



**Sandcastle  
Trust**

Supporting rare families



## OUR MISSION

Our 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.



Our vision is a future where every family in the UK impacted by a rare genetic condition has access to high-quality services to support their emotional wellbeing and resilience

## CONTACT US

☎ 0207 1998 261

✉ [info@sandcastletrust.org](mailto:info@sandcastletrust.org)

🌐 [www.sandcastletrust.org](http://www.sandcastletrust.org)

📘 @sandcastletrust

📷 @sandcastletrust

✕ @SandcastleTrust

📍 The Sandcastle Trust  
PO BOX 873  
Haywards Heath  
RH16 9QL

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



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# SUPPORTING RARE FAMILIES

[WWW.SANDCASTLETRUST.ORG](http://WWW.SANDCASTLETRUST.ORG)



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## WHY WE ARE NEEDED

**6,000**

Approx.  
diagnosed  
genetic  
conditions

**3M+**

3 million+ people  
affected in the UK,  
making it less  
'rare' than it  
seems

**84%**

experience mental  
health issues

**87%**

feel isolated

**94%**

regularly  
experience  
feelings of  
anxiety

**93%**

regularly  
experience  
extreme stress

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## OUR SERVICES



### SANDCASTLE MEMORIES

Respite UK breaks, annual attraction pass or a special day trip. We work directly with the family to work out the best bespoke package for them.



### COUNSELLING SERVICES

Free, confidential counselling service for family members and individuals aged 18+ impacted by rare genetic condition.



### SANDCASTLE SMILES

Regular family respite opportunities within the home. Sandcastle Smiles are fun, creative, sensory activities that can be enjoyed by a family together to foster and strengthen family relationships and create positive family memories.



### SANDCASTLE CONNECTIONS

Our Sandcastle Connections Service is here to help families facing rare genetic conditions build meaningful connections and peer support networks, reducing feelings of isolation.



### SUPPORT HUB

Web hub of organisations, guidance, advice, practical help if a member of your family has been diagnosed with a rare genetic condition

## YOUR SUPPORT

Your support helps us assist more families across the UK.

Last year, thanks to people like you, we provided a listening ear through our counselling service and offered much-needed respite breaks by the sea.

Every bake sale, 5 km run, quiz, or donation contributes to creating magical memories for families with rare genetic conditions—whether in our adapted caravans, through bespoke experiences, or at-home activity packages.

We truly can't do it without you—thank you so much!

**£20**

could pay for a fun hour of home-based activities, baking or crazy foam messy play for a family that finds it difficult to access fun activities outside the home

**£100**

could help a carer of a loved one with a rare genetic condition improve their emotional wellbeing and build resilience through group peer support sessions

**£500**

can pay for a week's rental and delivery of specialist mobility equipment, enabling a parent with a rare genetic condition to take their family on holiday for the first time

