

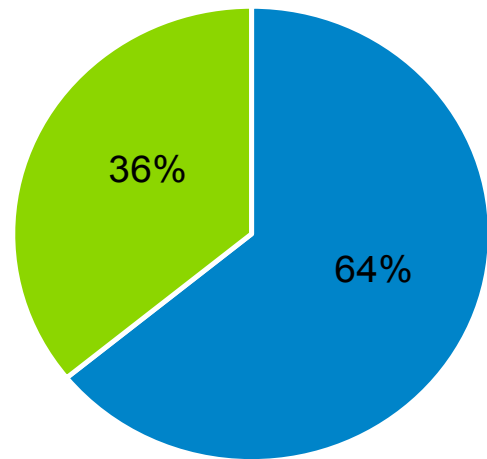


# Alström Syndrome UK

Strength for today, hope for the future

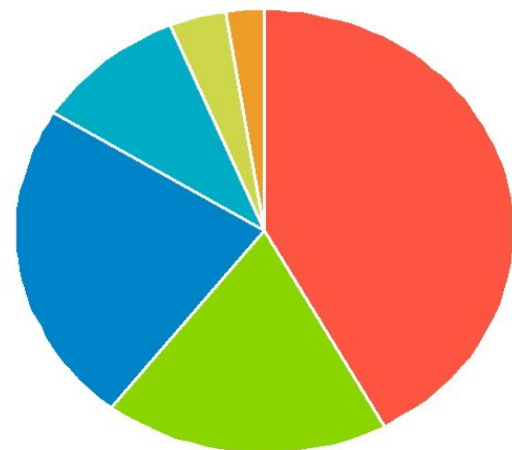
## Review of the year 2018-19

- We supported **77** families throughout the year
- **60** children and adults attended **11** Alström Syndrome (AS) specialised clinics
- We visited **53** families at home
- We visited **35** children in School or College
- **100%** of families who completed evaluation forms told us they were **'happy'** or **'very happy'** with the AS clinics and ASUK Support Services
- 'Moving on Up' transition project, supported **3** young people in preparation to move onto adult services
- Breaking Down Barriers worked with **15** rare disease organisations



■ Male ■ Female

Age Range



■ <18    ■ 18-24    ■ 25-34  
■ 35-44    ■ 45-54    ■ 55-65+



- **82** people (known to us) have AS. Most professionals will never meet a patient with AS because it is an ultra-rare disease. It is likely that there are more individuals with AS, who remain undiagnosed—we are working hard to change this!

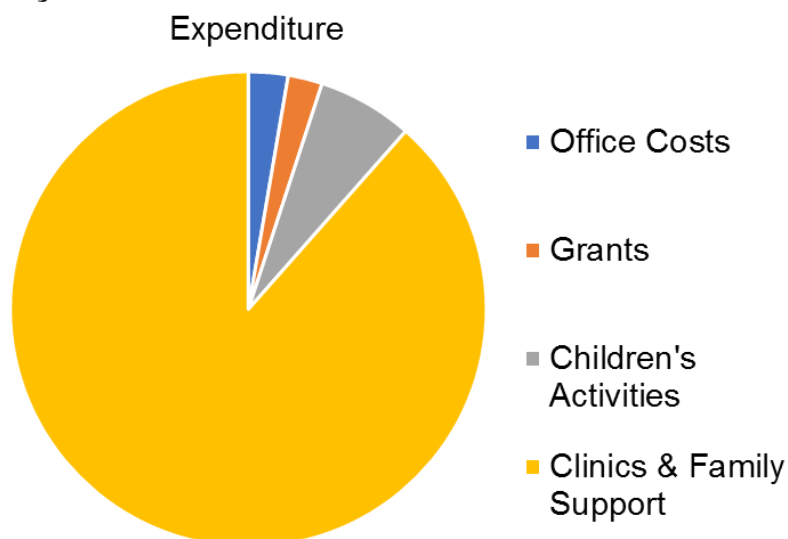
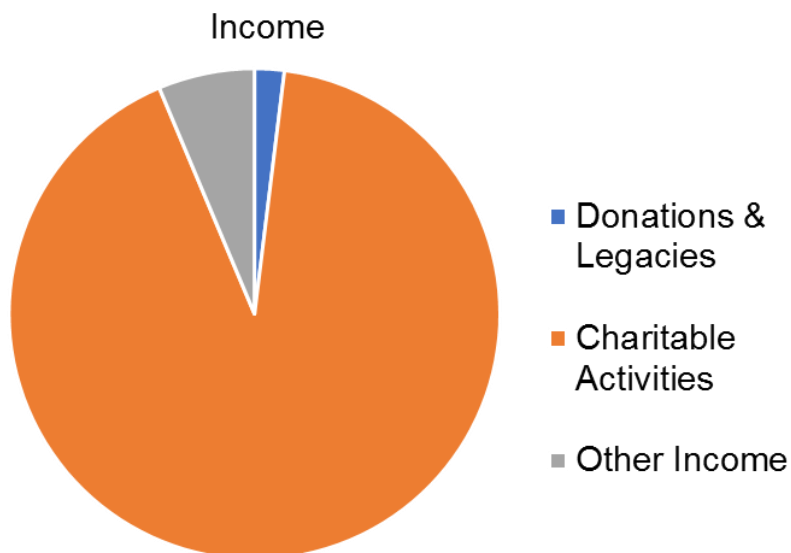
Advancing Diagnosis, Care, Treatment and Support for those living with Alström Syndrome in the UK

## Thanks to Children in Need funding:

- **11** families joined in Foodie Friends Clubs
- **13** young people enjoyed an audio described theatre show and back stage tour
- **9** families were given Google Assist technology
- **1** young person flew a plane
- For the year 2018/19 there were **7** Trustees on the ASUK Board
- **7** people work for ASUK, supporting families, promoting research and raising awareness



- We gave grants to **14** families:
  - ⇒ **3** items of exercise equipment/ gym membership
  - ⇒ **7** once in a lifetime experiences
  - ⇒ **4** items of accessible equipment
  - ⇒ Our website reached **57,500** views from **126** countries
  - ⇒ Our 'Living with a Rare Disease' animation helped to raise awareness of AS reaching an incredible **1,014** views.



# Thank you!

We are always immensely grateful to everyone who continues to support ASUK each and every year, whether it's through donating, holding a charity event, or giving generously from a Trust fund. We make every penny count to ensure that we learn more about Alström Syndrome, that families and individuals get help when needed and have the opportunity to meet up and share stories and experiences. We would also like to thank all the medical professionals at the Queen Elizabeth Hospital and Birmingham Children's Hospital who work tirelessly to seek new treatments and ways to further manage Alström Syndrome.

*All information is provided from the financial period 31st March 2018—1st April 2019.  
The full annual report and accounts can be found on the ASUK website [www.alstrom.org.uk](http://www.alstrom.org.uk)*