



**Sandcastle
Trust**
Supporting rare families

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

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Thank you!

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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:

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Redhill Chambers, 2D High Street
Redhill, Surrey
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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

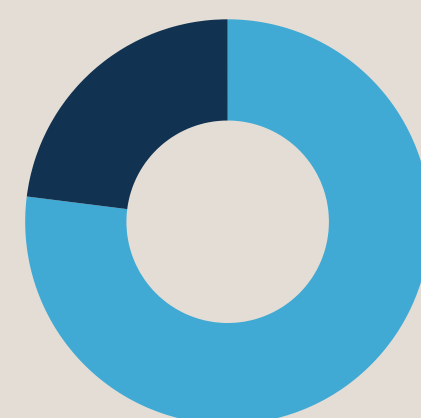
What our community told us

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

68%

have experienced relationship crisis or breakdown



84%

have at least one family member experiencing mental health challenges.

69%

Have suffered anticipatory grief/loss

94%

regularly feel anxious

93%

are chronically stressed

77%

would describe themselves as depressed

87%

are isolated



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/respite 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 respite 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

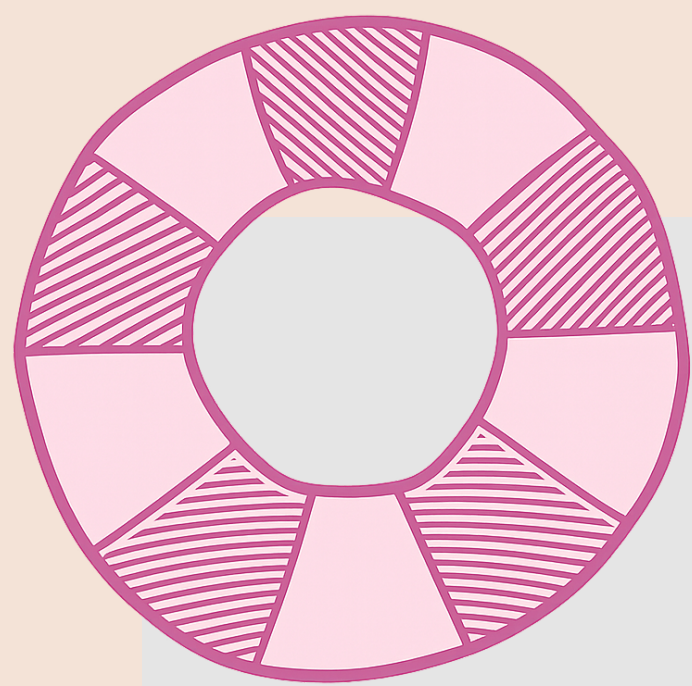
Our Family Respite Service gives families the opportunity to spend quality time together away from their daily routine to refresh, re-energise and reconnect. Many families tell us that rare genetic conditions can put pressure on relationships, limit opportunities for positive shared experiences, and 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 available for 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

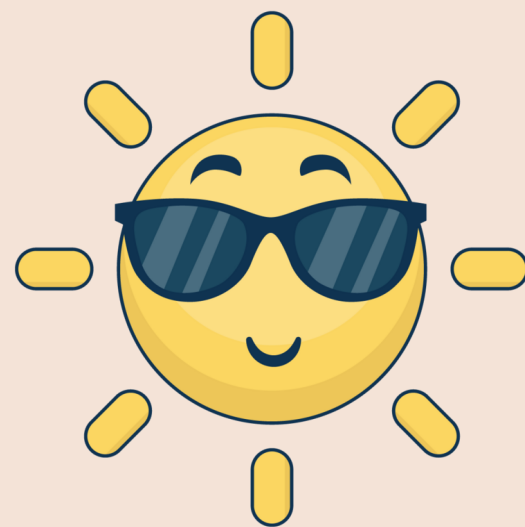


Sandcastle Memories

(free short breaks, special days & annual passes)

157 families

made up of 664 individuals

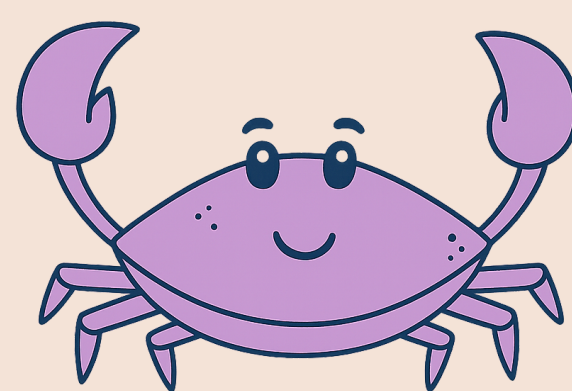


Sandcastle Fair Breaks

(subsidized short breaks)

3 families

made up of 12 individuals



Sandcastle Smiles

(home based respite activities)

75 families

made up of 285 individuals



961

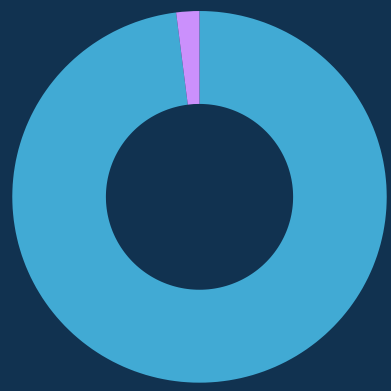
individuals supported

Impact



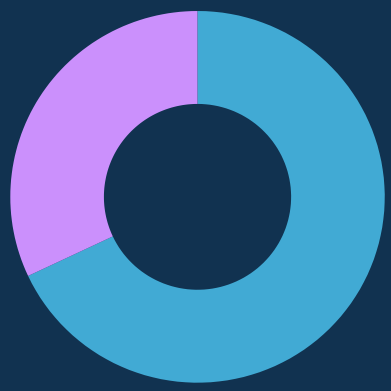
100%

created positive family memories



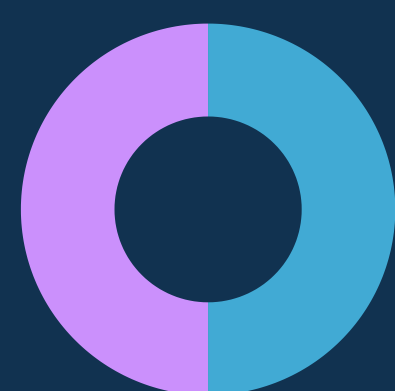
98%

reported improved quality of life



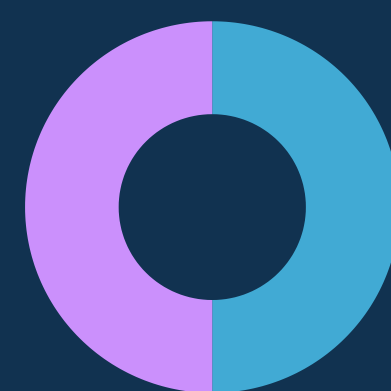
72%

reported reduced stress



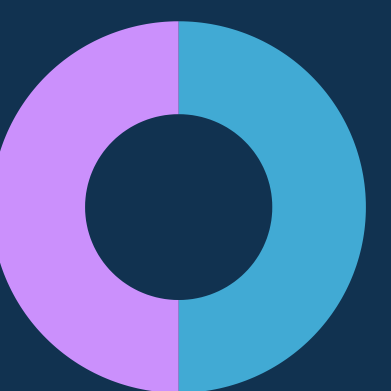
69%

felt less isolated



62%

reported a positive impact on confidence



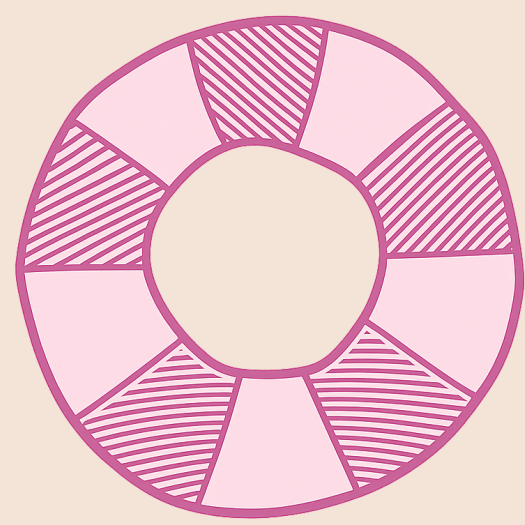
82%

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

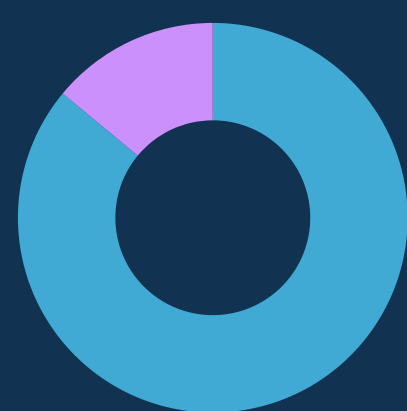
individuals
supported

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

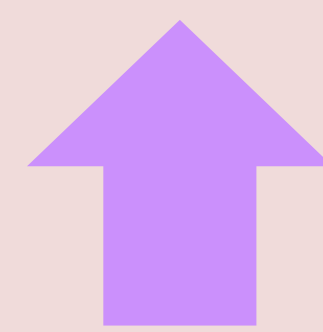
81



“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.

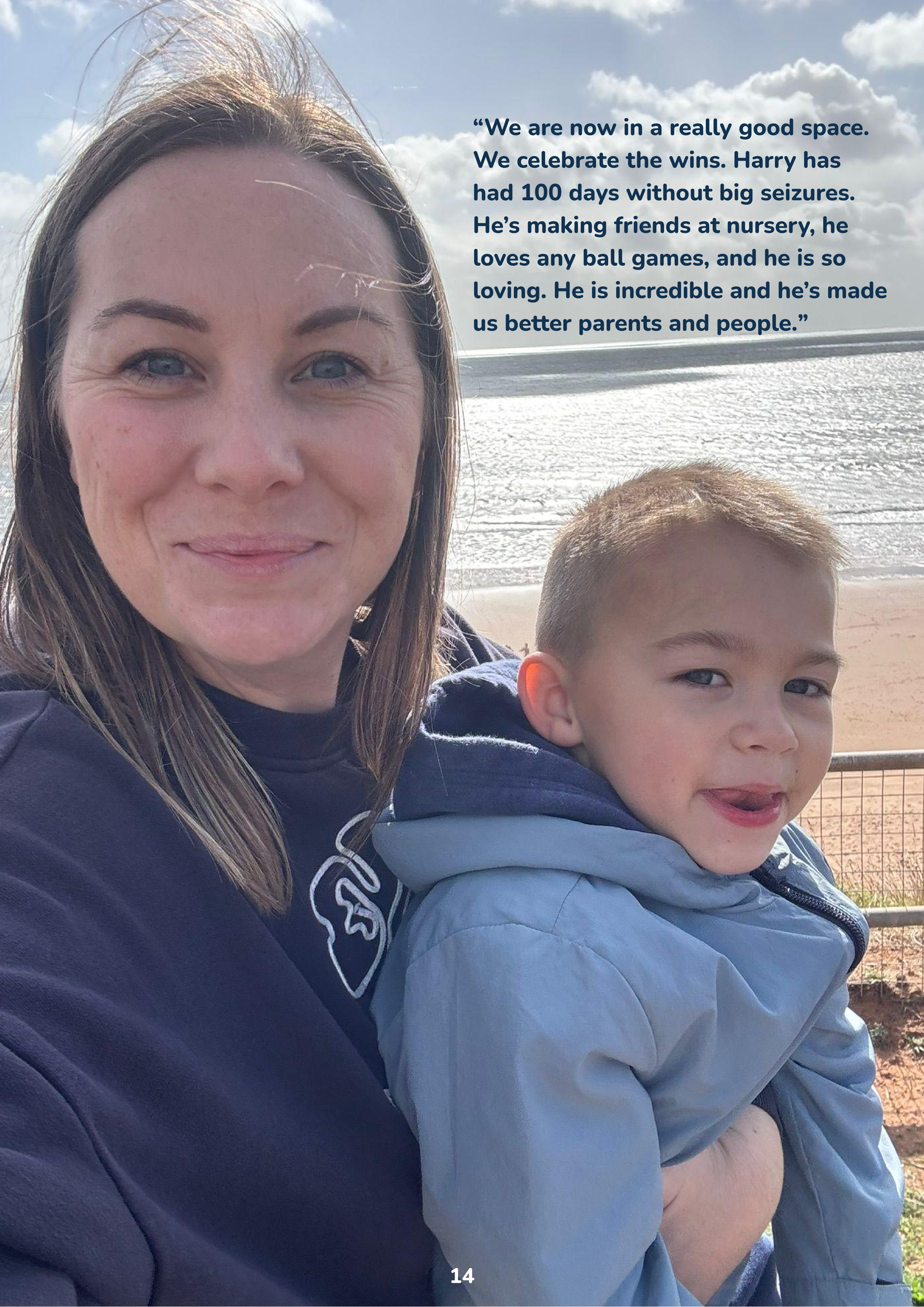
"Counselling helped me deal with those overwhelming feelings and emotions. It helped keep me going. We refer to it as a big purple monster that sits in the corner of the room but now we acknowledge it is there and we just ask it to stay there so we can carry on. Sometimes it will come and wipe us out. 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).

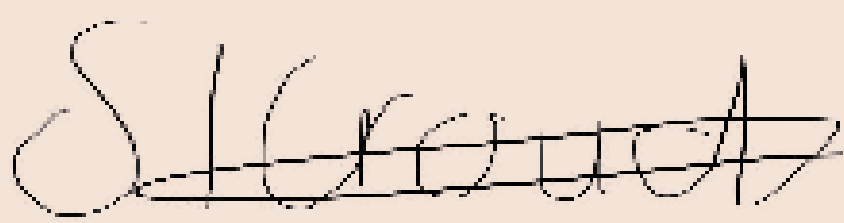
The law applicable to charities in England and Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing these financial statements, 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>
		£	£	£	£
INCOME					
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
TOTAL INCOME		28,740	130,738	159,478	92,999

NOTES		2025			2024
		<u>Unrestricted</u>	<u>Restricted</u>	<u>Total</u>	<u>Total</u>
		£	£	£	£
EXPENDITURE					
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
TOTAL EXPENDITURE		15,892	88,976	104,868	89,187

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

RECONCILIATION OF FUNDS

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

Balance Sheet

As At 5 April 2025

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

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
TOTAL	26,653	130,738	157,391	89,294

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
TOTAL	9,688	945	10,633	7,973

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
TOTAL	5,934	6,403	12,337	12,387

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

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
TOTAL	17,445	111,475	128,920

-