

# THE SANDCASTLE TRUST

ANNUAL REPORT AND ACCOUNTS  
FOR THE YEAR ENDED 5 APRIL 2022

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**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

## **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.



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**

	<b>Notes</b>	<b>Unrestricted</b>	<b>2022 Restricted</b>	<b>Total</b>	<b>2021 Total</b>
		<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
<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		<u>12,092</u>	<u>10,757</u>
<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>£25,072</b>	<b>£39,320</b>	<b>£64,392</b>	<b>£36,968</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>£60</b>	-	<b>£60</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>

