**Trustees Present:** Trevor Parkin (Chair and Treasurer), Dawn Mayes (Vice Chair), Kez Hayat, Alex Griffiths-Rayson and Dr Richard Paisey.

**Apologies:** Dr Elena Riva

**In attendance:** Ann Chivers (CEO), Kerry Leeson-Beevers (National Development Manager), Catherine Lewis (Office Manager), Liz Loughery (Project Manager), Steve Scoffield (Finance Manager), Michelle Hough (Family member),

Melissa Crowland, Prof. Tim Barrett, Dr Elena Riva and Sharon Bates (to be proposed as new Trustees)

1. **Welcome and Introductions from ASUK Chair and Treasurer, Trevor Parkin**

Trevor welcomed everyone to the AGM.

1. **Minutes of the previous Annual General Meeting held on the 24th January 2019**The minutes were approved as a true and fair record of the meeting with no actions arising.  
   Proposed by Trevor Parkin

Seconded by Dawn Mayes

Approved unanimously

1. **Financial report**

The Accounts and Annual Report were presented by ASUK Finance Manager, Steve Scoffield. Steve explained that the charities finances are currently in a healthy position. The Accounts have been independently examined and comply with current legislation and the SORP. The Independent Examiner has given an unqualified report, with no matters to draw to the attention of the members.

1. **Annual Report Summary**

Trevor gave an overview of the charities key achievements over the past 12 months, including statistics of people being diagnosed with AS, the type of support they have received and grants awarded.

1. **Trustees**

**Election of New Trustees**

Melissa Crowland, Professor Tim Barrett, Dr Elena Riva and Sharon Bates would like to be proposed for election as Trustees.

Proposed by Dr Richard Paisey

Seconded by Dawn Mayes

Approved unanimously

Trevor welcomed the new Trustees to the Board.

**Trustees Standing Down**

Michelle Hough, Rick Steeds and Parminder Jutla decided to stand down from the Board of Trustees.

The Chair thanked them, the Trustees are extremely appreciative of the time and support they have given to ASUK~~.~~

**Re-election of Trustees**

Currently no Trustees to be re-elected.

1. **Approval of Accounts**

The Treasurer recommended that the Accounts and Annual Report be approved.

Proposed by Trevor Parkin

Seconded by Alex Griffiths-Rayson

Approved unanimously

1. **Appointment of Independent Examiner**

The Chair recommended the appointment of Thomas Westcott Chartered Accountants, Barnstaple as Independent Examiner for the forthcoming year.   
Proposed by Trevor Parkin  
Seconded by Dawn Mayes

Approved unanimously

1. **Other Resolutions**

There were no other resolutions.

1. **Any Other Business**

**Questions from members had been emailed:**

**Question 1.**

*“I am aware of a couple of children in the south west who have had a cardiomyopathy collapse in infancy and are currently undiagnosed.*

*What work is ASUK doing to actively seek out potential AS patients?  
Would it be prudent to engage with major children’s hospitals to review past collapses?”*

Prof Tim Barrett explained that he had been looking at this with Geneticist Denise Williams. There is a new genome testing service in the NHS which means every patient presenting with cardiomyopathy will have their DNA sent for a gene panel to look for causes of the cardiomyopathy. At the moment the panel does not include the Alström gene so Denise is working with NHS England to get the AS gene put on the panel so everyone who gets tested for cardiomyopathy will also get tested for AS. This will hopefully be starting in April next year when the NHS genome service starts.

**Question 2.**

“*With national charities such as Guide Dogs providing support such as education provision, technology, Education, Health, Care plans, mobility training etc. Not just for children but for adults as well.  
Does ASUK need to review its services to ensure it’s not replicating its services that other organisations are significantly funded more for?”*

Kez Hayat answered:

Families and individuals with AS have a very complex condition. Definitely feel our current family support workers really focus on signposting which is crucial; such as Victa for equipment and Sense for deafblind assessments, holiday etc. However the complexities of the condition mean the family support workers have a key role at endorsing those complexities. Such as during multi-agency meetings, representatives from ASUK play a key role in offering support and explaining the complexities of the condition alongside signposting for specific support and resources.

**Note from a member:**

Pass on thanks to the new Trustees for taking up the role.

Trevor Parkin reiterated that he felt honoured to have them all on board.

He thanked everyone for attending the meeting and closed the meeting.

**The AGM closed at 14:24**