PWSA UK
PRADER-WILLI SYNDROME ASSOCIATION UK

ANNUAL REPORT
TO 31ST MARCH 2022

THE YEAR IN NUMBERS

Membership

422 Subscribed members

312 Members with PWS

Supported families and professionals with **1,030** issues, resulting in **2,311** phone calls, letters and meetings to resolve them

35 new diagnoses reported to us, and **25** possible new diagnoses

390 people attended our virtual conference in November 2021

56 virtual meet-ups, coffee & chats, and Teddy Bears' picnics, attended by:

224 adults with PWS

83 children with PWS

453 parents of those with PWS

Income: **£361,569**

Spend: **£364,343**

Balance of free reserves: **£280,878**

RESEARCH > We continue to work closely with Soleno Therapeutics as they pursue regulatory approval for DCCR.
> Funded £10,000 towards Elena Bochukova's research project 'Genotype to phenotype: understanding how our genome leads to variability in the Prader-Willi syndrome genotype'.

COMMUNICATIONS > Our website continues to develop, including new dedicated research and events pages.
> Website updated with new photos of our community taken at increasing number of post-lockdown events and activities.
> Social media followers (March 2022): 5,731 on Facebook, 1,446 on Twitter, 962 on Instagram. Closed Facebook groups: PWSA UK Community Hub: 651 members, PWSA UK - Sibs Hub: 34 members. We are also members of a further 6 parent-led Facebook pages.

SPECIALIST CLINICS Staff and volunteers have, in previous years, attended PWS Specialist Clinics in Birmingham, Brighton, Edinburgh, Glasgow, London and Stoke, offering support and advice to families, but due to Covid-19, these have mostly been done virtually and support from PWSA UK has been through referrals by the clinics.

TRAINING & INFORMATION > We delivered 31 online training sessions to 296 attendees.
> We constantly review and update all our information and publications, identifying and filling any gaps in information. In this financial year, we updated 20 different information documents to ensure that our information remains the most up to date possible.