



**Susie Norbury**

Director of Operations  
& Fundraising



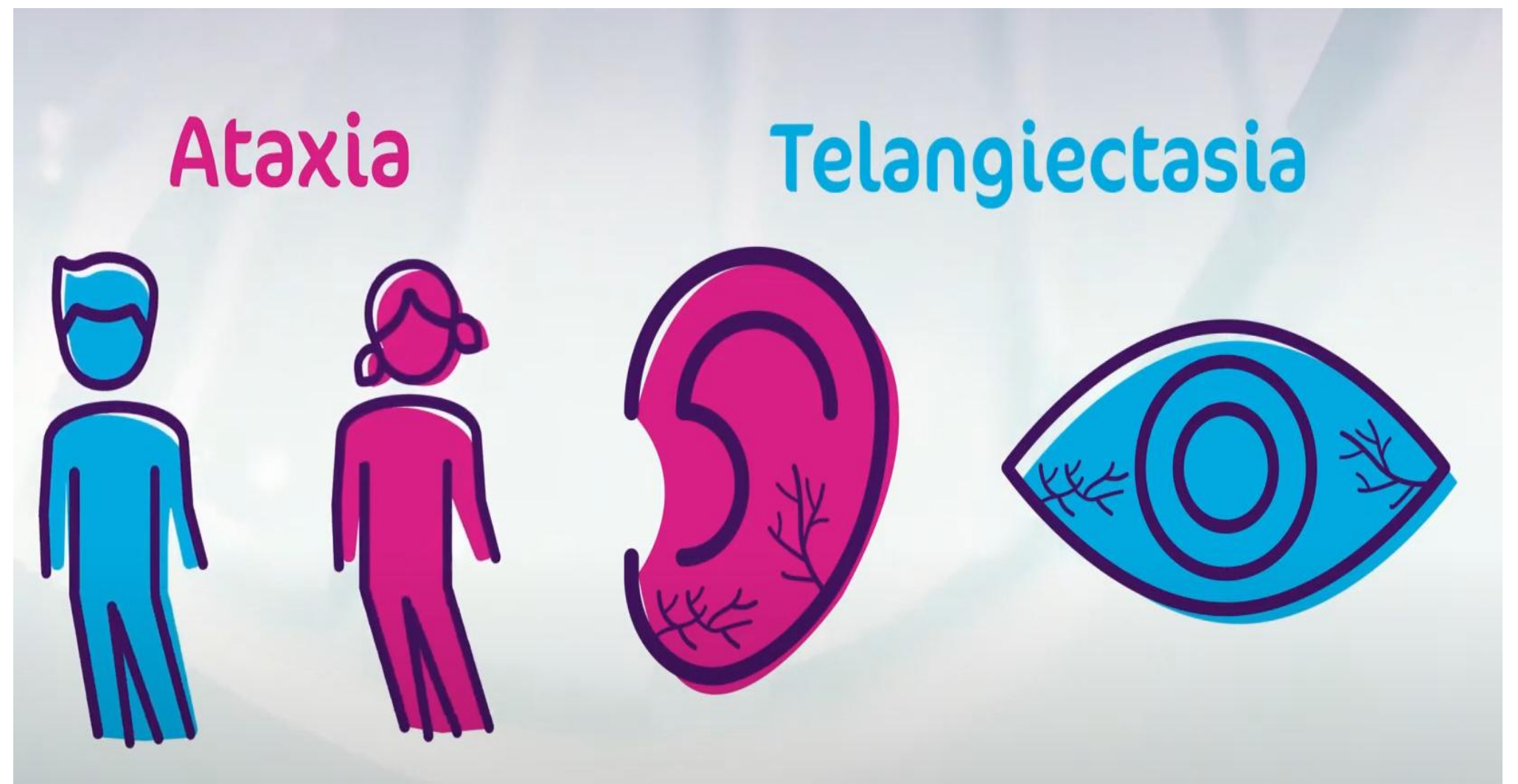


The AT Society **supports** people living with the disabling and life-limiting condition **ataxia telangiectasia** and funds **research** to find a cure.



# What is AT

- **Ataxia:** Loss of muscle control, lack of balance, poor coordination
- **Telangiectasia:** Dilated blood vessels in eyes



# Symptoms

**Toddlers:** loss of coordination & wobbly legs; coughs, colds, infections; red 'spider veins' on eyes & ears from 5yrs

**Young children/teens:** difficulty with speech, eating, swallowing, controlling eye-movements; regular wheelchair use by 10 years

**Teens/young adults:** involuntary jerky movements, tremor or muscle tightness, severe fatigue

**Shortened life expectancy:** cancers & lung disease



## Facts

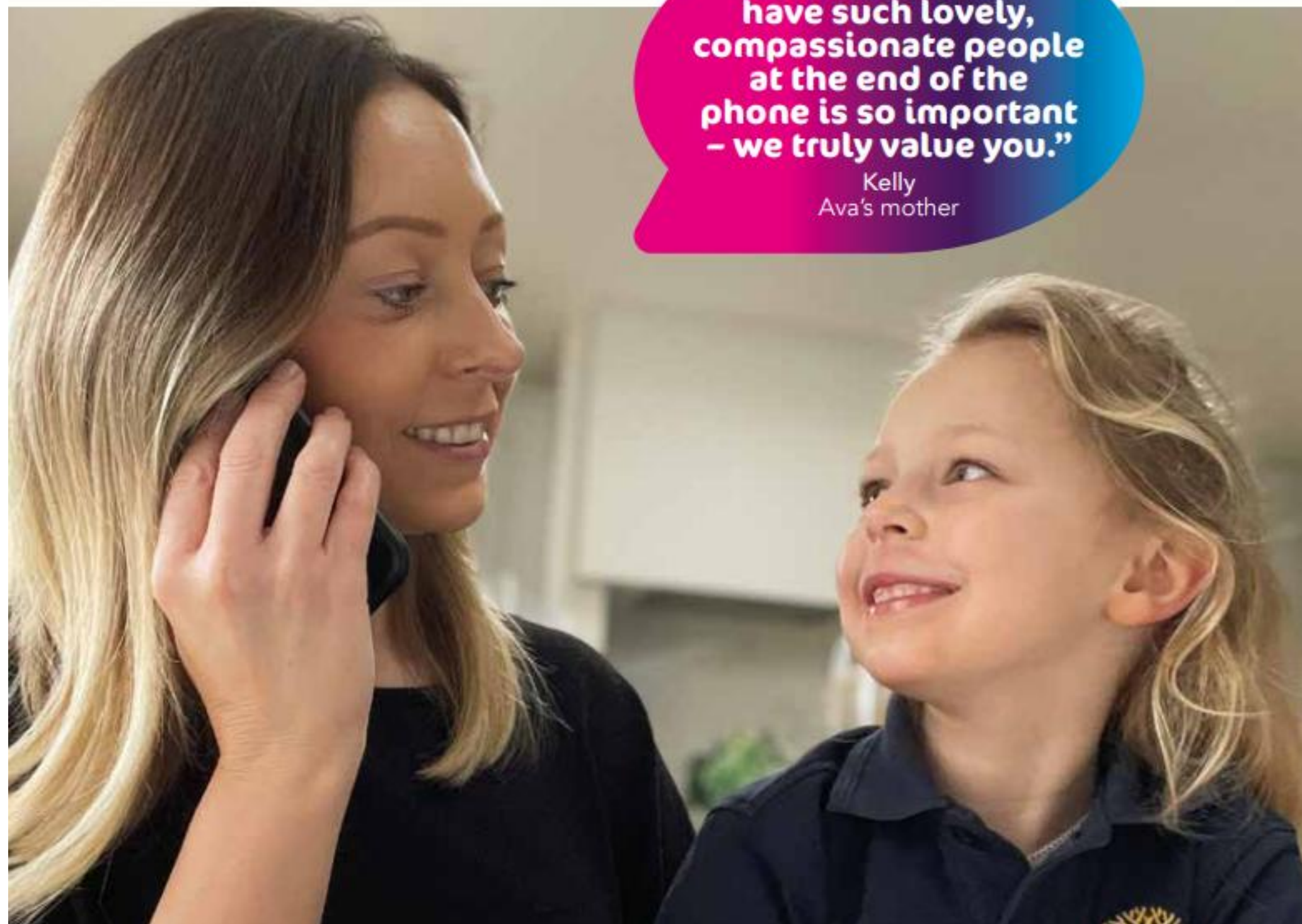
- 230 people in the UK with AT, or AT-like, in UK (3 per million)
- Diagnosis around 3-4 years
- 14% of UK families have more than one child with AT
- 31% from ethnic minority background
- Carriers increased risk of breast cancer
- Extreme physical, mental, financial, social, emotional, educational challenges



# What we do

Advocacy & Outreach

Helpline support, information and advice to meet the challenges of living with AT



# What we do

National AT  
specialist medical  
clinics

AT training to  
schools, social  
workers and health  
professionals

Raising  
awareness of  
AT



**“We’re so grateful  
to receive emotional,  
physical and mental support  
from professionals who  
understand about AT.”**

Siema  
Ibby's mum (Ibraheem)

# What we do

Organise social weekends and connection events

Psychological support for children & adults





# What we do

Provide patient organisation representation for clinical trials

Promote and fund high quality AT research



## Research

- Led by **Professor Penny Jeggo**, AT Society Trustee, and by our Scientific Advisory Board, chaired by **Professor Rob Dineen**
- Current strategy: to better understand & develop treatments for AT neurological symptoms
- Roughly 50% of income invested in research
- Co-funding projects where we can
- Drug repurposing, gene therapy, early diagnosis ...



## Clinical Trials

**Dexamathesone (Quince):** delaying progression of ataxia in AT  
**IB1001 (Intrabio):** improve ataxia symptoms

Patient organisation, supporting the development and implementation of trials and patient recruitment

Close liaison with:

- pharmaceutical companies
- medical teams
- families
- other AT organisations



## Challenges

- **Funding:** squeeze on statutory provision & economic landscape
- **Research:** understanding most important pathway for progressive ataxia; early diagnosis; cognition in AT & impact on service provision; etc
- **EDI:** equitable access to support, research & trials; preventing barriers to participation
- **Campaigning:** robust strategy needed if regulated treatments refused; advocacy continues to grow; etc





Collaborate





**2025 AT Clinical Research Conference**  
25th-27th June, Loughborough University, UK

**Register here for early bird discounts:**

<https://atsociety.org.uk/at-clinical-research-conference/>



Thank you

