Sandcastle Trust

Supporting rare families

Strategic Plan for 2025-2030

INTRODUCTION

The Sandcastle Trust is a small national charity but our commitment to the rare genetic condition community is big!

We believe that every member of a family impacted by a rare genetic condition should have access to high-quality emotional wellbeing support, but we know that this is currently not the case.

In addition, with millions of people in the UK collectively being impacted by a range of complex and rare genetic conditions, the demand for The Sandcastle Trust's support has never been greater. Unfortunately, that demand significantly exceeds our charity's size and capacity.

This new strategy sets out how we are going to strive to meet this demand and work towards making our vision a reality over the next five years. It will provide a framework to help the Trustees and staff team plan ahead, ensuring that the targets and objectives are clear each year, so that they are confident that all the operational activities work towards achieving our Charity's vision.

Our Strategy has been developed by The Sandcastle Trust's Trustees and staff, with the valued input of the families who access our services.

We want to send a big thank you to all who took the time and effort to share their thoughts, knowledge, ideas and insights with us as part of our strategy consultation process in 2024.

Samantha Crouch
Chair of Trustees

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THE SANDCASTLE TRUST'S HISTORY

14 years ago - aged just 28 - my husband, Dave was diagnosed with very rare genetic condition. He had been having problems walking for a couple of years prior to that and in our naivety, we thought something simple like a slipped disk or a trapped nerve was to blame.

As it became clear that it was more serious than that, we entered what is often called a 'Diagnostic Odessey,' something I later learned is common to many who receive a diagnosis with a very rare genetic condition – a long exhausting battle to kick down every door and shout loud enough to get a definitive diagnosis.

Despite this we were completely blindsided by the diagnosis of a rare, potentially life limiting, inherited condition (AMN); as was the consultant who, not having come across a case before, googled the condition in front of us.

Despite the confusion and the sudden realisation of the genetic implications for our family, we initially felt a sense of relief—at last, we had answers. We thought this meant we could now access the support Dave and our family so desperately needed.

How wrong we were! Although regular hospital appointments and invasive treatments became a way of life for Dave, we were isolated and scared and received very little emotional support to help us navigate the challenges ahead.

It was out of this difficult experience that the idea for The Sandcastle Trust began to take shape, and the charity was formed in 2016. I am immensely proud that what started as small-scale fundraising with some excited and willing volunteers to offer special days out for families impacted by rare genetic conditions, has since grown into an established charity providing several impactful emotional wellbeing services to the rare genetic condition community.

We have made some great friends and gained wonderful supporters along the way, and I am excited to see what the future brings.

Danielle Singleton
Co-Founder and Head of Service Delivery & Operations

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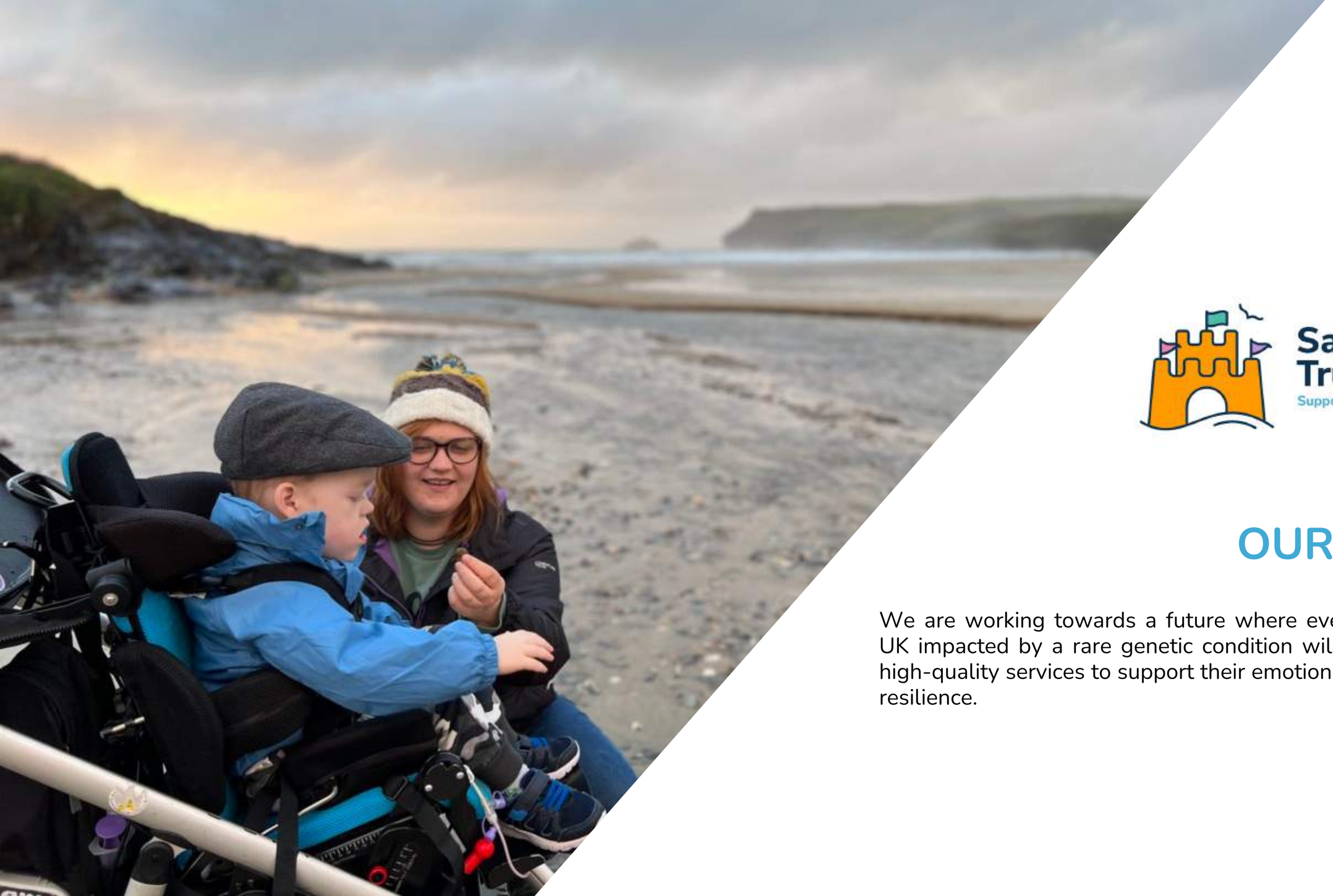

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OUR VISION

We are working towards a future where every family in the UK impacted by a rare genetic condition will have access to high-quality services to support their emotional wellbeing and resilience.

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OUR MISSION

The Sandcastle Trust's mission is to reduce inequalities in emotional wellbeing outcomes for families living with a rare genetic condition. We walk alongside families helping to strengthen and nurture emotional wellbeing through a range of services that build positive family memories, strengthen family relationships, reduce isolation and improve resilience.

We also increase public awareness of the inequalities and barriers to emotional wellbeing that families living with rare genetic conditions face and advocate for positive change.

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OUR VALUES

Families come first
Families impacted by rare genetic conditions are the sole reason we are here. For every decision we make and every action we take, we ask ourselves how this takes us closer to achieving our vision. Our community will be involved in service design and delivery wherever possible and the safeguarding of everyone involved with The Sandcastle Trust will remain our top priority.

Inclusive
Our services are inviting and welcoming to people of all backgrounds and identities in the UK whose life has been impacted by a rare genetic condition and we promise to treat people fairly and with respect.

Approachable
We’re open, warm and here for families living with a rare genetic condition, when they need us.

Collaborative
We choose to work in partnership with organisations that share our values so that we can make a bigger difference.

ABOUT RARE GENETIC CONDITIONS & WHY WE ARE NEEDED

There are approximately 6,000 diagnosed genetic conditions. Each affects less than 0.1% of the population, but together they impact the lives of 3 million people in the UK (source: National Human Genome Research Institute) making them far less ‘rare’ than they might seem. Collectively, they represent one of the most significant causes of disability and early death.

Rare genetic conditions are caused by changes in an individual's genetic makeup. These changes may be inherited (in which case multiple members of the same family can be impacted) or happen randomly. Some 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 may result in physical disabilities (for example, Ataxia Telangiectasia and Spinal Muscular Atrophy) and/or learning disabilities (for example, Angelman Syndrome and Williams Syndrome) and/or sensory disabilities (for example, Norrie Disease or Usher Syndrome which both cause severe eyesight and hearing impairment). Despite the variety in symptoms and experiences, many people living with these conditions face similar challenges in accessing appropriate care and support.

No one can be prepared for the overwhelming and devastating diagnosis of a rare genetic condition and the journey that follows is emotionally demanding. It can involves low mood, anxiety, emotional exhaustion, and has the potential to trigger thoughts of hopelessness or suicidal ideation.

There are other invisible disadvantages too - like financial challenges, negative attitudes and discrimination, barriers to work and education which then compound these feelings further.

The Sandcastle Trust is dedicated to ensuring that no family has to face this journey alone.

We walk alongside families living with the challenges of a rare genetic condition, breaking down barriers, strengthening and nurturing emotional wellbeing and resilience.

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OUR STRATEGY CONSULTATION: A SNAPSHOT

94% of respondents regularly experienced anxiety

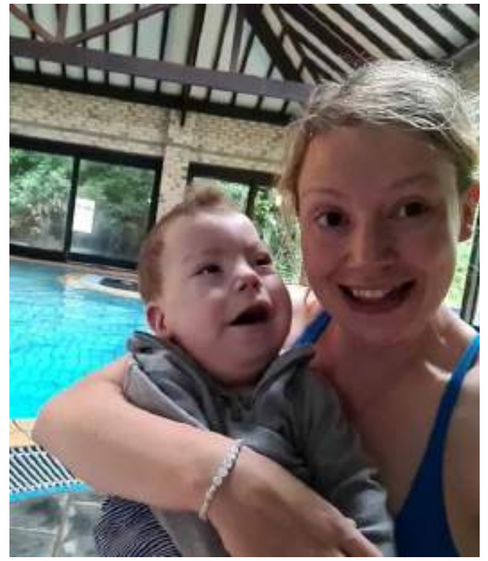
87% of respondents felt isolated

93% of respondents regularly experienced extreme stress

100% of respondents agreed with the statement that the challenges of living with a rare genetic condition extended far beyond medical needs, impacting many areas of daily life. Examples included relationships, identity, education, work, and finances.





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OUR CONSULTATION: IN DETAIL

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Insights from our work consistently show that families living with a rare genetic condition are more likely to experience poor emotional well-being due to the challenges they face. Throughout 2024, we undertook a strategy consultation that included a survey with contributions from 139 community members, as well as numerous face-to-face conversations in which families generously shared their challenges in a very personal way. The results of this consultation revealed the significant extent of the emotional distress often experienced by these families

- **84%** of respondents reported mental health issues
- **87%** felt isolated
- **93%** experienced stress
- **75%** felt unsupported in their caregiving role
- **94%** suffered from anxiety
- **71%** feared for the mental health of young people in their families, particularly those acting as young carers

Common words and themes that emerged highlighted significant levels of social isolation, mental health struggles, and a sense of disconnect from broader support systems:

- **Loneliness**, **emotional pain**, and feelings of **uselessness**
- Concerns about **not being around to care** for loved ones
- Negative impact on **family relationships/dynamics**
- Feelings of **loss** and **grief**
- Feelings of **stress** and **burnout** as a result of caring
- A sense of being **trapped** and facing **uncertainty** about the future
- Anxiety about the impact of caregiving on **siblings** and **young carer**s
- In some cases, **thoughts of self harm and suicide** were expressed

The findings highlighted significant gaps and barriers in accessing appropriate emotional wellbeing support:

- Many families had never had the opportunity to meet another family who share the same condition or who are experiencing similar symptoms or issues
- **75%** of respondents reported that their emotional wellbeing was never or rarely addressed during medical appointments for their rare genetic condition
- **44%** of respondents reported that no specific charity exists to support their condition
- **Financial constraints**
- **Lack of information** about available resources
- **Logistical challenges**, such as transportation, care giving duties and **exclusion/inaccessibility**
- **Feeling overwhelmed with daily demands**
- **Limited availability** of services

All of this underscores the urgent need for comprehensive and holistic emotional wellbeing support for families living with a rare genetic condition.

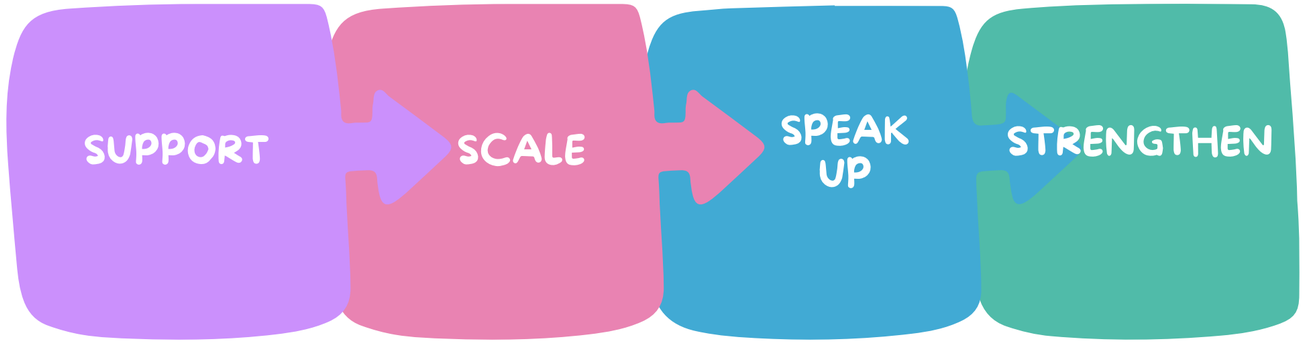
OUR FUTURE

Looking ahead, our ambition is that over the next five years The Sandcastle Trust will transition from a charity focused primarily on providing families with respite breaks and the chance to make precious family memories, to one which provides a wide range of impactful emotional well-being initiatives, and amplifies the voices and experiences of families impacted by rare genetic conditions at a national level.

We are all individuals, with our own preferences and needs. Different things matter to each of us, at different times. Our aim is to offer a personalised approach providing a whole ‘toolbox’ of ways for families to feel more emotionally well and resilient, in ways that work for them.

AMBITION TO REALITY

Our five-year strategy centres around four pillars:



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PILLAR ONE : SUPPORT

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TODAY

Our Sandcastle Memories respite service was the first support provided by the charity when it was formed it 2016 and is now our largest programme. It provides families living with a rare genetic condition the opportunity to spend quality time together away from their daily routine to refresh and re-energise, supporting them with the emotional rigour of caring in the long-term.

Since 2020 we have introduced a number of new, additional services attempting to bridge the significant gaps in emotional wellbeing support available to families impacted by a rare genetic condition:

- Our Sandcastle Counselling Service provides 1:1 emotional support as early as possible to prevent those living with a rare genetic condition or family carers reaching crisis point.
- Our Sandcastle Smiles Service provides registered families with fun, creative, sensory respite activities that can be enjoyed by a family together at home to foster and strengthen family relationships and create positive family memories.
- Our Sandcastle Connections service alleviates 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.
- 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.

FROM 2025 TO 2030 WE WILL:

Sustain and improve our existing services, whilst growing and expanding our offer, trying new approaches and ideas to address the interconnected and complex emotional wellbeing needs of the whole family unit.

OUR STRATEGIC OBJECTIVES TO ACHIEVE THIS ARE:

- Grow our existing services and broaden our support offer – Every activity we undertake at The Sandcastle Trust will focus on areas that families impacted by rare genetic conditions have told us contribute to them feeling emotionally well and resilient and/or guided by the 5 Ways to Wellbeing framework, created by the New Economics Foundation, which is supported by evidence and research.
- We will work with our community - Families have always been at the heart of our work and we have conducted a wide range of research and analysis to help us decide which areas to focus on in this strategy, but we will continue the conversations to keep us on track and accountable. We will formalise and develop our collaborative approach so that families feel empowered to share their experiences and expertise and they get support in ways that works best for them.
- We will extend our partnership working - We want to work more closely with hospices and other relevant charities, NHS services and organisations who support families impacted by rare genetic conditions to ensure there are no gaps in support.
- We will develop a volunteer programme - We will increase volunteering opportunities to help us reach and support more families and provide a new way for people to engage with our work.
- We will improve the way we evidence, demonstrate and promote the impact of our work to leverage more funding to both reach more people and to meet the changing diversity of need of the people we work alongside.

PILLAR TWO : SCALE

TODAY

Collectively, rare genetic conditions impact the lives of 3 million people in the UK (source: National Human Genome Research Institute).

This number has grown significantly in recent years due to initiatives like the DDD (Decoding Developmental Disorders) study and the 100,000 Genomes Project which have uncovered new genetic variants linked to rare conditions. By identifying previously undiagnosed conditions, these scientific breakthroughs offer us the opportunity to facilitate new connections within the rare genetic conditions community and ensure families receive tailored support to stay emotionally well and resilient.

FROM 2025 TO 2030 WE WILL:

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

OUR STRATEGIC OBJECTIVES TO ACHIEVE THIS ARE:

- We will double the number of families accessing our services. In 2023-4 we supported 2,068 families and so we will aim to support 4,136 families annually by the end of this strategy. This is the number which will continually drive us forward.
- We will work towards our service user database having a balanced representation from each UK nation. For example, since 8% of the UK population resides in Scotland, our goal is for 8% of our database to consist of Scottish families affected by a rare genetic condition.
- We need to raise our profile and get our messages to those who need to hear them, in a way that they can receive them.
- We will strengthen our links with other organisations that work with families impacted by rare genetic conditions to leverage their networks to help us connect with a broader audience, ensuring more families are informed about the support we offer and how to access it and vice versa.
- We need to do better at reaching diverse groups, including people from black and minority ethnic communities and non-English speakers, ensuring that the most marginalised in the rare genetic condition community are accessing our services.

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PILLAR THREE : SPEAK UP

TODAY

While providing direct services to families will always be our primary focus, we recognise that in order to break down the barriers to emotional wellbeing and resilience that families living with a rare genetic condition face, we will need to help raise awareness and influence broader systemic change.

FROM 2025 TO 2030 WE WILL:

Increase our reputation as a ‘trusted voice’ bringing our understanding of what works to support the emotional wellbeing and resilience of families impacted by rare genetic conditions, while also amplifying the voices of these families and empowering them to speak up about the barriers they face in accessing this support, to the widest possible audience.

OUR STRATEGIC OBJECTIVES TO ACHIEVE THIS ARE:

- We will develop a structured approach to planning campaigns, content, and communications that drive awareness and engagement.
- We will take an active role in disability coalitions and partnerships, and establish a distinctive Sandcastle Trust voice on nurturing and supporting the emotional wellbeing and resilience of families impacted by rare genetic conditions.
- We will amplify the voice of people with lived experience through our contributions. Empowering families impacted by rare genetic conditions to share their experiences and speak up about the barriers they face in accessing support.
- We will share more about The Sandcastle Trust and the impact of our services: Expanding our use of digital to bring people closer to our work and sharing the stories of the families we support.

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PILLAR FOUR : STRENGTHEN

TODAY

In the past five years, we have doubled the amount of income we raise. We couldn't be more grateful for this incredible support, it's helped us reach many more families living with the challenges of a rare genetic condition.

But in order to fund the planned expansion of the charity's services and ensure our work has a secure, sustainable future, we need to develop new unrestricted income streams and strengthen our commitment to working at the highest levels of governance and safeguarding.

FROM 2025 TO 2030 WE WILL:

Our goal is that The Sandcastle Trust is a sustainable charity, working at the highest levels of governance and safeguarding that will be here to support families living with rare genetic conditions for many years to come.

OUR STRATEGIC OBJECTIVES TO ACHIEVE THIS ARE:

- Operate at the highest level of governance and safeguarding with a culture of continuous improvement.
- Have a strong, relevant, and inclusive brand and voice.
- Develop new and diverse income streams.
- Build reserves to 6 months of future expenditure
- Ensure we have a strong employment offer that attracts and retains staff and volunteers who are committed to our mission

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OUR SUCCESS MEASURES:

A range of delivery plans will sit beneath our strategic pillars to turn our ambitions into outcomes and lasting impact.

Success in delivering on our strategy will be measured through monitoring and tracking, and the strategy will be reviewed annually, to ensure we continue to meet the changing needs of families impacted by rare genetic conditions in the UK – a diverse population with complex needs.

Throughout the years, our website will feature updates and key achievements, making sure that our supporters, partners, funders and other interested parties can follow our progress, and be inspired by our work.

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MONDAY TO FRIDAY
from 9:00 am to 5:00 pm

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