

THE YEAR IN NUMBERS



467
subscribed
members
302
members
with PWS



Supported families
& professionals with
673
issues, resulting in
1,129
phone calls, letters
& meetings
to resolve them



38
new diagnoses
reported to us,
and
41
possible new
diagnoses

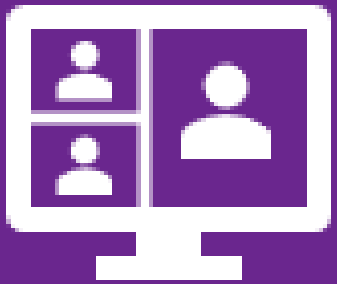


22
volunteers running
the Familynet
project
across the UK



Income:
£547,574
Spend:
£328,376
Balance of
free reserves:
£396,565*

*This reflects a legacy income of £172,070 which is much higher than the norm and trustees are planning new projects that this will fund.



52 virtual meet-ups,
coffee & chats, and
Teddy Bears' Picnics

attended by
826
people

consisting of
200 adults with PWS
150 children with PWS
476 parents of those with PWS

RESEARCH

- We continue to work closely with Soleno Therapeutics as it pursues regulatory approval for DCCR.
- We are currently working with two further pharmaceutical companies interested in bringing trials to the UK.
- Also supported Cerebra, and Suzannah Lester investigating interpersonal trust development between young children.



EVENTS

- Our national conference was held on 7th November 2020 across Zoom, due to Covid restrictions, attracting 396 attendees.
- Whilst face-to-face family events are resuming, our adult and parent-to-parent Zooms will continue.

TRAINING & INFORMATION

- We updated the Residential Care Providers List, The Future Pack, EHCP Information and Guidance Pack, Information for GPs, Information for Hospitals and New Diagnosis Pack.
- Covid restrictions meant that we moved all training onto virtual platforms. However, most care providers were self-isolating clients and most schools were remote teaching, so we delivered 6 training sessions in this financial year to 52 attendees.



SPECIALIST CLINICS

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



COMMUNICATIONS

- We introduced a revolving carousel on our website's homepage so we can flag important information.
- We have introduced a new 'I Have PWS' page for adults with PWS written in easy read and containing information of particular interest to this audience.
- Our New Diagnosis page has been updated following feedback from new parents, the Latest News section is regularly updated, and the Coronavirus page has continued to carry the latest information relevant to our community.
- In March 2021, we had 5,677 followers on Facebook, 1,365 Twitter followers and 711 followers on Instagram. Our closed Facebook group for UK families (PWSA UK Community Hub - Empowering Life with PWS) has 583 members. Our closed group for siblings (PWSA UK - Sibs Hub) has 30 members. We are also members of a further 6 parent-led Facebook pages.

