



# Alström Syndrome UK

Strength for today, hope for the future

## ANNUAL GENERAL MEETING

Year 2021 - 2022

**Webinar, 23<sup>rd</sup> November 2022**

**19:00 – 20:05**

### **Minutes of the meeting**

The AGM was held virtually on zoom.

Notice of the meeting was given 12 weeks in advance so that members could join the meeting virtually and/or by telephone.

**Trustees Present:** Trevor Parkin, Sharon Bates, Melissa Crowland, Prof. Tim Barrett, Dr Richard Paisey, Haris Hamid, Mokey Yates, Jane Biglin, and Carol Prescott.

**In attendance:** Kerry Leeson-Beevers (CEO), Catherine Lewis (Office Manager), Sarah Oliver (Care Coordinator), Marie McGee (Transition Coordinator) and Steve Scoffield (Finance Manager)

**Apologies** Ann Chivers (AS Global Executive Director)

**1 Member joined the meeting.**

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

Trevor welcomed everyone to the AGM, he stated that the meeting would be recorded and checked that everyone attending gave their permissions to do this. There were no objections. Due to length of service, Trevor resigned on the 31.03.22, he introduced everyone to Sharon Bates, who was elected as the newly appointed Chair of ASUK in March. Trevor thanked everyone at ASUK for their support during his tenure. Sharon thanked Trevor his many years of service to the Board of Trustees.

#### **2. Apologies**

Apologies have been received from Ann Chivers, Global Executive Director

#### **3. Minutes of the previous Annual General Meeting held on the 8th December 2021**

One action from previous meeting – noting the length of service of Trustees which is now added to our annual report.

The minutes were approved as a true and fair record of the meeting including all actions.

Proposed by Sharon Bates

Seconded by Tim Barrett

Approved unanimously



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### 4. 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, although some funding has been reduced due to the funding, we received in the previous year in response to the Covid-19 pandemic. 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.

### 5. Annual Report Summary

Sharon gave an overview of the charities key achievements over the past 12 months, she talked about how difficult it had been for families and how the ASUK staff team had supported families with practical and emotional support through virtual sessions and clinics. She told the meeting how many new children and adults were diagnosed, and that the registry had been completed by 62 individuals and we were working with 59 other charities as part of the Breaking Down Barriers Network.

Kerry also added more information about the work to support families through grants, gifts, and practical equipment. As well as giving an overview of the work of ASUK and the team. Catherine gave a summary of the AS Global conference, which brought together 82 attendees from 21 countries.

The complete annual report will be posted to the website, sent to the ASUK community by email and as always if individuals would like it in any other format to contact Catherine.

### 6. Trustees

#### Election of New Trustees and Re-election of Trustees

Due to the length of time served on the board:

**Trevor Parkin** and **Alex Line** resigned from the board on 31<sup>st</sup> March 2022

**Kez Hayat** resigned from the board on 22<sup>nd</sup> October 2022

3 Trustees need to be re-elected to serve for a further 3 years:

#### **Sharon Bates**

Proposed by Richard Paisey

Seconded by Melissa Crowland

#### **Melissa Crowland**

Proposed by Richard Paisey

Seconded by Sharon Bates



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### **Prof. Tim Barrett**

Proposed by Richard Paisey

Seconded by Melissa Crowland

4 Trustees require approval to join the board:

### **Haris Hamid**

Proposed by Tim Barrett

Seconded by Melissa Crowland

### **Carol Prescott**

Proposed by Melissa Crowland

Seconded by Sharon Bates

### **Jane Biglin**

Proposed by Tim Barrett

Seconded by Sharon Bates

### **Mokey Yates**

Proposed by Richard Paisey

Seconded by Melissa Crowland

Appoint the new Chair of the Board: **Sharon Bates**

Proposed by Tim Barrett

Seconded by Jane Biglin

Appoint the new Treasurer of the Board: **Mokey Yates**

Proposed by Sharon Bates

Seconded by Tim Barrett

## **7. Approval of Accounts**

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

Proposed by Sharon Bates

Seconded by Tim Barrett

Approved unanimously

## **8. Appointment of Independent Examiner**

The Chair recommended the appointment of Thomas Westcott Chartered Accountants, Barnstaple as Independent Examiner for the forthcoming year.



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Proposed by Sharon Bates

Seconded by Tim Barrett

Approved unanimously

### **9. Other Resolutions**

There were no other resolutions.

### **10. Any Other Business**

Sharon reiterated the thanks to the Board for their time and support.

### **11. Questions**

**Q1** Dr Richard Paisey asked how many people have signed up to the patient registry?

Kerry answered that 62 people had registered and we were still working hard to ensure as many people as possible input their data.

#### **Further comments**

Marie, commented about how well Kerry was adapting to her role as CEO, underpinned by Catherine and the fantastic work they and the team do to support families.

Kerry thanked all the team for their ongoing support and hard work.

Sharon thanked the team, trustees, and everyone for attending and closed the meeting.

**The AGM closed at 20:05**