



# Alström Syndrome UK

Strength for today, hope for the future

## ASUK GRANT MAKING POLICY

### Purpose

The purpose of this policy is to set out the principles, criteria and processes that govern how the Board of Trustees (the Board) at Alström Syndrome UK (ASUK) awards grants to people diagnosed with Alström Syndrome and their families.

The Board of ASUK reserves the right to change its grant making, depending on the funds it has available.

ASUK defines a grant as a financial award made from its funds to support children, young people, adults, and families living with Alström Syndrome.

### Introduction

ASUK is a registered charity (number 1071196) and limited company (number 3557191). The beneficiaries of ASUK are people diagnosed with Alström Syndrome and their families particularly (but not exclusively) those living in the United Kingdom.

ASUK is governed by a Board of Trustees. ASUK employs a staff team who are led by the Chief Executive Officer (CEO) who has delegated responsibility for the day-to-day activities of the charity.

The Board governs ASUK's grant-making in 3 ways:

1. Through grant-making and decision-making principles that underline how ASUK gives grants. When people or organisations give a donation to ASUK, they may specify that the funding is to be used in a specific way (such as for people living in a certain area), but the decisions are ultimately made by ASUK's Trustees. Donors may recommend grants, but do not award them.
2. Through determining that the grant-making criteria align with ASUK's charitable objectives (see appendix 1).
3. By accepting that, on some occasions, they may make grants outside of the agreed criteria, but that all grants will be charitable in law.

### Grant-making Principles

The aim of ASUK's grant making principles is to strike a balance between the proper oversight of

decision-making and the speed and responsiveness of giving grants.

The principles are as follows:

- The Board of Trustees has collective responsibility for all grant-making decisions, in line with ASUK's charitable purposes, including any restrictions on the funds.
- The Board may assign certain decision-making responsibilities to ASUK sub-committees, Board members or staff. These delegated decisions will be monitored and reviewed by the Financial Services Committee who report to the Board. In the absence of this committee the review will be carried out directly by the Board.
- The Board reserves the right to apply conditions to any grant.
- The Board also reserves the right not to approve any application or recommendation if they (or those acting with their delegated authority) determine that the grant would not be charitable, would conflict with ASUK's policies or damage its reputation.

### **Grant-making Criteria**

As a registered charity, ASUK can only make grants to support activities and equipment which are charitable in law. ASUK's first aim is to support people diagnosed with Alström Syndrome but recognises that their families may need financial support too. The Board is mindful of the added financial burden that families experience when supporting someone with a disability and/or long-term health condition.

The Board is aware that other charities can offer grants and financial assistance that people diagnosed with Alström Syndrome and their families may be eligible to apply for and encourages ASUK staff to consider exploring and approaching these charities first.

The Board expects that grants will normally support one or more of the following outcomes:

- Improvements to health and well-being, such as exercise equipment
  - Health and Wellbeing – funding limit £500
- Developing independence, such as daily living equipment
  - Independence - funding limit £500
- Support during times of financial hardship, such as a cash contribution or an essential appliance
  - Cost of Living - funding limit £500
- Contribution to funeral costs
  - Funeral Contribution – funding limit £1000

ASUK also has an Activities Fund to support friendships and peer-to-peer support. This funding is used by ASUK to organise and facilitate group activities and to support the Alström Syndrome

community to come together. Financial expenditure using the Activities Fund does not comprise a grant within this policy.

### **Grant requests which the Trustees will not normally support are:**

- Statutory duties and obligations that should be made by a public body such as the NHS or Local Authority
- Activities that have already taken place
- Items that have already been purchased

Each individual/family can only be awarded 1 grant within each financial year (April – March).

The Board is unlikely to offer consecutive grants for the same item or activity.

Applications for support are made through the grant application form by members of staff or occasionally by a Trustee.

### **Grant-making Processes**

The Board aims for ASUK's grant-making processes to be simple, transparent, and timely. A decision regarding each grant will usually be made within 3 weeks.

Grant application decisions are agreed by a minimum of 2 people. This will usually be the Chief Executive Officer (CEO) and the Chair of the Board of Trustees (Chair). Another member of the staff team and/or the Board may be given delegated authority in the absence of the CEO and/or the Chair.

The process of applying for a grant is:

1. Individual or family members will make a grant request to a member of the ASUK team and together they will research options. ASUK staff will look at alternative funders and gather information including costs and any previous grant requests.
2. A member of staff will complete the grant application form. The application is sent to the CEO who will forward it to the Chair.
3. The CEO and Chair will review the application. The CEO and/or Chair may request further information or clarification about the grant.
4. The CEO will make a recommendation, but the decision about whether to award a grant is made by the Chair or another Board member acting with delegated authority. The decision is fed back to the member of staff who submitted the application and to the Finance Manager.
5. A member of staff will then inform the grant receiver.
6. A member of staff will contact the grant receiver 3 months after the grant has been awarded to discuss the impact the grant has had. If appropriate, the grant receiver may be asked to consider providing a short article for the ASUK newsletter.

Recommendations or applications to approve unique or exceptional circumstance grants of any type are not delegated and must be referred to the Board.

ASUK has staff members and Trustees who have lived experience of Alström Syndrome. These staff members and Trustees have the same right to apply for ASUK grants either as a person diagnosed with Alström Syndrome or a family member. The same grant-making processes will apply but with the following additional requirements:

- An additional record of these grants will be logged and shared with the full Board of Trustees.
- The 2 people reviewing these applications must not have any personal connection to the grant request. In this instance, the delegated responsibility for approving the application will be passed on to another member of the team or Board.

The Board of Trustees will review this policy annually and make changes when needed. This policy and any future updates will be made available on the ASUK website.

This policy was approved by the Board on the 7<sup>th</sup> May 2025

## **APPENDIX 1**

### **Objectives**

### **Purposes and aims**

Alström Syndrome UK's objectives, as set out in the company's memorandum and articles of association are:

1. To promote the health and wellbeing of people with Alström Syndrome - particularly (but not exclusively) through the provision of awareness raising, support, advice and information for people living with Alström Syndrome, their families, carers and those working with them.
2. To promote research into Alström Syndrome and related conditions in the UK and abroad and disseminate the results to the public.