Operate at the highest level of governance and safeguarding.
- ➔ Have a strong, relevant, inclusive brand and voice.
- ➔ Develop new and diverse income streams.
- ➔ Build our reserves to 6 months expenditure.
- ➔ Ensure we have a strong employment offer that attracts and retains staff.



# Our Support: The Toolbox

The Sandcastle Trust walks alongside families living with the challenges of a rare genetic condition to help support their emotional well-being and resilience.

Families can access our support directly through self-referral or be referred by a wide range of partners, including condition-specific charities, regional genetic centres, hospices, and health, community and social care organisations.

We offer a flexible toolbox of support, with some services designed for individual family members and others supporting the whole family together.

420 families registered with us to access our services in 2024/5 compared to 329 in 2023/4, a 28% increase.

We carry out beneficiary surveys to monitor the impact of each of our services in outcome areas that contribute to improved emotional well-being and resilience. This data, combined with qualitative feedback, demonstrates our toolbox improves mental health outcomes, reduces isolation, helps carers to maintain their quality of care and generally provides a positive focus which can empower families with a new enthusiasm and strength to deal with the ongoing daily challenges of living with rare genetic conditions.



## Family Respite Service

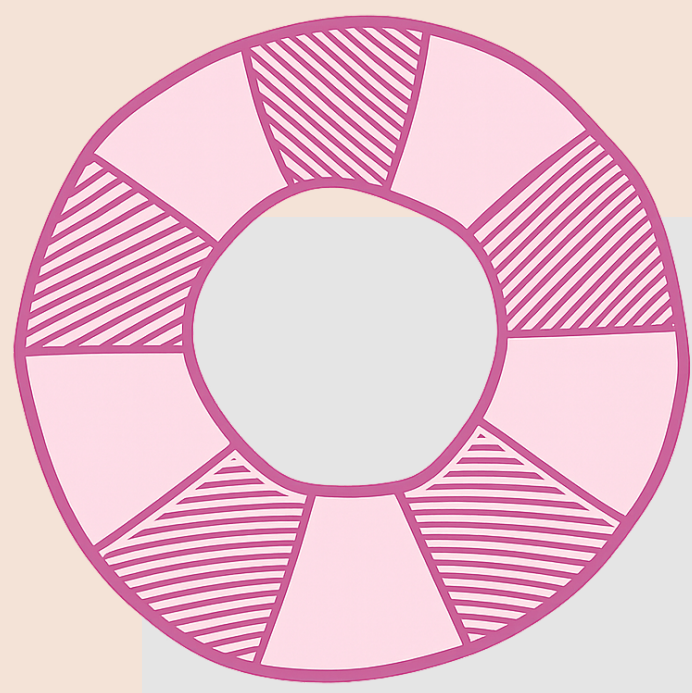
Our Family Respite Service gives families the opportunity to spend quality time together away from their daily routine to refresh, re-energise and reconnect. Many families tell us that rare genetic conditions can put pressure on relationships, limit opportunities for positive shared experiences, and make getting out together feel difficult, whether due to accessibility challenges, the emotional energy needed to plan, or the financial pressures of disability-related costs. Our respite experiences remove these barriers and make meaningful time together feel possible, helping families improve day-to-day emotional well-being, strengthen relationships and build resilience for the long term.

We tailor respite to each family through three strands:

**Sandcastle Memory Breaks** are free short breaks or special days out that help families create positive shared experiences without worrying about cost or accessibility. Breaks take place in our wheelchair-accessible caravans (in Skegness and North Wales, with fundraising underway for a third on the South Coast). Where our caravans are geographically inaccessible, unsuitable for the size of a family, or unable to meet their specific accessibility requirements, we instead offer alternative short breaks with trusted accessible holiday accommodation partners, or arrange special day trips and annual passes to inclusive attractions (for example, farms or steam railways).

**Sandcastle Fair Breaks** give families who have previously received a free break the option to rent one of our caravans again at a heavily subsidised rate. This keeps ongoing respite fair and accessible, reducing financial barriers and allowing families to continue building positive memories over time.

**Sandcastle Smiles** are wellbeing-focused, creative and sensory home-based respite activities, such as baking kits or craft boxes. These offer stress-free fun and connection without the challenges of travel, which can be especially valuable for families navigating palliative care or complex medical needs.



## Counselling Service

Despite the profound emotional impact of rare genetic conditions, specialist emotional support

is provided to individuals impacted by a rare genetic condition and provides a safe, non-judgemental space to feel heard, understood and supported. Recognising the strain that a rare genetic condition can place on relationships, we also offer couples counselling to support partners navigating these challenges together.

Our registered therapists are specialists in the emotional and psychological impact of rare conditions and are experienced in delivering support online or by telephone, making help accessible even for families who cannot travel or who have demanding caring responsibilities. The sessions are also fully funded to remove any financial barriers.



## Peer Support

Our Peer Support Programme currently offers two routes for families living with rare genetic conditions to connect with others who understand their challenges. The **Sandcastle Connections Family Matching Service** enables individuals and families to be introduced to others facing the same rare genetic condition, helping them share lived experiences, learn from one another, and feel less alone. Alongside this, the **Family Spotlight** is a monthly email that features a family seeking peer advice or support on a particular issue. By inviting responses from those with comparable experiences, even when their rare genetic conditions differ, the Family Spotlight encourages collective problem-solving and emotional support across the wider community, showing that while the diagnoses may vary, many of the challenges that families face are shared.

These existing strands will soon be brought together and expanded through the launch of a new project, the **Sandcastle Connections Café**, an online space designed to strengthen and grow peer support for the rare genetic condition community.



## Signposting and Information Hub

Our Support and Signposting Hub is an online resource bringing together trusted organisations and sources of guidance, advice and practical help for families living with a rare genetic condition. We experienced a huge increase in the number of people accessing the hub this year – it received 9,409 unique page views, compared to 1,800 in the previous year.



## Rare Voices

Rare Voices is a core project within our Speak Up strategic pillar through which we support and empower individuals and families to share their personal experiences of how rare genetic conditions affect emotional well-being, and the barriers that are often faced in accessing appropriate emotional support.

We amplify Rare Voices through thoughtful storytelling, digital campaigns, and partnerships, increasing public understanding and awareness, with the longer-term aim of influencing thinking and contributing to improvements in emotional wellbeing support.

Rare Voices also plays a vital role in our peer connection work. By sharing real family stories, we help individuals and families see their own experiences reflected in others, reducing isolation and fostering a sense of belonging within a wider community of people who understand what life with a rare genetic condition can mean.

# Trustees Report

## Achievements and Performance

### Our Impact

### Family Respite Service



#### Sandcastle Memories

(free short breaks, special days & annual passes)

**157 families**

made up of 664 individuals

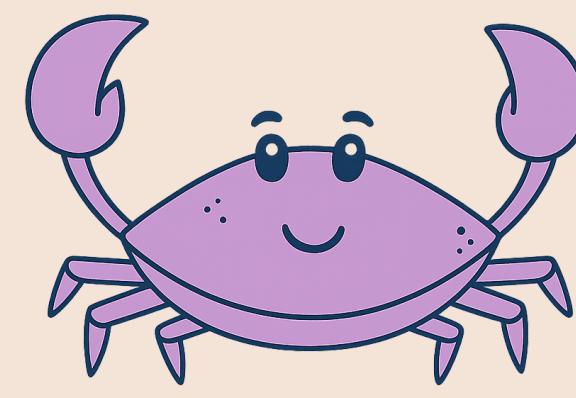


#### Sandcastle Fair Breaks

(subsidized short breaks)

**3 families**

made up of 12 individuals



#### Sandcastle Smiles

(home based respite activities)

**75 families**

made up of 285 individuals



**961**

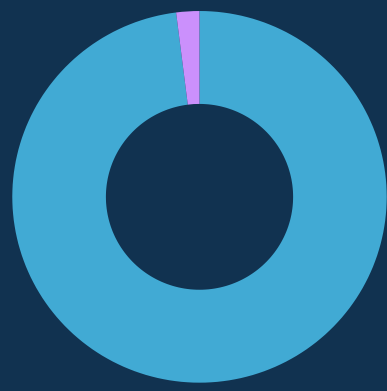
individuals supported

### Impact



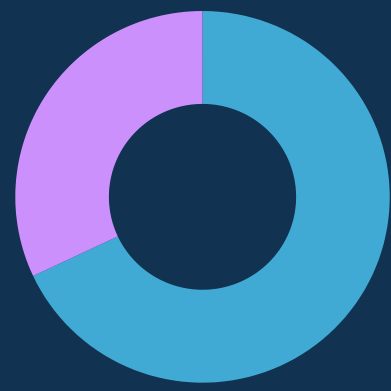
**100%**

created positive family memories



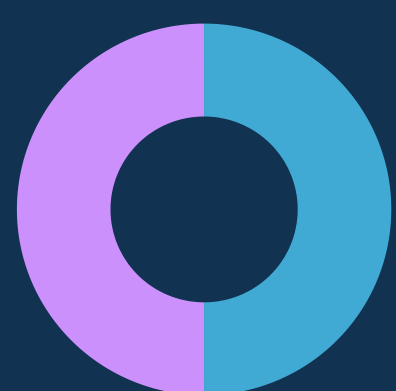
**98%**

reported improved quality of life



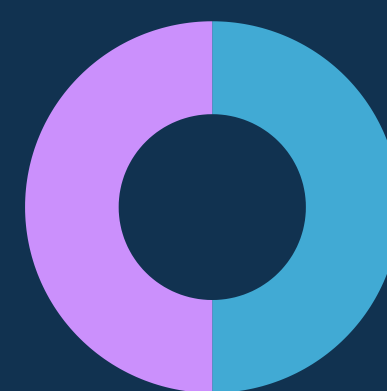
**72%**

reported reduced stress



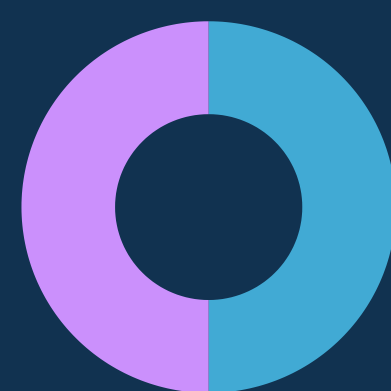
**69%**

felt less isolated



**62%**

reported a positive impact on confidence



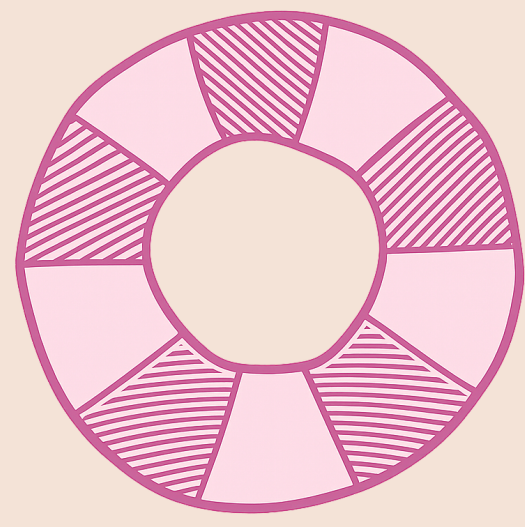
**82%**

experienced a positive impact on their family relationships

“Bardet–Biedl syndrome has impacted our lives for decades. We lost one son to it when he was just three years old, and that loss is something we carry with us every single day. Alongside that grief, caring for Christopher has been relentless, day in, day out, for over 30 years. As he’s grown into adulthood, so many services have fallen away, leaving it all on us just as we’re growing older and facing our own health challenges. When you care like this for so long, it wears you down physically, mentally and emotionally. On a basic pension, the financial strain is huge, we simply couldn’t afford a break on our own. Our Sandcastle Trust holiday gave us space to breathe and precious time together without hospital appointments, carers to organise or constant worry. We went to the pier, went to the market and sat on the promenade. It wasn’t crowded on the pier and Christopher loved that, as he could drive his wheelchair easily and feel free. It really was a much need break.”



## Counselling Service



Individual  
Sessions

150 delivered



Couples  
Sessions

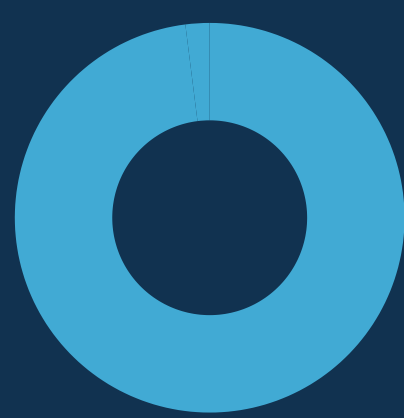
16 delivered



34

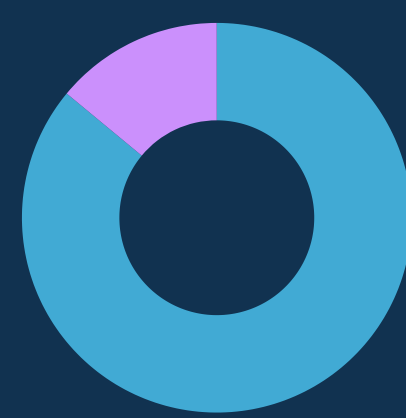
individuals  
supported

### Impact



98%

felt better equipped to manage the emotional impact of the rare genetic condition following counselling



86%

felt that it was 'very helpful and important' to have a counsellor who understood the impact of the rare genetic condition



100%

of individuals who completed counselling showed improvement in their CORE-10 scores\*



100%

of couples who completed their sessions showed an improvement in their CSI-32 relationship satisfaction scores \*\*

\* CORE-10 (Clinical Outcomes in Routine Evaluation) is a measure widely used in counselling and psychotherapy to assess levels of psychological distress and emotional well-being. It provides an overall distress score, allowing changes to be tracked over the course of counselling.

60% of individuals accessing our counselling service finished their sessions within the Low or Healthy ranges, compared with only 13% beginning in these ranges. Those who started with the highest levels of distress experienced particularly strong gains: 100% of those starting in the Severe or Moderately Severe categories moved into lower distress categories by the end of their sessions.

\*\* The Couples Satisfaction Index (CSI-32) is a validated questionnaire used to measure partners' perceptions of relationship satisfaction. It is widely used in couples therapy to track changes in relationship wellbeing over time. Despite starting at different levels of relationship distress and with the size of improvement varying, 100% of couples completing counselling reported increased relationship satisfaction, with most experiencing moderate to large gains in their CSI-32 scores.



"When my eldest was diagnosed, it felt like the ground had disappeared beneath my feet and with my other children now being tested, the fear is constant. The Sandcastle Trust's counselling gave me space to breathe again. It's helped me cope with the grief, the guilt, and the weight of the unknown. What made such a difference was not having to wait months on a waiting list – I don't know how I'd have coped if I'd had to. It's not just talking, it's been a lifeline."

S, Mum of 3



## Sandcastle Connections Peer Support



Registered Peer Supporters

777



Connections Made

81

“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 – its been lifechanging really.”

## Sandcastle Signposting and Support Hub



↑ **9,409** visitors  
This was a significant increase, up from 1,800 in 2023/4

## Communications

Communications are a key enabler of our work, helping us amplify lived experience to influence change and connecting us with families, supporters, and partners.

A particular highlight for us this year was our short film featuring Ollie and Amelia, siblings who live with the rare genetic condition Batten disease, winning both a Bronze Judges' Award and a Gold People's Choice Award at the Charity Film Awards. This recognition reflects the power of lived experience storytelling in increasing public understanding of the emotional well-being challenges and barriers to support that families living with rare genetic conditions face. You can watch the film [here](#).



**5,521** Followers

Our posts reached 37,382 accounts



**1,240** Followers

Our posts reached 13,800 accounts



**1,835** subscribers

30,413 emails delivered with an average open rate of 35.6%



**353** Views

Videos on our YouTube profile were viewed 353 times

# Trustees Report

## Achievements and Performance

### Harry's Family Story

Harry Degiorgio's first birthday should have been a fun filled day with family, cake, balloons and presents. But instead, Harry woke up on the morning of his birthday in a hospital bed after an hour-long seizure. Worse was to come a few weeks later when little Harry had ten seizures in 72 hours. The fear and unpredictability of these life-threatening seizures left parents Beth and Craig Degiorgio, from Solihull, West Midlands, feeling their family life was lived on a knife edge.

Beth, 34, explains. "Those three days of seizures were hell. Harry had been diagnosed with infantile epilepsy months before and started on medication, but we knew something really wasn't right at all. When we left hospital, we saw at the bottom of the discharge letter 'query Dravet Syndrome?' We had never heard of it, and none of the doctors had mentioned it to us. We had to google what it was. Weeks later we all had genetic testing and just had to wait for the results."

It was when Harry was just four months old that he had what doctors said was a febrile convulsion, after a routine vaccination. At hospital, a consultant reassured the family, but also advised them if Harry did have another one, they should film it.

Harry had two more seizures over the next few months and Beth filmed those, which provided doctors with a clear record of the type of seizures. Tests and an MRI followed, and Harry was given medication to control infantile epilepsy, plus rescue medication.

"It was terrifying and traumatic, but we were of the belief that he would grow out it, and we'd deal with it," Beth, who is also Mum to Tilly, now seven, recalls. "The summer of 2022 Harry had no seizures, but he wasn't quite where he needed to be developmentally. His balance wasn't great, and he would fall backwards to one side when sitting up. Then in the Autumn, Harry turned one and we were in and out of



Birmingham Children's Hospital. Then followed a bad Christmas and New Year with seizures.

"I describe the seizures as a monster that followed us around. We'd think 'should we go to that place or event?' Are we doing something that will be a trigger for seizures? You are constantly playing a worst-case scenario in your mind. Every seizure had been induced by a virus, but our daughter Tilly was in nursery and going on playdates, so that was hard. We wanted to make sure she had a normal childhood too. Tiredness was also a trigger for seizures and Harry didn't sleep."

The diagnosis came in January 2023 in a phone call to Beth's office.

Beth recalls: "The consultant told me the genetic tests were positive for Dravet Syndrome. In that moment, standing outside my office, my world fell apart. It was in his DNA. I don't remember the rest of the phone call. I walked back into the office and I broke down. Life had changed forever."

Dravet Syndrome is a potentially life-limiting genetic condition, caused by a change in the SCN1A gene.

Harry's alteration is 'de novo', meaning it was not inherited. Symptoms include seizures and a range of comorbidities, including severe sleep disorder, which Harry also has. It affects one in 15,000 babies born in the UK. There is no cure, and the epileptic seizures are extremely hard to treat as the Degiorgio family discovered.

Beth explains: "The medications stopped working. We entered a Dravet world of many hospital appointments. We watched our child start to walk, learn a new skill and then lose it again after a seizure. One was so bad he had to be resuscitated. One in five children with Dravet won't make it to adulthood. It is a life-changing, horrible condition.

Beth continues: "Harry spent his second birthday having a seizure and the paramedics came out. We'd got to a point where Harry was having up to four seizures a week and two hospital stays a month.

"It affects every aspect of our lives, both of us as parents were experiencing trauma but in different ways, I was mainly heading up Harry's medical care and dealing with that which was demanding and stressful, however Craig was having to go to work, knowing he had to miss appointments and being in hospital with Harry, to ensure he was earning money to keep us afloat which takes its toll on him. On top of that we are both sleep deprived and having to watch our child suffer so much with the seizures and that takes a big toll on your relationship and at this point, I felt I wasn't coping very well. I was anxiety ridden. It is a big step to accept you need help."

Beth's GP offered anti-depressants and when Beth refused them, she was contacted by a counsellor who she spoke with for around half an hour.

The counsellor then sent Beth links to YouTube videos on cognitive behaviour therapy techniques and

offered no further sessions.

"We'd heard of The Sandcastle Trust because we'd been fortunate enough to have a 'Sandcastle Santa Day' gifted by them over Christmas 2023. It was a really great day out meeting Santa at Drayton Manor. Special days out are great and to know that day has been gifted to you is amazing. I saw in a newsletter the Trust was providing counselling and I applied."

In the Summer of 2024, Beth started counselling sessions over Zoom. Through counselling she was given tools which help her cope with everyday challenges, anxieties and fears for the future. Beth says: "Before the counselling I felt grief, anger, trauma and resentment at the diagnosis and what it was doing to our children, and I know Craig felt guilty that he had to go to work. I felt pressure and didn't know how we would cope. A genetic condition has an impact on the whole family, the parents, who are already sleep deprived and have to be ready to act in an emergency, and the siblings.

"Counselling helped me deal with those overwhelming feelings and emotions. It helped keep me going. We refer to it as a big purple monster that sits in the corner of the room but now we acknowledge it is there and we just ask it to stay there so we can carry on. Sometimes it will come and wipe us out. Counselling doesn't magic it better, but it gives you an understanding of how to find a way of living with it, how to focus on the things we can control and way to manage the things we can't. After six months of sessions, I still had all the trauma and responsibility, but I had coping mechanisms.

"Now I can find the hope, see the small milestones and appreciate them and see how fortunate we are. I am so grateful to The Sandcastle Trust for the counselling sessions."

Harry is now four years old and reached a huge milestone in starting nursery a few mornings a week, building up gradually before Reception class, where they hope he will have a one-to-one assistant. Beth admits she has days where, "the cloud is big and heavy" but with the skills she's learnt during counselling she recognises negative feelings and works them through.

"We are now in a really good space," says Beth. "We celebrate the wins. Harry has had 100 days without big seizures. He's making friends at nursery, he loves any ball games, and he is so loving. He is incredible and he's made us better parents and people."





**“We are now in a really good space. We celebrate the wins. Harry has had 100 days without big seizures. He’s making friends at nursery, he loves any ball games, and he is so loving. He is incredible and he’s made us better parents and people.”**

# Trustees Report

## Future Plans

### Future Plans

Our plans for 2025/26 are shaped by a clear sense of ambition, alongside a realistic understanding of our financial position. As a small and growing charity, the majority of our income is currently restricted, meaning that growth in our activities is closely linked to securing grant funding. Increasing our unrestricted income will therefore be a key focus over the next five years, to enable greater flexibility, responsiveness and long-term sustainability. Encouragingly, we begin this year in a stronger position than the previous two years, following focused work to improve our organisational structure, income generation and financial monitoring. This provides a solid platform from which to start to deliver against the strategic goals of our new five-year strategy, while continuing to build resilience for the future.

Our focus for Year 1 of the strategy for each of our strategic goals is as follows:

#### 1. SUPPORT: Our focus this year will be:

- To develop our peer connection offer via the launch of our online Connection Café, supported by multi-year funding from National Lottery Reaching Communities awarded in the final month of this reporting period (grant paid in 2025/6 reporting year).
- To pilot a group therapy programme to try to address the exceptionally high demand for counselling we are currently unable to meet due to limited resources.
- Subject to securing funding, we plan to pilot additional financial support linked to our respite breaks for low-income families, such as providing vouchers to help with food costs and activities. This responds directly to our consultation findings that financial pressures are often a barrier to engaging in activities that support emotional well-being, such as a short break away. Our aim is to ensure that financial constraints do not prevent families from accessing, or fully benefiting from, our support, even when the break itself is free.

- To strengthen our monitoring and evaluation by building on our existing framework and embedding a clear Theory of Change.

#### 2. SCALE: Our focus this year will be:

- To build on and strengthen existing referral networks, continuing to raise our profile with hospices, regional genetics centres and condition-specific charities, with a particular focus on improving reach and engagement in Wales, Scotland and Northern Ireland.
- To explore ways to increase awareness of our support through more targeted and accessible communications, using digital channels and partner networks to better reach underrepresented families, including those from ethnic minority backgrounds and non-English speakers.

#### 3. SPEAK UP: Our focus this year will be:

- To develop a more structured approach to our campaigns and communications, amplifying lived experience through our Rare Voices project,

#### 4. STRENGTHENING: Our focus this year will be:

- To embed and strengthen our refreshed brand by building on the brand review completed alongside the launch of our new strategy, which identified the need to clarify our purpose. This includes undertaking a targeted refresh of our website to improve clarity and accessibility.
- To implement a new CRM and case management system. This will underpin delivery of our new online Community Café, improve how we manage relationships with families and referrers, strengthen safeguarding and data management, and support more effective fundraising, reporting and monitoring.
- To develop our individual giving programme and community income streams.

# Trustees Report

## Financial Review

### Financial Review

Our strategy consultation this year reinforced what we have long understood through our direct work with families: those impacted by rare genetic conditions are significantly more likely to experience poor emotional wellbeing outcomes, and there are substantial gaps in the support available to them. We also know that many more families could benefit from The Sandcastle Trust's support, meaning our services must continue to grow both in depth and reach. Our ability to respond to this level of need is directly linked to our capacity to fundraise, which presents a considerable challenge for a small charity with a limited profile operating in a difficult fundraising environment. Despite these pressures, the charity has maintained positive momentum during the year and has remained ahead of rising costs.

This has been largely due to continued growth in income from Trusts and Foundations, which has enabled us to sustain and develop our work. However, much of this income is restricted, and we recognise that building unrestricted income is essential to ensure the charity can remain responsive and sustainable in the long term. A key focus over the coming year will be exploring ways to develop new income streams, strengthening our financial resilience. We anticipate an increase in fundraising costs during 2025/26 as we take a more proactive approach to income generation in order to support the charity's future growth.

#### INCOME

The total income for the year was £159,478 (2023/4: £92,999). Donations came from a mix of companies, individual supporters, and trusts and foundations.

The breakdown is as follows:

- Unrestricted income from donations, fundraising, charity lottery, gifts in kind, Sandcastle Retreats listing income and Sandcastle Fair Breaks income: £13,414 (2023/4: £18,073), a decrease of nearly 26%.
- Restricted grants from trusts and foundations: £130,738 (2023/4: £61,400), an increase of nearly 113%.
- Unrestricted grants from trusts and foundations: £15,200 (2023/4: £13,400), an increase of 13.4%.

#### EXPENDITURE

During the year, The Sandcastle Trust incurred total expenditure of £104,868, of which £81,898 was spent on charitable activities (2023/4: £89,187 total expenditure, including £68,827 on charitable activities).

#### CASH POSITION

As at 5 April 2025, The Sandcastle Trust had accumulated funds of £128,920 (2024- £74,310). £17,299 in unrestricted and £111,621 restricted.

#### RESERVES

The Trustees' policy is to aim to hold free reserves equal to a minimum of approximately three months running costs less secured income. Our current reserves are in line with our policy.

Looking ahead, over the course of our five year strategy it is our goal to build our reserves to the approximate equivalent of six months running costs, to ensure long-term sustainability of our services.



# Thank you!

The Sandcastle Trust's work would not be possible without the communities we work alongside, and the trusts, foundations, businesses, accessible holiday partners and supporters who make our work possible. Your belief in our mission enables us to deliver transformational outcomes for families impacted by rare genetic conditions, and for that, we are truly grateful.

## Trusts and Foundations

Paul Bassham Charitable Trust  
W E Dunn Charitable Trust  
Cheshire Community Foundation  
Sussex Community Foundation  
Bruce Wake Trust  
Sir John Priestman Trust  
Arnold Clark Community Fund  
Stockwell Cliffe Charitable Trust  
Masonic Charitable Foundation  
The Archer Trust  
Bernard Sunley  
The Archer Trust  
The Belvedere Trust  
The Postcode Lottery  
Garfield Weston  
Margaret Davies Charitable Trust  
Ian Askew Charitable Trust  
Matthew Wrightson Trust  
Awards for All - Scotland  
Awards for All - Wales  
Awards for All - England  
The Chalk Cliff Trust  
Jeans for Genes  
The Eveson Trust  
The Toy Trust

And those that prefer to remain anonymous.

## Companies and Accessible Holiday Donors

Stanley Gibbons Baldwins Limited  
Hfan y Mynydd Accessible Shepherd's Hut  
disabledholidays.com  
Crescent Hideaway, Somerset  
Harrods Cornish Cottages, Cornwall  
Cowries, St Merryn, Padstow  
Holistic Thinking Holidays  
Southwaite Green Holiday Cottages, The  
Lake District  
Cossington Park, Somerset

## Heartfelt thanks to...

all our regular givers, individual donors, fundraisers, schools and community groups who have helped us raise vital funds throughout the year.

And last but by no means least, to all the wonderful families in the rare genetic condition community who inspire us every day.

# Trustees Report

## Statement of Trustees Responsibilities

### 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).

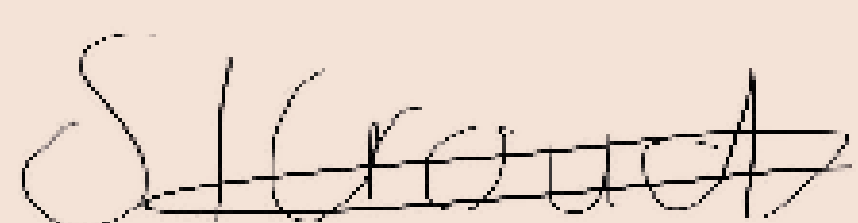
The law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing these financial statements, 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 18 December 2025 and signed on their behalf by:



.....  
**Samantha Crouch**  
**Chair of Trustees**



.....  
**Luke Brooker**  
**Treasurer**

# Trustees Report

## Statement of Trustees Responsibilities

### 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 2025.

#### 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 23 December 2025**



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

**Cheeld Wheeler & Co,**

**Chartered Certified Accountants**

**Redhill Chambers,**

**2d High Street, Redhill,**

**Surrey, RH1 1RJ.**

# Statement of Financial Activities

For The Year Ended 5 April 2025

	NOTES	2025			2024
		<u>Unrestricted</u>	<u>Restricted</u>	<u>Total</u>	<u>Total</u>
<b>INCOME</b>		<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
Grants and donations	3	26,653	130,738	157,391	89,264
Other trading activities	4	1,961	-	1,961	3,609
Interest income		126	-	126	126
<b>TOTAL INCOME</b>		<b>28,740</b>	<b>130,738</b>	<b>159,478</b>	<b>92,999</b>

	NOTES	2025			2024
		<u>Unrestricted</u>	<u>Restricted</u>	<u>Total</u>	<u>Total</u>
<b>EXPENDITURE</b>		<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
Costs of raising funds	5	9,688	945	10,633	7,973
Charitable activities		0	81,898	81,898	68,827
Support costs	6	6,204	6,133	12,337	12,387
<b>TOTAL EXPENDITURE</b>		<b>15,892</b>	<b>88,976</b>	<b>104,868</b>	<b>89,187</b>

<b>NET INCOME FOR THE YEAR</b>		<b>12,848</b>	<b>41,762</b>	<b>54,610</b>	<b>3,812</b>
TRANSFERS BETWEEN FUNDS		550	-550	-	-
<b>NET MOVEMENTS IN FUNDS</b>		<b>13,398</b>	<b>41,212</b>	<b>54,610</b>	<b>3,812</b>

## RECONCILIATION OF FUNDS

Total funds brought forward		3,901	70,409	74,310	70,498
<b>Total funds carried forward</b>	6	<b>17,299</b>	<b>111,621</b>	<b>128,920</b>	<b>74,310</b>

# Balance Sheet

## As At 5 April 2025

NOTES	2025		2024	
	£	£	£	£
<b>FIXED ASSETS</b>				
Tangible assets		92,997		38,452
<b>CURRENT ASSETS</b>				
Debtors	7,427		776	
Bank account	30,296		36,882	
<b>TOTAL CURRENT ASSETS</b>		<b>37,723</b>		<b>37,658</b>
Creditors - amounts falling due within one year		1,800		1,800
<b>NET ASSETS</b>		<b>128,920</b>		<b>74,310</b>
<b>The funds of the charity:</b>				
	7			
Unrestricted		17,299		3,901
Restricted		111,621		70,409
<b>TOTAL CHARITY FUNDS</b>		<b>128,920</b>		<b>74,310</b>

# Notes to the Accounts

## For The Year Ended 5 April 2025

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

### 2 Transactions with Trustees and Other Connected Persons

No remuneration is paid to the Trustees and no expenses were reimbursed to trustees in this reporting period,

### 3. Income from donations and grants

	2025			2024
	<u>Unrestricted</u> £	<u>Restricted</u> £	<u>Total</u> £	<u>Total</u> £
Donations	11,453	-	11,453	14,464
Grants	15,200	130,738	145,938	74,800
<b>TOTAL</b>	<b>26,653</b>	<b>130,738</b>	<b>157,391</b>	<b>89,294</b>

### 4. Income from other trading activities

	2025			2024
	<u>Unrestricted</u> £	<u>Restricted</u> £	<u>Total</u> £	<u>Total</u> £
Fundraising and organised challenges	1,961	-	1,961	3,609

### 5. Expenditure on raising funds

	2025			2024
	<u>Unrestricted</u> £	<u>Restricted</u> £	<u>Total</u> £	<u>Total</u> £
Fundraising Materials	6,965	-	6,965	6,289
Advertising and marketing	2,723	945	3,668	1,684
<b>TOTAL</b>	<b>9,688</b>	<b>945</b>	<b>10,633</b>	<b>7,973</b>

### 6. Support costs

	2025			2024
	<u>Unrestricted</u> £	<u>Restricted</u> £	<u>Total</u> £	<u>Total</u> £
Depreciation	169	-	169	169
Insurance	255	-	255	346
Bank charges	85	-	85	86
Postage and stationary	444	-	444	365
Storage costs	728	-	728	874
IT and software	1,133	-	1,133	924
Staff costs	638	-	638	352
Telephone and internet	583	-	583	634
Consultations	0	5,773	5,773	6,600
Subscriptions	99	-	99	41
Independent examiner	1,800	630	2,430	1,996
<b>TOTAL</b>	<b>5,934</b>	<b>6,403</b>	<b>12,337</b>	<b>12,387</b>

# Notes to the Accounts

## For The Year Ended 5 April 2025

### 7. Reserves

	<u>As at 6 April 2025</u>	<u>Income</u>	<u>Expenses</u>	<u>Transfers</u>	<u>As at 6 April 2025</u>
	£	£	£	£	£
<b><u>Unrestricted</u></b>					
General Fund	3,901	28,740	-15,892	550	17,299
Restricted	70,409	130,738	-88,976	-550	111,621
<b>TOTAL</b>	<b>74,310</b>	<b>159,478</b>	<b>-104,868</b>	<b>0</b>	<b>128,920</b>

### 8. Analysis of funds

**2025**

	<u>Unrestricted</u>	<u>Restricted</u>	<u>Total</u>
	£	£	£
Fixed assets	5,138	87,859	92,997
Debtors	741	6,686	7,427
Cash at bank	13,366	16,930	30,296
Creditors	-1,800		-1,800
<b>TOTAL</b>	<b>17,445</b>	<b>111,475</b>	<b>128,920</b>

**THE SANDCASTLE TRUST**

England & Wales - Charity number 1169523

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# Accounts

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# 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).

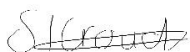
The law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing these financial statements, 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.



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

Dated 24 December 2024

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>£</u>	<u>£</u>		
		<u>Total</u>	<u>Total</u>		
		<u>£</u>	<u>£</u>		
<b>INCOME</b>					
Grants and donations	3	27,864	61,400	89,264	111,078
Other trading activities	4	3,609	-	3,609	1,361
Interest income		126	-	126	42
		<hr/>	<hr/>	<hr/>	<hr/>
<b>TOTAL INCOME</b>		31,599	61,400	92,999	112,481
		<hr/>	<hr/>	<hr/>	<hr/>
<b>EXPENDITURE</b>					
Costs of raising funds	5	7,973	-	7,973	5,290
Charitable activities		43,362	25,465	68,827	49,702
Governance costs	6	9,747	2,640	12,387	6,529
		<hr/>	<hr/>	<hr/>	<hr/>
<b>TOTAL EXPENDITURE</b>		61,082	28,105	89,187	61,521
		<hr/>	<hr/>	<hr/>	<hr/>
NET (LOSS)/INCOME FOR THE YEAR		(29,483)	33,295	3,812	50,960
TRANSFERS BETWEEN FUNDS		12,390	(12,390)	-	-
		<hr/>	<hr/>	<hr/>	<hr/>
<b>NET MOVEMENT IN FUNDS</b>		<b>£(17,093)</b>	<b>£20,905</b>	<b>£3,812</b>	<b>£50,960</b>
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		20,994	49,504	70,498	19,538
		<hr/>	<hr/>	<hr/>	<hr/>
Total funds carried forward	7	<b>£3,901</b>	<b>£70,409</b>	<b>£74,310</b>	<b>£70,498</b>
		<hr/>	<hr/>	<hr/>	<hr/>

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

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
	<b>£27,864</b>	<b>£61,400</b>	<b>£89,264</b>	<b>£111,078</b>

**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	<b>£3,609</b>	-	<b>£3,609</b>	<b>£1,361</b>

**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
	<b>£7,973</b>	<b>£ -</b>	<b>£7,973</b>	<b>£5,290</b>

**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
	<b><u>£9,747</u></b>	<b><u>£12,640</u></b>	<b><u>£12,387</u></b>	<b><u>£6,529</u></b>

**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>
	£	£	£	£	£
<b>Unrestricted</b>	20,994	31,599	(61,082)	12,390	3,901
<b>Restricted</b>	49,504	61,400	(28,105)	(12,390)	70,409
<b>Total</b>	<b><u>£70,498</u></b>	<b><u>£92,999</u></b>	<b><u>£(89,187)</u></b>	<b><u>£ -</u></b>	<b><u>£74,310</u></b>

**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	<b>38,452</b>
Debtors	776	-	<b>776</b>
Cash at bank	696	36,196	<b>36,882</b>
Creditors	(1,800)	-	<b>(1,800)</b>
	<u><b>£3,901</b></u>	<u><b>£70,409</b></u>	<u><b>£74,310</b></u>

**THE SANDCASTLE TRUST**

England & Wales - Charity number 1169523

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# Accounts

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# THE SANDCASTLE TRUST

ANNUAL REPORT AND ACCOUNTS  
FOR THE YEAR ENDED 5 APRIL 2023

## CONTENTS

	Page(s)
Reference and Administrative Information	1
Trustees' Report	2–9
Statement of Trustees' Responsibilities	10
Independent Examiner's Report to the Trustees	11
Financial statements	12- 14
Notes to the Financial Statements	15 - 20

**THE SANDCASTLE TRUST**

**REFERENCE AND ADMINISTRATION INFORMATION**

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

**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)

**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 2023.

### **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 walks alongside families living with a rare genetic condition to help them build positive family memories, strengthen family relationships, reduce isolation, and improve emotional wellbeing and resilience.

We increase public awareness of the needs and issues that families living with rare genetic conditions face; signpost to sources of support 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. 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.

**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 include physical disability, learning difficulty, mental health and social issues.

Significant financial challenges are likely to present themselves for most families living with a rare genetic condition. Many family members find they have to take on a full-time caring role, which understandably can add to the economic strain as well as having an emotional and practical impact. The families we supported in 2022/23 reported facing significant and multiple socio-economic challenges in their lives:

- Mental health issues - 83%;
- Isolation - 86%;
- Increased stress - 93%;
- Feeling unsupported in caring role - 71%;

- Concern for unaffected siblings identifying as young carers -69%
- Annual household income below the national average – 69%
- Living in relative income poverty (i.e. less than 60% of the average UK household income) – 26%
- Caring responsibilities directly impact on the number of hours they or their partner were able to work - 98%
- Disability benefits not meeting the additional costs their family incurs as a direct result of a rare genetic condition – 94%
- Financial implications of their situation mean it is difficult to spend quality family time together outside of their day to day routine which has a detrimental impact on emotional wellbeing – 96%

**Our Support:** Our work is delivered through our four Sandcastle Support Services.

1. Our Sandcastle Memories Family Respite Service is our largest support programme and provides bespoke family respite 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 registered families with regular opportunities for family fun and engagement activities within the home. Families can also apply for well-being focused or therapeutic equipment. 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. Finally, 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.

## ACHIEVEMENTS AND PERFORMANCE

- We supported 207 families with a *Sandcastle Memory family respite break, annual pass or day out* in 2022/23.
- We provided 194 families with a *Sandcastle Smile* in 2022/23.
- 404 new families registered as *Sandcastle Families* to access our services during the reporting period and 401 indicated they were willing to provide peer support to other families as part of our *Sandcastle Connections* programme.
- Our *Sandcastle Support Hub* had 1792 unique page views in this reporting period.

2022-23

A snapshot of what we have been up to this year!

### ADAPTED CARAVAN

Following the pandemic the cost of UK breaks in accessible accommodation rocketed. In order to continue to meet the high demand for our Sandcastle Memories Family Respite Service, we launched a fundraising appeal to purchase our own accessible static caravan.

We are hugely grateful to everyone that donated or held a fundraising event to support this appeal, which enabled us to purchase a second hand fully accessible caravan on the Southview Holiday Park in March 2023.



### SANDCASTLE SMILES

In June we hosted a virtual 'Bake your Own' Platinum Jubilee Family Afternoon Tea to help the rare genetic condition community come together to celebrate the Queen's Platinum Jubilee whilst creating some fun family memories. 192 families received a box containing everything they needed to bake lots of yummy treats together and throw a family Platinum Jubilee Afternoon Tea, including Union Jack decorations!



## SANDCASTLE MEMORIES - SAM'S STORY



In February 2021, aged 13 months, Sam was diagnosed with infantile-onset Pompe Disease, a metabolic genetic condition that affects all muscles of the body, including the heart and lungs. Without treatment the prognosis is bleak and doctors told parents Harriette and Graham they didn't think Sam would survive.

"It was heart-breaking, and our lives started unravelling before us," Harriette recalls. "You never think this will happen to you."

Luckily Sam was approved for a new experimental treatment of enzyme therapy. After four months in hospital and two weeks in a hospice to support the couple in caring for Sam at home, he was able to go home. His parents were trained to give the enzyme replacement therapy infusion, every fortnight, at home.

Since then Sam has defied the doctors' expectations. He has regained some movement in his arms and upper body and improved his core strength, so he can sit with support and play with toys, greatly improving his quality of life. He has many complex medical needs; he is fed through a gastrostomy tube and he needs to use a wheelchair. He sleeps with a ventilator as he can stop breathing during the night and has an overnight carer five nights a week. However, he no longer needs 24-hour oxygen, which is a real breakthrough.

Harriette says: "Sam's condition will always be life-limiting, but doctors are thrilled with how he is doing. He is non-verbal but he babbles and uses Makaton. You can definitely tell what he wants!"

With Sam no longer needing full-time oxygen, the couple started to think about the possibility of a holiday together and applied for the Sandcastle Trust's Sandcastle Memories Service, which offers respite for families living with a rare genetic condition, in the form of UK breaks and days out. They arranged a week's stay for the family in Polzeath, Cornwall.

Harriette and Graham drove from their home in Worcestershire, with the car full of all the equipment needed to look after Sam, including his wheelchair, night-time ventilator, peg feeding equipment, medication, and rescue oxygen. It was the first time the couple felt confident enough taking Sam away for a week, due to his complex medical needs.

Harriette says: "Sam loved it. He has never really seen the sea before, and he had never been to a beach. The weather was rough, and he loved watching the waves crashing against the rocks. He just wanted to stare at the sea for an hour. He was able to build sandcastles with his dad and we carried him into the sea to get his feet wet. We went to the Eden project which was amazing and so sensory and accessible for Sam and in Padstow he loved seeing the boats in the harbour and saw lifeboats launching."

"It was lovely to get away and do something just for us," Harriette adds. "It is a full-time job and exhausting looking after a child with medically complex needs. In Cornwall we could switch off from the day to day, press pause and allow us to be a normal family. We are so grateful to the Sandcastle Trust."

### SUPPORT SERVICES COORDINATOR RECRUITED

In October we welcomed our first permanent member of staff - a Support Services Coordinator. Meet Ali who plays a key role in ensuring that our services and projects are planned and delivered smoothly. She also builds relationships with referral partners within the genetic condition community to help promote our services and increase their reach and uptake.



### SANDCASTLE SANTA 2022

It was no coincidence that Sandcastle Santa 2022 was our biggest yet - we treated 179 families living with a rare genetic condition to an accessible, festive day out. Families living with a rare genetic condition are finding the cost-of-living crisis hard to navigate, many having to sacrifice basic necessities like heating or food in order to meet the costs of keeping vital, often life-saving equipment running and to pay for transport to and from hospital.

Giving the gift of a festive day out is a small thing but one that brings joy and lets families in our community know that The Sandcastle Trust is here and we understand.



### FINALISTS IN THE SMILEY CHARITY FILM AWARDS

Our short film featuring Oscar and Theo's parents sharing their experience of living with a rare genetic condition and how The Sandcastle Trust supported them, was an entrant in the Smiley Charity Awards.

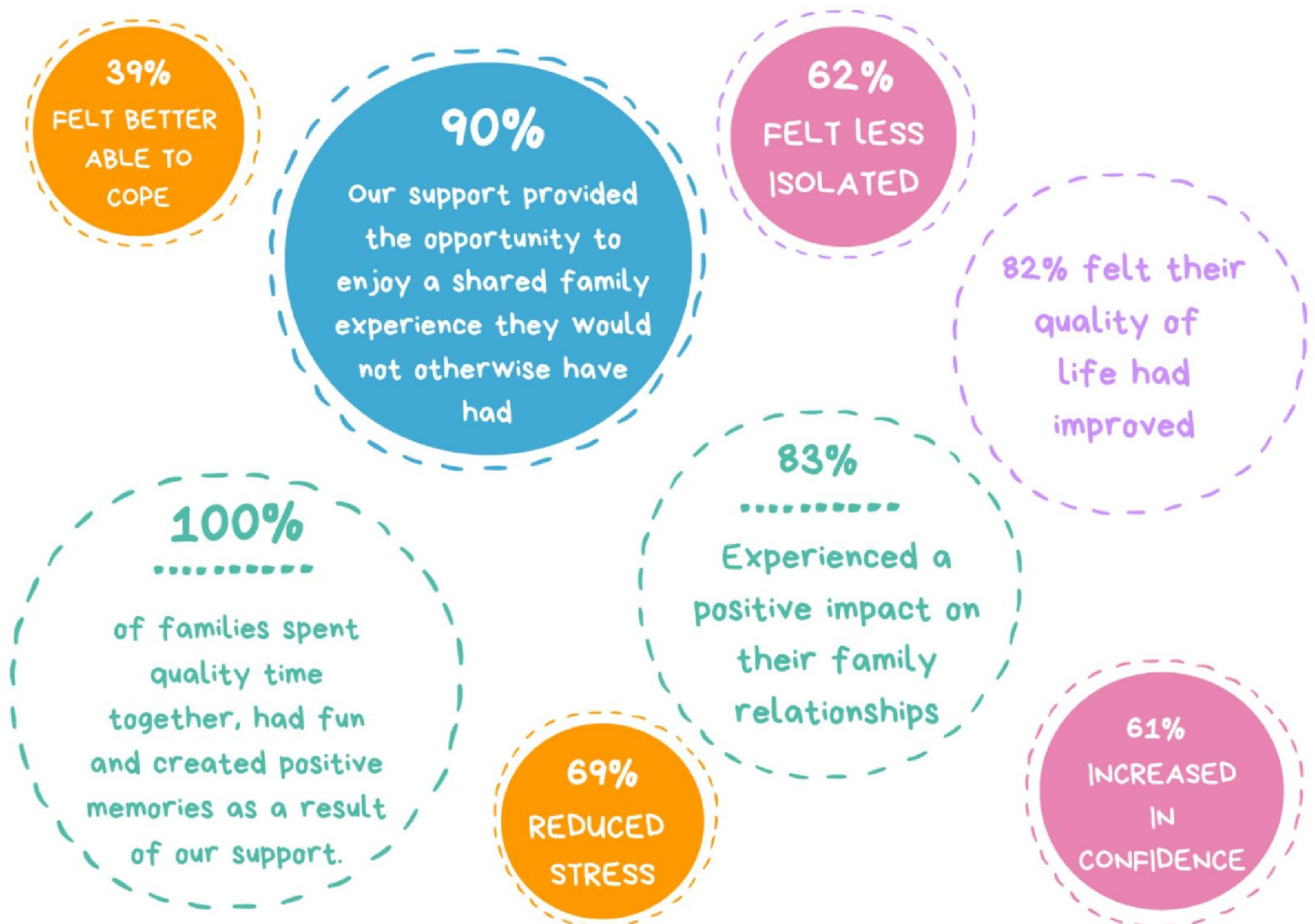
In February we were thrilled to be announced as finalists! While we did not win in our category, we felt privileged to be involved and it was a great opportunity to raise awareness of rare genetic conditions and the support provided by our charity.



There's so many things that just happen day to day that you wouldn't think of

**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.



## **FINANCIAL REVIEW**

We are incredibly grateful to the individuals who have donated to or fundraised for The Sandcastle Trust this year and to the trusts and foundations that have supported our work.

As a result, we saw our income grow this year from £64,452 in the prior year to £112,481. During the year The Sandcastle Trust spent £49,702 on charitable activities, compared to £48,592 in the previous period. As at 5 April 2023, the Trust had accumulated funds of £70,498 of which £49,504 (2022- £12,092) were in restricted funds and £20,994 (2022 - £7,446) were in unrestricted funds.

The growth of income during 2022/23 has improved the financial position of the charity, however the need and demand for our services continues to grow at a much faster rate.

## **FUTURE PLANS**

In 2023/24 we intend to continue delivering our four key services – Sandcastle Memories, Smiles, Connections and Support but further develop some of the activities within those programmes and extend the reach of our work, so that every family living with a rare genetic condition in the UK can access our support.

In order to achieve this, we will need to improve our fundraising performance, continue to grow our supporter base and effectively steward our supporters to gain their long-term commitment. 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.

**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).

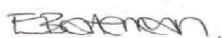
The law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing these financial statements, 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 1 December 2023 and signed on their behalf by:



.....  
 Eleanor Bateman  
 Trustee



.....  
 Luke Brooker  
 Treasurer

**THE SANDCASTLE TRUST**  
**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 2023.

**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').

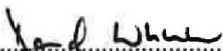
I report in respect of my examination of the Trust's accounts as required under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**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: 4 December 2023

David Wheeler – Independent Examiner  
David Wheeler F.C.C.A  
Cheeld Wheeler & Co, Chartered Certified Accountants  
Redhill Chambers, 2d High Street, Redhill,  
Surrey, RH1 1RJ.

**THE SANDCASTLE TRUST**  
**STATEMENT OF FINANCIAL ACTIVITIES**  
**FOR THE YEAR ENDED 5 APRIL 2023**

	<u>Notes</u>	<u>2023</u>	<u>2022</u>		
		<u>Unrestricted</u>	<u>Restricted</u>		
		<u>£</u>	<u>£</u>		
		<u>Total</u>	<u>Total</u>		
		<u>£</u>	<u>£</u>		
<b>INCOME</b>					
Grants and donations	4	42,128	68,950	111,078	64,392
Other trading activities	5	1,361	-	1,361	60
Interest income		42	-	42	-
<b>TOTAL INCOME</b>		<b>43,531</b>	<b>68,950</b>	<b>112,481</b>	<b>64,452</b>
<b>EXPENDITURE</b>					
Costs of raising funds	6	3,343	-	3,343	2,890
Charitable activities		21,468	28,234	49,702	48,592
Governance costs	7	8,476	-	8,476	11,192
<b>TOTAL EXPENDITURE</b>		<b>33,287</b>	<b>28,234</b>	<b>61,521</b>	<b>62,674</b>
<b>NET (LOSS)/INCOME FOR THE YEAR</b>		<b>10,244</b>	<b>40,716</b>	<b>50,960</b>	<b>1,778</b>
TRANSFERS BETWEEN FUNDS		3,304	-3,304	-	-
<b>NET MOVEMENT IN FUNDS</b>		<b>£13,548</b>	<b>£37,412</b>	<b>£50,960</b>	<b>£1,178</b>
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		£7,446	£12,092	£19,538	£17,760
Total funds carried forward		<b>£20,994</b>	<b>£49,504</b>	<b>£70,498</b>	<b>£19,538</b>

**THE SANDCASTLE TRUST**  
**STATEMENT OF FINANCIAL ACTIVITIES**  
**FOR THE YEAR ENDED 5 APRIL 2023**

The charity had no recognised gains or losses for the year ended 5 April 2023 other than those included in the Statement of Financial Activities.

The notes on pages 15 to 20 form part of these accounts.

**THE SANDCASTLE TRUST**  
**BALANCE SHEET AS AT 5 APRIL 2023**

	<u>Notes</u>	<u>2023</u>		<u>2022</u>	
		£	£	£	£
<b>FIXED ASSETS</b>					
Tangible assets	9		33,212		4,288
<b>CURRENT ASSETS</b>					
Debtors		1,003		493	
Bank account		38,083		21,620	
<b>TOTAL CURRENT ASSETS</b>			39,086		22,113
Creditors – amounts falling due within one year			1,800		6,863
<b>NET ASSETS</b>			<b>£70,498</b>		<b>£19,538</b>
<b>The funds of the charity:</b>	8				
Unrestricted			20,994		7,446
Restricted			49,504		12,092
<b>TOTAL CHARITY FUNDS</b>			<b>£70,498</b>		<b>£19,538</b>

Approved by the Trustees on 1 December 2023 and signed on their behalf by:



.....  
 Eleanor Bateman  
 Trustee



.....  
 Luke Brooker  
 Treasurer

The notes on pages 15 to 20 form part of these accounts.

**THE SANDCASTLE TRUST**  
**NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2023**

**1. ACCOUNTING POLICIES**

**1.1 General Information**

The Sandcastle Trust is a Charitable Incorporated Organisation, registered with the Charity Commission in England & Wales (No. 1169523) and the Official Scottish Charity Register (No. SC051645) . The address of the registered office is The Sandcastle Trust, PO Box 873 Haywards Heath, RH16 9QL.

**1.2 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.

**1.3 Income**

Income is accounted for when received by the Trust.

**1.4 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.

**1.6 Taxation**

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

**1.7 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**  
**NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2023**

**2. Transactions with Trustees and Other Connected Persons**

No remuneration is paid to the Trustees, but expenses of £264 (2021/22: £308 ) were reimbursed to two of the trustees and £50 was donated by a Trustee.

**3. Related Party Transactions**

There were no related party transactions during the course of the year.

**4. Income from donations and grants**

	<u>2023</u>			<u>2022</u>
	<u>Unrestricted</u>	<u>Restricted</u>	<u>Total</u>	<u>Total</u>
	£	£	£	£
Donations	10,139	-	10,139	9,989
Just Giving	20,149	-	20,149	6,874
Grants	11,840	68,950	80,790	47,529
	<b><u>£42,128</u></b>	<b><u>£68,950</u></b>	<b><u>£111,078</u></b>	<b><u>£64,392</u></b>

Funding is acknowledged under the terms and conditions of the following grants:

Funder	Project	Value
Charles F French Charitable Trust	Sandcastle Memories Family Respite (Essex and North London)	£10,000
The Skelton Trust	Sandcastle Memories Family Respite (North West)	£1,000
National Lottery Awards for All England	Sandcastle Memories Family Respite (England)	£10,000
The Pears Foundation	Support Services Coordinator Position	£8,500
The Eveson Trust	Sandcastle Memories Family Respite (West Midlands)	£5,000

**THE SANDCASTLE TRUST**  
**NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2023**

The Sussex Community Foundation	Sandcastle Memories (Sussex)	£4,950
The Clothworkers Foundation	Caravan – Skegness	£10,000
Bernard Sunley Foundation	Caravan - Skegness	£5,000
The Brian Murtagh	Caravan - Skegness	£10,000
National Lottery Awards for All Wales	Caravan - Wales	£10,000
The Rothley Trust	Sandcastle Memories (North East)	£1,000
Albert Hunt Trust	Sandcastle Memories Family Respite	£2,500
Jeans for Genes	Core Funding	£3,340
The Arnold Clark Community Fund	Sandcastle Memories	£1,000

**5. Income from other trading activities**

	<u>2023</u>			<u>2022</u>
	<u>Unrestricted</u>	<u>Restricted</u>	<u>Total</u>	<u>Total</u>
	£	£	£	£
Fundraising & Organised Challenges	<b>£1,361</b>	-	<b>£1,361</b>	<b>£60</b>

**6. Expenditure on Raising Funds**

	<u>2023</u>			<u>2022</u>
	<u>Unrestricted</u>	<u>Restricted</u>	<u>Total</u>	<u>Total</u>
	£	£	£	£
Fundraising Materials	3,343	-	3,343	1,509
Events	-	-	-	1,381
	<b>£3,343</b>	<b>£ -</b>	<b>£3,343</b>	<b>£2,890</b>

**THE SANDCASTLE TRUST**  
**NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2023**

**7. Governance Costs**

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2023</u> <u>Total</u>	<u>2022</u> <u>Total</u>
	£	£	£	£
Insurance	217	-	217	290
Bank charges	180	-	180	291
Advertising and marketing	1,947	-	1,947	1,141
Postage and stationery	286	-	286	1,558
Other costs	4,526	-	4,526	1,065
Independent examiner	1,320	-	1,320	600
	<b><u>£8,476</u></b>	<b><u>-</u></b>	<b><u>£13,342</u></b>	<b><u>£4,945</u></b>

**8. Movement in Funds**

	<u>At 6</u> <u>April</u> <u>2022</u> £	<u>Income</u> £	<u>Expenditure</u> £	<u>Transfers</u> £	<u>At 5</u> <u>April</u> <u>2023</u> £
<b>Unrestricted</b>					
General fund	7,446	43,531	-33,287	3,304	20,994
<b>Restricted</b>					
Sandcastle Memories	12,092	25,450	-23,368	-3,304	10,870
Caravan project	0	35,000	0		35,000
Salary Costs	0	8,500	-4,866		3,634
	<u>12,092</u>	<u>68,950</u>	<u>-28,234</u>	<u>-3,304</u>	<u>49,504</u>
<b>Total</b>	<b><u>£17,760</u></b>	<b><u>112,481</u></b>	<b><u>-61,521</u></b>	<b><u>-</u></b>	<b><u>70,498</u></b>

**THE SANDCASTLE TRUST**

**NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2023**

**9. Fixed Assets**

	<u>Office Equipment</u>	<u>Caravan</u>	<u>Total</u>
Cost at 6 April 2022	4525	0	4525
Additions	<u>150</u>	<u>28995</u>	<u>29145</u>
Cost at 5th April 2023	<u>4675</u>	<u>28995</u>	<u>33670</u>
Depreciation at 6 April 2022	237	0	237
Charge in year	<u>40</u>	<u>181</u>	<u>221</u>
Depreciation at 5th April 2023	<u>277</u>	<u>181</u>	<u>458</u>
Net book value 5 April 2023	<u><u>4398</u></u>	<u><u>28814</u></u>	<u><u>33212</u></u>
Net book value 5th April 2022	<u><u>4288</u></u>	<u><u>0</u></u>	<u><u>4288</u></u>

**10. Analysis in funds**

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2023 Total</u>
	£	£	£
Fixed assets	8,393	24,819	<b>33,212</b>
Debtors	1,003	-	<b>1,003</b>
Cash at bank	13,398	24,685	<b>38,083</b>
Creditors	-1,800	-	<b>-1,800</b>
	<u><u>£20,994</u></u>	<u><u>£49,504</u></u>	<u><u>£70,498</u></u>

**THE SANDCASTLE TRUST**

**NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2023**

**11. Employees**

The average number of employees during the year was 1.

**12. Volunteers**

The charity receives the benefit of work carried out by volunteers. The average number of volunteers during the year was 5.

**THE SANDCASTLE TRUST**

England & Wales - Charity number 1169523

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# Accounts

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# THE SANDCASTLE TRUST

ANNUAL REPORT AND ACCOUNTS  
FOR THE YEAR ENDED 5 APRIL 2022

## 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	16 - 18

**THE SANDCASTLE TRUST**  
**REFERENCE AND ADMINISTRATION INFORMATION**

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

**Committee of Trustees**

Mrs D. Singleton  
D. Singleton  
L. Dodd  
C. Bateman  
E. Bateman  
I. Bateman  
L Brooker  
M. Holland

**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

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## THE SANDCASTLE TRUST TRUSTEES' REPORT

The Trustees present their report and the accounts for the year ended 5 April 2022.

### **STRUCTURE GOVERNANCE & MANAGEMENT**

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#### **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 walks alongside families living with a rare genetic condition help them build positive family memories and to support their emotional wellbeing and resilience.

We increase public awareness of the needs and issues that families living with rare genetic conditions face; signpost to sources of support and affect positive change through our work.

We do this through our four Sandcastle Support Services: Sandcastle Memories, Sandcastle Smiles, Sandcastle Connections and our Sandcastle Support Hub.

Through this unique service offering, consisting of bespoke family respite, wrap around fun, well-being focused family engagement activities, peer support and digital advice and information, we are able to support families living with a rare genetic condition based on their individual needs from across the UK.

### **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. 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.

### **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 include physical disability, learning difficulty, mental health and social issues.

Caring for a loved one with a genetic condition is emotionally exhausting. It impacts the whole family and as a result the families we support face significant barriers and multiple disadvantages in their lives, in particular mental health issues (82% of our beneficiaries in 2021/22), isolation (87%), increased stress (93%), lack of support in caring role (75%) and concern for unaffected siblings identifying as young carers (71%).

In addition, 73% of the families we supported had a household annual income of less than £20,000, 98% told us that caring responsibilities directly impacted on the number of hours they or their partner were able to work, 94% told us that disability benefits did not meet the additional costs their family incurs as a direct result of a rare genetic condition and 96% told us that the financial implications of their situation meant they found it incredibly difficult to spend quality family time together outside of their day to day routine which has had a detrimental impact on their emotional wellbeing.

## **Our Support**

Our work is delivered through our four Sandcastle Support Services.

1. Our Sandcastle Memories Family Respite Service is our largest support programme and provides bespoke family respite 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.

There is no 'one-size-fits-all' approach and we work directly with affected families to ensure the respite provided is diverse and completely tailored to a family's interests and needs. It could take the form of a short UK break or where a short break is not suitable, annual passes to attractions such as zoos, farms and steam railways or a special day trip.

2. The Sandcastle Smiles programme provides registered families with regular opportunities for family fun and engagement activities within the home. Families can also apply for well-being focused or therapeutic equipment. 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. Finally, 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.

## ACHIEVEMENTS AND PERFORMANCE

- The Sandcastle Trust supported 180 families with a *Sandcastle Memory* or *Sandcastle Smile* in 2021/22.
- 330 new families registered as Sandcastle Families to access our services during the reporting period.
- 256 families indicated they were willing to provide peer support to other families as part of our Sandcastle Connections programme during the reporting period.
- Our Sandcastle Support Hub had 1,348 unique page views in this reporting period.

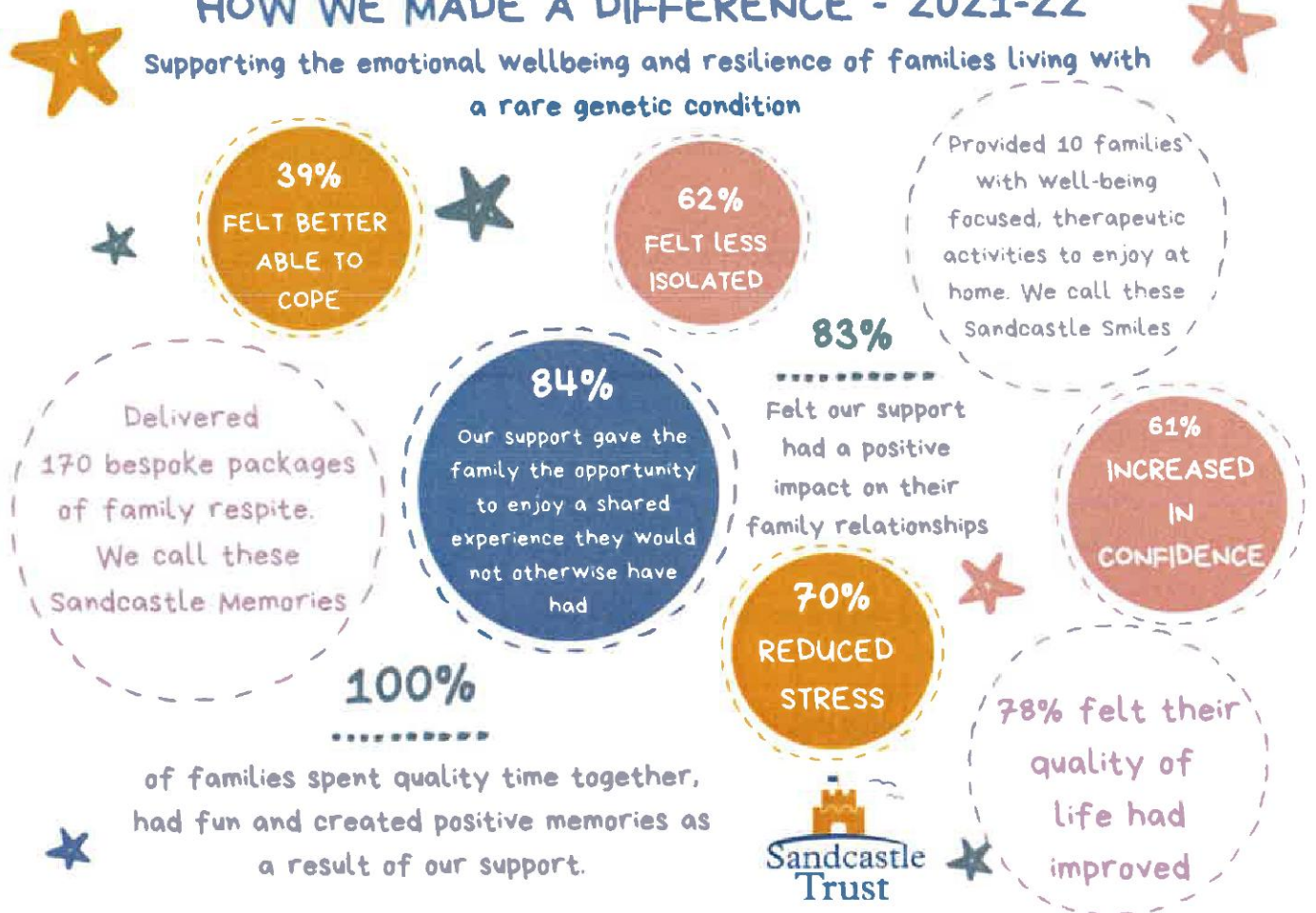
As well as collecting qualitative feedback on our services, we carry out beneficiary surveys to monitor the impact of each of our support programmes. This helps us to demonstrate the longer-term difference that The Sandcastle Trust makes in various outcome areas that we have identified as contributing to improved emotional wellbeing and resilience.

The data collected via this survey is summarised in the diagram below. It demonstrates that the benefit of our support is not short lived; it offers holistic respite for the whole family, improves mental health outcomes, reduces isolation, helps carers to maintain their quality of care and generally provides a positive focus which can empower families with a new

enthusiasm and strength to deal with ongoing daily struggles of illness, gruelling hospital treatment and sometimes a devastating loss.

## HOW WE MADE A DIFFERENCE - 2021-22

Supporting the emotional wellbeing and resilience of families living with a rare genetic condition



## CASE STUDIES

### Reuben's Story – Sandcastle Memory



Sophie Byrne's favourite picture of her sons was taken in Devon. For Sophie this image is even more precious because four months after the joyful picture was taken, Reuben passed away.

Sophie, says: "Reuben passed five days before Christmas, he was two.

"We feel so lucky to have had that time away with him as a family. All our favourite photos of Reuben looking happy are from that holiday.

"He absolutely loved the pool and came alive when he was in there."

Sophie and her husband Sean, had experienced loss before. Their first child Olivia was born in 2012 but died from the same genetic condition as Reuben at just eight months old.

Sophie, says: "Doctors told us lightning doesn't strike twice but they didn't know Olivia's condition back then.

"Harry was born in 2014 and was fine. On the day Reuben was born they told us lightning had struck twice he had the same thing. Just three weeks later they discovered the faulty gene that had caused both children's disabilities and told us both Sean and I were carriers.

"There was a one in 25 million chance of that happening and only 20 known children with the same faulty gene. I remember them saying most babies born with the condition don't live past their first year."

Reuben and Olivia shared the same symptoms: complex needs, seizures, and physical differences like a high palate. When Sophie and Sean realised Reuben's life would be short, like Olivia's, they decided to have another baby, another sibling for Harry because losing his beloved brother would be so devastating for their older son. Felix was born healthy in 2021, after tests in the womb showed he did not have the gene.

Sophie says: "When we approached the Sandcastle Trust, we knew our three boys might not have long together. The organisers said they would be able to arrange an autumn half term break but when we explained Reuben might not live that long, they pulled out all the stops to sort a holiday cottage in August, 2021. I will always be grateful for that."

The family spent an idyllic week at the cottage in Devon.

Sophie says: "It was just perfect, the dream holiday in the UK. It was so quiet and peaceful, perfect for Reuben.

"You could book the shared pool so we had it to ourselves. Reuben had only been in the water once or twice before at his children's hospice. He was so happy in there, kicking his legs. He loved the swing too.

"Felix had his first swim and Harry had loads of space to ride his bike and could go to the beach with Sean."

Looking back, Sophie says: "The life Reuben had was lovely, everything he experienced, everything he did, particularly our holiday in Devon, were special. He was an absolute joy, we learned so much from him."

### **Karen's Story – Sandcastle Smile**

Karen Clark, 46, has spinocerebellar ataxia type III (SCA 3), a hereditary genetic condition which affects balance, walking, grip, speech, swallowing and ultimately breathing. It is a life-limiting condition and Karen, who was diagnosed at the age of 30, is in the later stages of the disease.

Karen lives with her husband and their two teenage children. She was diagnosed in 2007 with SCA 3, a condition which her own mother died from at the age of 59. Karen's older brother, who lives in Canada, also has the genetic condition. The couple's children haven't had a test for the condition yet.

SCA 3 is more commonly known as Machado-Joseph Disease (MJD-III). It is a rare, inherited ataxia (lack of muscular control) affecting the central nervous system and characterized by the slow degeneration of areas of the brain which contain most of the brainstem and cerebellum.

Most people experience symptoms between the ages of 40 and 70 and the disease progresses slowly. Symptoms include unsteady gait, loss of muscle mass and difficulty coordinating movements of the arms and legs.

For Karen, as her fine motor skills have deteriorated, along with her speech, she has found it difficult communicating over a small mobile phone with their family who live all over the world.

That's where we at The Sandcastle Trust were able to help. Through our Sandcastle Smiles programme of support we gifted Karen an iPad, so she is able to communicate with her brother, who lives in a nursing home for young adults in Canada, and other relatives in Australia and New Zealand.

David, currently caring full time for his wife, says: "The first sign Karen had was when she was 30 years old and started tripping over and dropping stuff. We put it down to the post-natal period, but it was spinocerebellar ataxia. Karen's condition is similar to motor neurone disease in some ways and like Parkinson's she has muscle spasms, shakes and problems with her eyesight. It is very progressive, there is no cure and no treatment. The cerebellum is slowly dying.

"Now Karen fully uses a wheelchair, and her dexterity has got much worse. Sometimes I need to feed Karen, her speech is going, and she gets very tired. She needs personal care. It is very hard, and it is an absolute nightmare to get a carer who lasts. Eventually with this condition it stops your lungs from breathing.

"Karen was finding text messages, social media and face time very difficult to do as the buttons on a mobile are very small and that's difficult with her reduced dexterity. Her eyes can't focus on a small screen either. Karen's occupational therapist recommended an iPad."

The iPad has opened up communication for Karen and her whole family, enabling her to stay connected with family members and improving her mental wellbeing and emotional health, and reducing isolation. Karen plays interactive games online with her family, such as scrabble and is able to send emails and messages more independently, without being solely dependent on her family to do them for her.

“The iPad has helped a lot because it allows Karen to communicate,” David explains. “On an iPad the buttons are bigger so it’s not as fiddly. She can focus on the screen, which means she gets to read messages from friends and family who email her, and she can FaceTime them. It really makes a big difference.”

## **FINANCIAL REVIEW**

We are incredibly grateful to the individuals who have fundraised for The Sandcastle Trust this year and the trusts and foundations that have supported our work.

The Trustees can report a satisfactory year with income increasing from £38,318 in the prior year to £64,452. During the year The Sandcastle Trust spent £48,592 on charitable activities, compared to £23,154 in the previous period. As at 5 April 2022, the Trust had accumulated funds of £19,538.

## **FUTURE PLANS**

This year we intend to continue delivering our four key services – Sandcastle Memories, Smiles, Connections and Support and develop a new three-year strategy to significantly extend the reach of our work, so that every family living with a rare genetic condition can access our support.

In 2022/23 we will aim to improve our fundraising performance, continue to grow our supporter base and effectively steward our supporters to gain their long-term commitment. However, we anticipate that the UK fundraising environment will continue to be challenging for the next few years, due to the global and national impact of the war in Ukraine, rising inflation, and the increasing costs of living and so we will be exploring other ways that we can diversify and develop new income streams for the charity.

## **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.

## 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 21 January 2023 and signed on their behalf by:



.....  
Danielle Singleton  
Chair



.....  
Luke Brooker  
Treasurer

**THE SANDCASTLE TRUST**  
**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 2022.

**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.

*David Wheeler*

Dated: *25. June 2022*

David Wheeler – Independent Examiner

David Wheeler F.C.C.A

Cheeld Wheeler & Co, Chartered Certified Accountants

Redhill Chambers, 2d High Street, Redhill, Surrey, RH1 1RJ.

**THE SANDCASTLE TRUST**  
**STATEMENT OF FINANCIAL ACTIVITIES**  
**FOR THE YEAR ENDED 5 APRIL 2022**

	<u>Notes</u>	<u>Unrestricted</u>	<u>2022</u> <u>Restricted</u>	<u>Total</u>	<u>2021</u> <u>Total</u>
		£	£	£	£
<b>INCOME</b>					
Grants and donations	3	25,072	39,320	64,392	36,968
Other trading activities	4	60	-	60	1,350
<b>TOTAL INCOME</b>		<b>25,132</b>	<b>39,320</b>	<b>64,452</b>	<b>38,318</b>
<b>EXPENDITURE</b>					
Costs of raising funds	5	2,180	710	2,890	2,899
Charitable activities – Sandcastle Memories		18,527	30,065	48,592	23,154
Governance costs	6	9,502	1,690	11,192	4,945
<b>TOTAL EXPENDITURE</b>		<b>30,209</b>	<b>32,465</b>	<b>62,674</b>	<b>30,998</b>
<b>NET (LOSS)/INCOME FOR THE YEAR</b>		<b>(5,077)</b>	<b>6,855</b>	<b>1,778</b>	<b>7,320</b>
TRANSFERS BETWEEN FUNDS		5,520	(5,520)	-	-
<b>NET MOVEMENT IN FUNDS</b>		<b>£443</b>	<b>£1,335</b>	<b>£1,778</b>	<b>£7,320</b>
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		<b>£7,003</b>	<b>£10,757</b>	<b>£17,760</b>	<b>£10,440</b>
<b>Total funds carried forward</b>		<b>£7,446</b>	<b>£12,092</b>	<b>£19,538</b>	<b>£17,760</b>

The charity had no recognised gains or losses for the year ended 5 April 2022 other than those included in the Statement of Financial Activities.


The notes on pages 16 to 18 form part of these accounts.

**THE SANDCASTLE TRUST  
 BALANCE SHEET AS AT 5 APRIL 2022**

	<u>Notes</u>	<u>2022</u>		<u>2021</u>	
		£	£	£	£
<b>FIXED ASSETS</b>					
Tangible assets			4,288		-
<b>CURRENT ASSETS</b>					
Debtors		493		1,350	
Bank account		<u>21,620</u>		<u>17,010</u>	
<b>TOTAL CURRENT ASSETS</b>			22,113		18,360
Creditors – amounts falling due within one year			<u>6,863</u>		<u>600</u>
<b>NET ASSETS</b>			<u>19,538</u>		<u>17,760</u>
<b>The funds of the charity:</b>	<b>7</b>				
Unrestricted			7,446		7,003
Restricted			12,092		10,757
<b>TOTAL CHARITY FUNDS</b>			<u>19,538</u>		<u>17,760</u>

Approved by the Trustees on 21 January 2023 and signed on their behalf by:

  
 .....  
 Danielle Singleton  
 Chair

  
 .....  
 Luke Brooker  
 Treasurer

The notes on pages 16 to 18 form part of these accounts.

**THE SANDCASTLE TRUST**  
**NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2022**

**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.

**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.

**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.

**2. Transactions with Trustees and Other Connected Persons**

No remuneration is paid to the Trustees, but expenses of £307.82 were reimbursed to two of the trustees.

### 3. Income from donations and grants

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2022</u> <u>Total</u>	<u>2021</u> <u>Total</u>
	£	£	£	£
Donations	9,989	-	9,989	1,346
Just Giving	6,874	-	6,874	5,975
Grants	8,209	39,320	47,529	29,647
	<b><u>£25,072</u></b>	<b><u>£39,320</u></b>	<b><u>£64,392</u></b>	<b><u>£36,968</u></b>

Funding is acknowledged under the terms and conditions of the following grants:

Funder	Project	Value
Baron Davenport	Sandcastle Memories (families in City of Birmingham and West Midland counties)	£1,000
Cheshire Community Foundation	Sandcastle Memories (families in Cheshire)	£2,000
National Lottery (Connecting communities)	Sandcastle Connections	£2,500
National Lottery - Awards for All England	Sandcastle Memories	£9,800
National Lottery - Awards for All Northern Ireland	Sandcastle Memories (families in Northern Ireland)	£9,960
National Lottery - Awards for All Wales	Sandcastle Memories (families in Northern Ireland)	£9,460
The Toy Trust	Sandcastle Memories	£2,650
The Two Ridings Community Foundation	Sandcastle Memories (families in North and East Yorkshire)	£1,950

### 4. Income from other trading activities

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2022</u> <u>Total</u>	<u>2021</u> <u>Total</u>
	£	£	£	£
Fundraising & Organised Challenges	<b><u>£60</u></b>	-	<b><u>£60</u></b>	£1,350

## 5. Expenditure on Raising Funds

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2022</u> <u>Total</u>	<u>2021</u> <u>Total</u>
	£	£	£	£
Fundraising Materials	799	710	1,509	1,015
Events	1,381	-	1,381	1,884
	<u>2,180</u>	<u>710</u>	<u>2,890</u>	<u>£2,899</u>

## 6. Governance Costs

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2022</u> <u>Total</u>	<u>2021</u> <u>Total</u>
	£	£	£	£
Insurance	62	-	62	290
Bank charges	181	-	181	291
Advertising and marketing	1,608	-	1,608	1,141
Postage and stationery	894	-	894	1,558
Other costs	4,927	1,690	6,617	1,065
Independent examiner	1,830	-	1,830	600
	<u>9,502</u>	<u>1,690</u>	<u>11,192</u>	<u>£4,945</u>

## 7. Movement in Funds

	<u>At 6</u> <u>April</u> <u>2021</u>	<u>Income</u>	<u>Expenditure</u>	<u>Transfers</u>	<u>At 5</u> <u>April</u> <u>2022</u>
	£	£	£	£	£
<b>Unrestricted</b>					
General fund	7,003	25,132	-30,209	5,520	7,446
<b>Restricted</b>					
Sandcastle Memories	6,524	36,820	-25,732	-5,520	-12,092
Sandcastle Smiles	3,523	0	-3,523		
Sandcastle Connections	710	2,500	-3,210		
	<u>10,757</u>	<u>39,320</u>	<u>-32,465</u>	<u>-5,520</u>	<u>12,092</u>
<b>Total</b>	<u>£17,760</u>	<u>64,452</u>	<u>-62,674</u>	<u>-</u>	<u>19,538</u>



**THE SANDCASTLE TRUST**

England & Wales - Charity number 1169523

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# Accounts

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# THE SANDCASTLE TRUST

ANNUAL REPORT AND ACCOUNTS  
FOR THE YEAR ENDED 5 APRIL 2021

## CONTENTS

	Page(s)
Reference and Administrative Information	1
Trustees' Report	2-6
Statement of Trustees' Responsibilities	6-7
Independent Examiner's Report to the Trustees	8
Financial statements	9 - 10
Notes to the Financial Statements	10 - 13

**THE SANDCASTLE TRUST**

**REFERENCE AND ADMINISTRATION INFORMATION**

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

**Committee of Trustees**

Mrs D. Singleton  
D. Singleton  
L. Dodd  
C. Bateman  
E. Bateman  
I. Bateman  
G Webb (resigned March 2020)  
L Brooker  
M. Holland (appointed September 2020)

**Independent Examiner**

David Wheeler FCCA  
Cheeld Wheeler & Co  
Chartered Certified Accountants  
Goodman House  
13a West Street  
Reigate  
Surrey, RH2 9BL

**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 2021.

### **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 aim of the Sandcastle Trust as stated in our Articles of Association is to help and support families living within the UK whereby a member or members of that family have been diagnosed with a rare genetic condition.

Mission: The Sandcastle Trust supports families living with a diagnosis of a rare genetic condition, to build lasting positive family memories, strengthen their family relationships, break down barriers and improve mental health, wellbeing and resilience through the provision of bespoke family respite packages. We call these Sandcastle Memories.

We increase public awareness of the needs and issues that families face when accessing social opportunities; signpost to sources of support 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. 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.

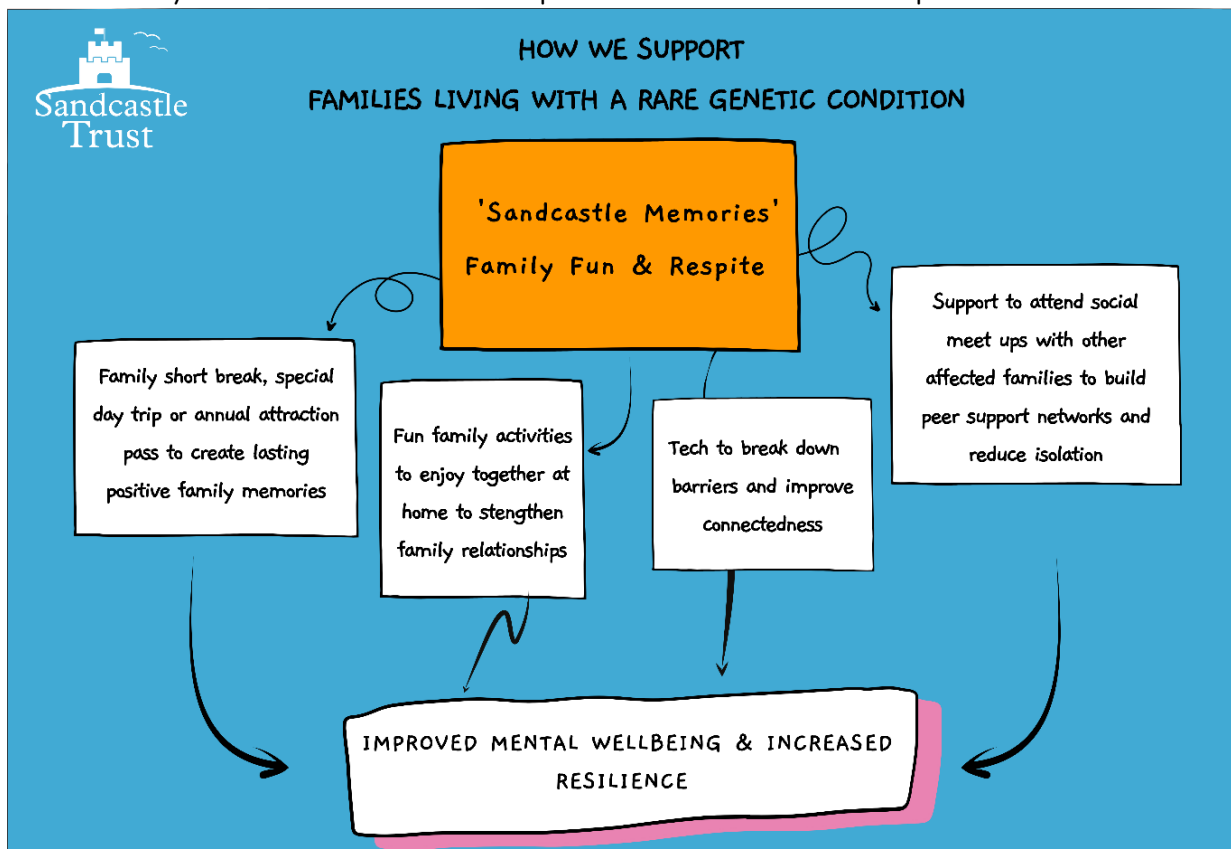
The Need: There are approximately 6,000 diagnosed genetic conditions. Each affects less than 0.1% of the UK's population, but together they are one of the greatest causes of disability and early death and affect the lives of 3 million people in the UK (source: National Human Genome Research Institute). Collectively, therefore, they are not rare at all. Symptoms of rare genetic conditions vary but can include physical disability, learning difficulty, mental health and social issues. Caring for a loved one with a genetic condition is emotionally exhausting. It impacts the whole family and as a result the families we support face significant barriers and multiple disadvantages in their lives, in particular mental health issues (72% of our beneficiaries in 2020/21) and isolation (81%). In addition to this 70% of the families had a household annual income of less than £20,000 and 90% told us that the financial implications of their situation meant they found it incredibly difficult to spend quality family time together outside of their day to day routine which has had a detrimental impact on their mental wellbeing.

Our Support: The Sandcastle Memories (family respite) we deliver are designed for an affected family to enjoy together, away from their daily routine to refresh and re-energise. Traditionally, Sandcastle Memories have taken the form of a short UK break or where a short break is not suitable, annual passes or one-off special day trips to attractions such as zoos, farms and steam railways so that families can experience regular fun days out together without worrying about the cost implications of a day out having to be cut short.

The medical complexity of the cared-for in the families we support meant that most were in the clinically vulnerable category and shielded for months during the height of the coronavirus pandemic. In March 2020 we temporarily suspended Sandcastle Memories involving travel, consulted our community and diversified our activities to introduce an additional category of support – ‘Sandcastle Memories – At Home.’ Examples of family respite delivered at home include back garden cinema, online Makaton singing sessions, accessible garden play equipment and annual bake box subscriptions that can be enjoyed by the whole family together throughout a year.

During the 2020-21 period, 96% of our family respite was delivered in this way. We envisaged continuing to deliver the respite from home until a successful vaccine programme had been rolled out and shielding ended, but due to the positive feedback received from families and the changing nature of the pandemic, this respite option is now a permanent category of support.

We also provide support to small disorder specific charities and patient groups without a disorder specific charity to arrange family meet ups and fun days together although unfortunately none of these events took place in 2020-21 due to the pandemic.

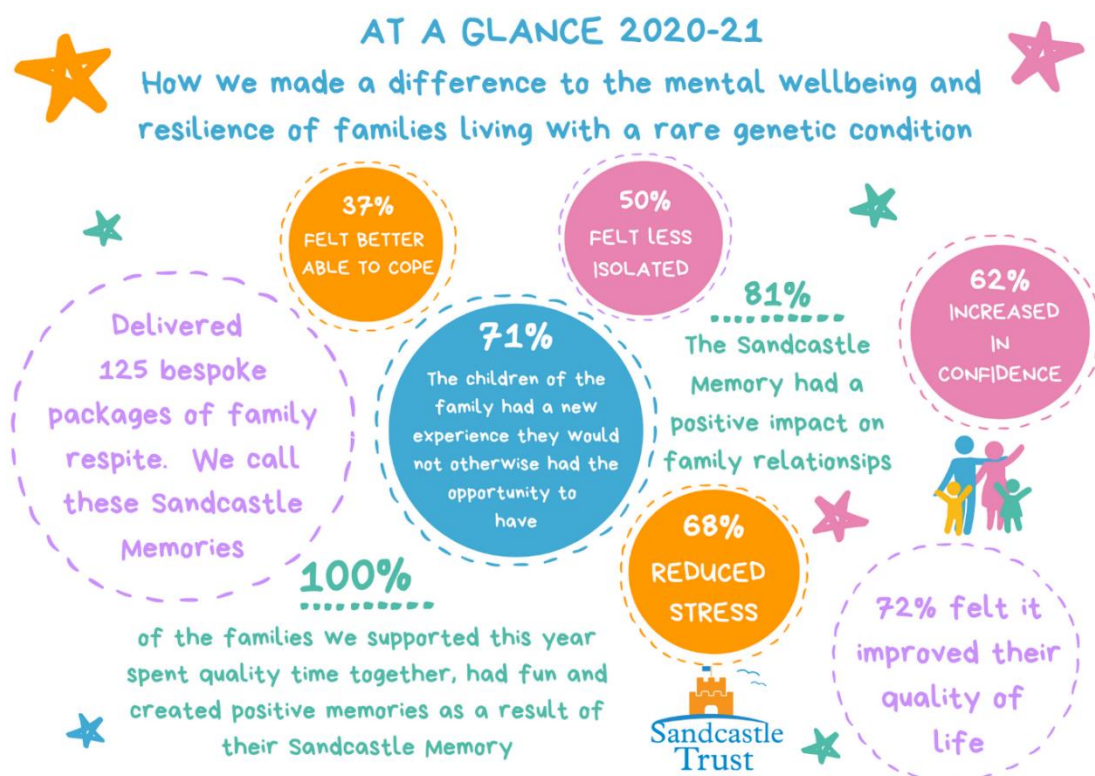


## ACHIEVEMENTS AND PERFORMANCE

Despite the pandemic and resulting restrictions The Sandcastle Trust supported 125 families with a *Sandcastle Memory* in 2020/21.

The impact of Covid-19 on families affected by a rare genetic condition has been immense. Every challenge inherent in living with a rare genetic condition has been exacerbated by covid-19 and the necessary measures taken to contain the pandemic. Support has been slashed and levels of social isolation have increased. We were able to pivot quickly this year to continue to providing family respite to this highly isolated and vulnerable group of families.

We carry out a beneficiary survey throughout the year to help us demonstrate the longer term difference that The Sandcastle Trust makes. The data collected via this survey is summarised in the diagram below and demonstrates the benefits of a Sandcastle Memory are not short lived; it can offer holistic respite for the whole family, improve mental health outcomes, reduce isolation, help carers to maintain their quality of care and generally provides a positive focus which can empower families with a new enthusiasm and strength to deal with ongoing daily struggles of illness, gruelling hospital treatment and sometimes a devastating loss.



## **FINANCIAL REVIEW**

2020/1 was an incredibly challenging year for The Sandcastle Trust. The COVID-19 pandemic created significant operational pressures on the charity and hindered the Trustees Fundraising Activity.

Despite income from our own fundraising activity and organised events declining, we are incredibly grateful to the individuals who took on virtual challenges to fundraise for The Sandcastle Trust this year and the trusts and foundations that have supported our work

The Trustees can report a satisfactory year with income increasing slightly from £38,703 in the prior year to £38,318 with net income increasing from £418 to £7,320. During the year the Trust spent £23,154 on charitable activities, (i.e. the provision of Sandcastle Memories) compared to £28,404 in the previous period. As at 5 April 2021, the Trust had accumulated funds of £17,760 of which £8,380 are restricted funds, leaving free reserves of £9,380.

## **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 Chanty's current activities in the short term while consideration is given to ways in which additional funds may be raised.

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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 25 JANUARY 2022 and signed on their behalf by:



.....  
Danielle Singleton  
Chair



.....  
Luke Brooker  
Treasurer

**THE SANDCASTLE TRUST**  
**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 2021.

**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.



.....

David Wheeler – Independent Examiner

David Wheeler F.C.C.A

Cheeld Wheeler & Co , Chartered Certified Accountants

Goodman House, 13a West Street

Reigate, Surrey, RH2 9BL

28 January 2021

Dated:.....

**THE SANDCASTLE TRUST**  
**STATEMENT OF FINANCIAL ACTIVITIES**  
**FOR THE YEAR ENDED 5 APRIL 2021**

	<u>Notes</u>	<u>2021</u>	<u>2020</u>		
		<u>Unrestricted</u>	<u>Restricted</u>		
		£	£		
		<u>Total</u>	<u>Total</u>		
		£	£		
<b>INCOME</b>					
Grants and donations	3	17,323	19,645	36,968	36,815
Other trading activities	4	1,350	-	1,350	1,888
<b>TOTAL INCOME</b>		<b>18,673</b>	<b>19,645</b>	<b>38,318</b>	<b>38,703</b>
<b>EXPENDITURE</b>					
Costs of raising funds	5	2,899	-	2,899	5,887
Charitable activities – Sandcastle Memories		7,290	15,864	23,154	28,404
Governance costs	6	2,405	2,540	4,945	3,994
<b>TOTAL EXPENDITURE</b>		<b>12,594</b>	<b>18,404</b>	<b>30,998</b>	<b>38,285</b>
<b>NET INCOME FOR THE YEAR</b>		<b>£6,079</b>	<b>£1,241</b>	<b>£7,320</b>	<b>£418</b>
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		<b>£3,301</b>	<b>£7,139</b>	<b>£10,440</b>	<b>£10,022</b>
<b>Total funds carried forward</b>		<b>£9,380</b>	<b>£8,380</b>	<b>£17,760</b>	<b>£10,440</b>

The charity had no recognised gains or losses for the year ended 5 April 2021 other than those included in the Statement of Financial Activities.

The notes on pages 11 to 13 form part of these accounts.

**THE SANDCASTLE TRUST**  
**BALANCE SHEET AS AT 5 APRIL 2021**

	<u>Notes</u>	<u>2021</u>		<u>2020</u>	
		£	£	£	£
<b>CURRENT ASSETS</b>					
Debtors		1,350		2,700	
Bank account		17,010		8,550	
<b>TOTAL CURRENT ASSETS</b>			18,360		11,250
Creditors – amounts falling due within one year			600		810
<b>NET ASSETS</b>			17,760		£10,440
<b>The funds of the charity:</b>					
	<b>7</b>				
Unrestricted			9,380		3,301
Restricted			8,380		7,139
<b>TOTAL CHARITY FUNDS</b>			17,760		£10,440

Approved by the Trustees on 25 JANUARY 2022 and signed on their behalf by:



.....  
 Danielle Singleton  
 Chair



.....  
 Luke Brooker  
 Treasurer

The notes on pages 11 to 13 form part of these accounts.

## THE SANDCASTLE TRUST

### NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2021

#### **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.

##### **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.

##### **1.5 Taxation**

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

#### **2. Transactions with Trustees and Other Connected Persons**

No remuneration is paid to the Trustees, but expenses of £76 were reimbursed to one of the trustees.

### 3. Income from donations and grants

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2021</u>	<u>2020</u>
	£	£	Total	Total
			£	£
Donations	1,346	-	1,346	3,430
Just Giving	5,975	-	5,975	20,315
Grants	10,002	19,645	29,647	13,070
	<b><u>£17,323</u></b>	<b><u>£19,645</u></b>	<b><u>£36,968</u></b>	<b><u>£36,815</u></b>

### 4. Income from other trading activities

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2021</u>	<u>2020</u>
	£	£	Total	Total
			£	£
Fundraising & Organised Challenges	<b><u>£1,350</u></b>	-	<b><u>£1,350</u></b>	<u>£1,888</u>

### 5. Expenditure on Raising Funds

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2021</u>	<u>2020</u>
	£	£	Total	Total
			£	£
Fundraising Materials	1,015	-	1,015	1,146
Events	1,884	-	1,884	4,741
	<b><u>£2,899</u></b>	-	<b><u>£2,899</u></b>	<u>£5,887</u>

## 6. Governance Costs

	<u>Unrestricted</u>	<u>Restricted</u>	<u>2021</u> <u>Total</u>	<u>2020</u> <u>Total</u>
	£	£	£	£
Insurance	290	-	290	-
Bank charges	291	-	291	276
Advertising and marketing	991	150	1,141	747
Postage and stationery	833	725	1,558	2,371
Other costs	-	1,065	1,065	-
Independent examiner	-	600	600	600
	<b><u>£2,405</u></b>	<b><u>£2,540</u></b>	<b><u>£4,945</u></b>	<b><u>£3,994</u></b>

## 7. Movement in Funds

	<u>At 6</u> <u>April</u> <u>2020</u>	<u>Income</u>	<u>Expenditure</u>	<u>Transfers</u>	<u>At 5</u> <u>April</u> <u>2021</u>
	£	£	£	£	£
<b>Unrestricted</b>					
General fund	3,302	16,173	-16,622	4,150	7,003
<b>Restricted</b>					
Adamson Trust	932	-	-932	-	-
Barchester Health	180	-	-	-	180
Barnwood	-	2,250	-995	-250	1,005
Brian Murtagh	-	3,250	-	-	3,250
Bruce Wake	1,500	-	-1,500	-	-
Cash 4 Kids	1,878	-	-	-	1,878
Edward Gosling	-	4,000	-477	-	3,523
National Lottery (Connecting communities)	-	2,500	-180	-1,610	710
National Lottery (Gov Covid-19)	-	10,145	-7,855	-2,290	-
Paul Bassham Trust	1,402	-	-1,402	-	-
Surrey Community Foundation	1,246	-	-1,035	-	211
<b>Total</b>	<b><u>£10,440</u></b>	<b><u>£38,318</u></b>	<b><u>£30,998</u></b>	<b><u>-</u></b>	<b><u>£17,760</u></b>