



# Sandcastle Trust

Helping families affected by rare genetic conditions build positive memories

## Sandcastle Memory Application Form

To apply for a Sandcastle Memory, you must fill in this form as fully as possible.

Without accurate and complete information we may not be able to process your application.

Do not leave any boxes unanswered. If more than one person in your family (adult or child) has a rare genetic condition please provide full details for each person.

When complete, please send to:

The Sandcastle Trust, PO Box 873, Haywards Heath RH16 9QL

If you need any help completing this form please contact us via email: [info@sandcastletrust.org](mailto:info@sandcastletrust.org)

About the applicant - this section should be used by the person completing the application to tell us how to contact them in the future, and for us to understand who they are.

\*Please note: We will only ask for information that we need to make a decision as to how we may be able to offer assistance. If you do not feel comfortable with answering any question then please contact us to discuss this. Please provide as much detail as possible.

Title  Mr  Mrs  Miss  Ms (Please Tick) Other

First Name(s)

Surname

Your Date of Birth  d  d /  m  m /  y  y  y  y

Address

Postcode

Home Phone Number  (Including Dialling Code)

Mobile Phone Number  Other (e.g. Minicom)

Email Address

What is your preferred method of contact?  By Email  By Letter  By Mobile (Please Tick)

If you are applying on someone's behalf please provide details of who they are and your relationship to them



My family has been living in the UK for the last year

Yes  No (Please Tick)

If no, please give details \_\_\_\_\_

My family automatically has the right to remain in the UK

Yes  No (Please Tick)

If no, please give details \_\_\_\_\_

Personal Information - this part of the form is used to tell us about the person with the genetic condition - this can be an adult or child. If more than one person in your family has the diagnosis please provide full details for each person.

- I am a parent or carer applying for a child or young person who lives with me.
- I am a parent who has a rare genetic condition applying on my own behalf.
- More than one person in my family has a rare genetic condition.
- I am a health professional applying on behalf of a family I am supporting and I have that family's consent to do so.
- Fast Track Applications - If you are applying on behalf of a family member who has a life-limiting condition, then your application will be expedited. Please tick if you are applying under this category and provide a copy of a supporting letter from a GP/ Consultant/Specialist Health Professional.

First Name(s)

Surname

Date of Birth

/   /

Male

Female (Please Tick)

Age

Please tell us about the diagnosis of the person with a genetic condition

Date of diagnosis (if Known)

1	<input type="text"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
2	<input type="text"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
3	<input type="text"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

(Please provide copies of supporting documentation from a GP/Consultant/Specialist Health Professional)

Please feel free to use this space to tell us any other relevant information in relation to the condition.

Personal Information - please use this part of the form to tell us in your own words the impact that the diagnosis has on the person diagnosed, and the rest of the family.

Please include physical, emotional, financial and family related impact. We are particularly keen to understand the impact on your ability to access short breaks, days out and the opportunity to enjoy family life in general. Please continue on a separate sheet if needed.



Access to support from The Sandcastle Trust is not means tested and you do not need to be in receipt of benefits to apply. However, we do ask for information on the household income because our support is discretionary and subject to available funding. We may therefore decide to prioritise an application over another where a family has a significant level of household income.

Please also ensure you enclose copies of the last 3 payslips of anyone in the household in employment. We also need to see a copy of your most recent benefit award letter dated within the last 12 months or a bank statement less than 3 months old.

USE WEEKLY FIGURES

Net Wages or Salary	£		
Net Wages or Salary (partner)	£		
Jobseeker's/ESA	£		
Income Support/Universal Credit	£		
Pension Credit	£		
DLA/PIP	£		
Carers Allowance	£		
Tax Credit (family/working/child)	£		
Retirement or Works Pension	£		
Child Benefit	£		
Maintenance/CSA	£		
Foster Parent's Income	£		
Rent/Board (other family members)	£		
Other	£		
Total Income	£		

Other - Please specify below

Support - please use this part of the form to tell us in your own words how you think The Sandcastle Trust can help you and your family. Please ensure you refer to the guidance on our website when completing this section for further information on what we will consider funding.

Have you received support from The Sandcastle Trust in the past (including Sandcastle Santa)?

Yes  No

If yes, please provide details below.

Have you applied to any of the following charities for support in the past?

Please tick the box and provide details of what support you received, ie. a holiday or something else.

<input type="checkbox"/> Family Fund	<input type="checkbox"/> Happy Days Children's Charity
<input type="checkbox"/> Family Holiday Association	<input type="checkbox"/> Make a Wish Foundation


What was the outcome?

Please note: Our funds are limited and although having received support from the above charities does not prevent you from applying for a Sandcastle Memory in the form of a short break from us, priority will be given to families who are not eligible to receive short break support elsewhere. We would therefore encourage you to apply for a special day trip or annual attraction pass or "At Home" Sandcastle Memory instead.

What type of Sandcastle Memory would you like to apply for?

<input type="checkbox"/> Short Break (UK Based)	<input type="checkbox"/> Special Day Trip
<input type="checkbox"/> An element of a short break you are planning yourself.	<input type="checkbox"/> Annual Attraction Pass
	<input type="checkbox"/> At Home Sandcastle Memory

Please provide full details:




Please tell us in your own words how a Sandcastle Memory will help your family.

Details of immediate family to benefit from this grant.

Full Name	Age	Date of birth	Relationship to applicant
		dd / mm / yyyy	
		dd / mm / yyyy	
		dd / mm / yyyy	
		dd / mm / yyyy	
		dd / mm / yyyy	
		dd / mm / yyyy	
		dd / mm / yyyy	
		dd / mm / yyyy	
		dd / mm / yyyy	

How did you hear about The Sandcastle Trust?



Professional Contact - please tell us about a health professional we can contact should we need more information about the person with the rare genetic condition, or their diagnosis - this can be a Consultant, Social Worker, Health Visitor, Teacher or similar who knows you or your child well (not your GP). We will inform you prior to contacting them and will ask you to sign a separate medical release form.

Name																									
Job Title																									
Address																									
																			Postcode						
Work Phone / Mobile																									
Email Address																									

Declaration - please read this section carefully before signing and returning to us.

(Please Tick)

- I understand that by submitting this application on behalf of my family I am confirming that all of the information I have provided is accurate and up to date
- I have read and understand the Eligibility Criteria and the Terms & Conditions attached to this form and understand that The Sandcastle Trust intends to rely on the terms contained in this document.
- I consent to mine and my family's personal information being processed in accordance with The Sandcastle Trust's Data Protection Statement (attached to this form and available on The Sandcastle Trust's website).

Name

Signature

Date  /  /

#### Communication Preferences

The Sandcastle Trust would like to stay in touch with you to provide updates on our work and information on fundraising campaigns and events – but it's really important to us that you choose how we contact you. Please indicate your communication preferences below, you can update or change these preferences at anytime by emailing [info@sandcastletrust.org](mailto:info@sandcastletrust.org)

- I consent to receiving email communications from The Sandcastle Trust
- I consent to receiving telephone communications from The Sandcastle Trust
- I consent to receiving postal communications from The Sandcastle Trust

## EQUALITY & DIVERSITY MONITORING

The Sandcastle Trust recognises the benefits of a diverse community of beneficiaries, volunteers, staff and supporters, and we are committed to being an inclusive organisation where everyone is treated with respect, dignity and where there is equal opportunity for all. Whilst we ask you complete the following information you are not obliged to do so and any answers you do provide will be treated as anonymous and stored confidentially and securely.

Gender  Male  Female  Rather not say (Please Tick)

Age  Under 25  26-35  36-45  46-55  56-65  66 or over  Rather not say

Please state what you consider your ethnic origin to be: Ethnicity is distinct from nationality and the categories below are based on the 2001 Census

Indian  Pakistani  Bangladeshi  Other

Caribbean  African  Other

Chinese  Other

White & black Caribbean  White & black African  White & Asian  Other

English  Irish  Scottish  Welsh  Other

Rather not say

Faith: Which group below do you most identify with?

Buddhist  Christian  Hindu  Jewish  Muslim  Sikh

Rather not say  Other

Do you consider yourself to have a disability?: The Disability Discrimination Act 1995 (DDA) defines a person as disabled if they have a physical or mental impairment which has a substantial and long term (i.e. has lasted or is expected to last at least 12 months) adverse effect on one's ability to carry out normal day-to-day activities.

Yes  No  Rather not say

Faith: Which group below do you most identify with?

Bisexual  Gay  Heterosexual  Lesbian  Rather not say

Are you currently:

Employed  Unemployed  Full-time parent or carer  Retired

Student/Adult student  Rather not say

How many children (aged 16 or under) do you have living in your household?:

What are the first 3 digits of your postcode?:

Under the terms of the Data Protection Act and the Data Protection Directive this information will be treated in a secure and confidential manner. The Sandcastle Trust may be required to give some of this information – only where relevant and appropriate - to the bodies responsible for regulating and/or funding The Sandcastle Trust.

### Eligibility Criteria

- The applicants must live in the UK.
- The applicants must have permanent legal residency in the UK and have lived in the UK for the last year.
- The organisation supports families whereby an individual or individuals 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 in relation to the individual(s) condition:
  - (i) it is degenerative
  - (ii) it is life threatening
  - (iii) it is life limiting
  - (iv) it causes severe, chronic disability or illness
  - (v) it results in complex health needs and/or learning disabilities that impact on their family's choices, ability to access social opportunities and enjoy family life.
  - (vi) It has had an enduring impact on your family life.
- Families who have suffered a bereavement as a result of a rare genetic condition are also eligible to apply.
- The Sandcastle Memory must be for the benefit of the person with a rare genetic condition together with members of their immediate family. Immediate family shall be defined as husband, wife, civil partner, partner, child, parent, guardian or sibling. Requests to include extended family will be considered on a case by case basis and only in exceptional circumstances.
- In some cases the charity will consider requests from families affected by rare genetic conditions where the individual with the

diagnosis will be not attending. The applicant family must demonstrate sufficient need with supporting evidence from a health professional that an activity that offers respite from their day to day caring role will have a positive impact on the entire family, including the individual with a diagnosis who will not be attending.

- The individual affected by a rare genetic condition must live with the family in the family home full time. If you share the care of any child named in the application with anyone else, (for example, the child lives half the time with their mother or half the time with their father) then you must notify The Sandcastle Trust of this.
- Any application in respect of a child in the care of the Local Authority, subject to a care order or living in foster care must be discussed with The Sandcastle Trust before an application is submitted.
- Access to support from The Sandcastle Trust is not means tested and you do not need to be in receipt of benefits to apply. However, we do ask for information on the household income in our application form. This is because our support is discretionary and subject to available funding. We may therefore decide to prioritise an application over another where a family has a significant level of household income
- The Sandcastle Trust can only consider one Sandcastle Memory application per family unless in exceptional circumstances, i.e. bereavement. Please contact The Sandcastle Trust if you believe this applies. This does not apply to any campaigns run by the Sandcastle Trust, for example, the Sandcastle Santa scheme. Families are welcome to apply every year to these schemes although funds are limited and preference will be given to families who have not received support from The Sandcastle Trust before.
- The Sandcastle Trust can provide assistance to rare genetic condition patient groups, family



support groups and small disorder specific charities to have 'meet-ups', 'away days', group family day trips and short breaks. The proposed activity or meet up should be family centred (as opposed to a charity information day/weekend).

- The Sandcastle Trust is a non-denominational charity and operates an equal opportunities policy. We are committed to achieving equality of opportunity for families affected by rare genetic conditions. In considering applications we therefore aim to ensure that no family receives less favourable treatment on the grounds of any protected characteristic or for any other reason.

### Terms & Conditions

- To be eligible to receive our support the applicant family must meet The Sandcastle Trust's Eligibility Criteria (attached to the application form and available on The Sandcastle Trust's website).

- All the information provided in the application form must be accurate and not misleading. The Sandcastle Trust will take all necessary steps to re-coup funds expended and losses as a result of dishonest applications.

- Applicants should provide copies of all supporting documentation requested in the application form. Applications cannot be processed without this supporting documentation. Please do not send original documents as these cannot be returned.

- The applicant must advise The Sandcastle Trust of any changes in circumstance that may affect the application – for example, any changes in the condition of the person with the rare genetic condition, care arrangements, earned income or living arrangements including the death of the person with the rare genetic condition or a child becoming subject of a care order. The applicant must notify The Sandcastle Trust of such changes as soon as they occur, whether they occur before or after the date of their application.

- The Sandcastle Trust may request that further information is provided in order to make a decision on an application. Failure to provide this additional information within a reasonable period will result in an application being declined and a full new application will be required.

- It is the responsibility of the applicant to take medical advice where appropriate, as to the suitability of the activity and the capacity (whether physical, mental or otherwise) of the person with the rare genetic condition to take part in it, all activities involved in it and all matters associated with it (such as, for example any travelling and accommodation which may be involved). The Sandcastle Trust is not qualified and will not provide advice in this regard.

- In accepting a Sandcastle Memory the applicant agrees that they will comply with any specific terms and conditions that The Sandcastle Trust notifies them of in relation to the award.

- Any support awarded by The Sandcastle Trust cannot be used in conjunction with an award from another charity or organisation.

- The Sandcastle Trust does not act as a travel company or tour operator. Families are advised to purchase suitable travel insurance for their break to cover all eventualities.

- Support from The Sandcastle Trust is discretionary and subject to available funding. There is no entitlement to our support and all cases are assessed on an individual basis.

- Under the terms of the Data Protection Act and the Data Protection Directive the information you provide in the course of your application will be treated in a secure and confidential manner. By making this application you consent to you and your family's personal information being processed in accordance with The Sandcastle Trust's Data Protection Statement (available on request or to view on The Sandcastle Trust's website).

## Data Protection Statement

### Who are we?

We, The Sandcastle Trust are a charity registered in England under the charity number 1169523. We are committed to respecting and protecting your privacy. Once you choose to provide us with personally identifiable information (any information by which you can be identified), it will only be used to support your relationship with The Sandcastle Trust. For your protection, we are registered under the Data Protection Act 1998.

### What information do we collect and process about you and why?

We need to assess whether your family meets our eligibility criteria and whether we are able to offer you support.

To make this assessment we need to collect information from you as set out below via our postal application form and possibly via telephone and email:

- You and your family's (including any children) names, address, email address and telephone number;
- Details of you or your child's diagnosis, associated health implications, needs, mobility, level of understanding and behaviour together with information on the impact of the diagnosis on your family life;
- Copy supporting documentary evidence from a health professional confirming the diagnosis;
- Details of your household income including any benefits received.

We will use this information to determine whether we are in a position to offer your family support and to process your application. We may confirm receipt of, and keep you updated about the progress of your application via post, email or text message. You will have an opportunity to indicate if you have a preference about the way we communicate with you on your application form.

We may collect and process photographs and/or moving film images of members of your family following award of a Sandcastle Memory for the purpose of sharing stories and encouraging charitable activities. We will ask your explicit consent before collecting and/or sharing any photographs or moving images of your family.

If you have concerns about the use of photographs or moving film images of you or your family, please contact us at [info@sandcastletrust.org](mailto:info@sandcastletrust.org)

### How is the information we collect stored and how long do we keep it for?

We will store your personal information securely and guard against data theft. Your information will only be accessed by staff and volunteers who have received data protection training.

We discourage the retention of data for longer than it is required and will only keep the information we hold about you for as long as we need it for the purpose we collected it. This will be for a period of at least six years for audit purposes. All personal data will be deleted or destroyed by us in a secure manner after this date.

### How to obtain a copy of the information we hold about you

To obtain a copy of the personal information we hold about you please write to The Sandcastle Trust, PO Box 873, Haywards Heath RH16 9QL. As soon as we are satisfied as to your identity we will send you, within 40 days of receipt of your written request, a copy of all the personal information we hold about you which we are legally required to disclose. Please contact us at the same address if you have any reason to believe that information we hold about you is inaccurate.

### What third parties might we disclose information to?

If you receive a Sandcastle Memory award from us then we will need to pass information about you to the relevant supplier(s) of that Sandcastle Memory. We will never sell or share



your data with any other third parties unless required to do so by law.

**Will you receive information about our services, marketing or fundraising?**

When you submit an application to The Sandcastle Trust for support we will ask you if you are happy for us to contact you by post, email, text message or telephone to let you know more about other services, schemes or activities that you can apply for which may be of benefit to you and your family. We will also ask for your consent to keep you updated on what we are up to and ways that you can support our charitable aims as a potential donor, volunteer or fundraiser.





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conditions build positive memories

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

The Sandcastle Trust, PO Box 873, Haywards Heath RH16 9QL  
Reg Charity No. 1169523

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