



## 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.

