APS Support UK

For people with antiphospholipid syndrome

Another Kiltwalk, same big heart

Falling for a good cause

Teeing off "Fore" APS

From startline to support

Annual Report 2024

Overview

Antiphospholipid syndrome (APS) is a potentially life-threatening autoimmune disease that causes the blood to clot too quickly.

APS can cause low-grade symptoms including headaches and migraines, memory problems, joint pain and fatigue. It can also trigger potentially fatal symptoms such as deep vein thrombosis (DVT), blood clots on the lung, strokes and heart attacks.

In pregnancy, APS is the most significant treatable cause of recurrent miscarriage and can increase the chance of stillbirth up to five times; it is also associated with other complications such as pre-eclampsia, low weight babies and premature births.

As of yet, we simply don't know why people develop APS, why some patients go on to have blood clots while others don't, why some women (but not all) have pregnancy problems and why some people are affected by symptoms more than others – vital research is needed before we can answer these questions.

However, we do know that being diagnosed as early as possible and treated correctly seems to have a direct bearing on how well people will feel in the future.

The national charity, APS Support UK, aims to achieve earlier diagnosis and offer support to anyone affected by APS through awareness, education and research.

Pete's reverse marathon

Paul and James take flight!

Introduction and Message from the Chair

We are pleased to present the APS Support UK Annual Report for 2024 and would like to thank everyone who has supported and collaborated with our charity throughout this year.

Throughout the year we have continued to support research into APS with our grants awards and were delighted to see a research project we funded in 2022: 'Complement activation in antiphospholipid syndrome patients with ischaemic stroke or other ischaemic brain injury: a therapeutic target?' resulting in a groundbreaking paper being published in December 2024. We find it very encouraging that our seed funding is helping to drive research into the future treatment of APS, and we plan to fund more research in 2025.

We believe this was a pivotal year regarding baby loss. As APS is the most significant potentially treatable cause of recurrent miscarriage, our charity continues to support women and families who have suffered multiple miscarriages and we have lobbied for greater compassion and recognition. So, when we were contacted by the Department of Health and Social Care to give feedback on the voluntary Certificate of Baby Loss in England, we were very happy to oblige.

The scheme was launched in February 2024 and introduced a voluntary Certificate of Baby Loss in England to acknowledge babies lost before 24 weeks of pregnancy.

We continue to be actively involved with the national annual Baby Loss Awareness Week campaign. There are now over 50 other charities involved, with SANDS and Tommy's the Baby Charity as the lead organisations. In 2024, the media coverage for the campaign was outstanding with the 'Wave of Light' initiative reaching global proportions and patient stories appearing in all the national media outlets including the BBC and ITVX, plus lots of local news articles. We would like to thank all our APS patients who kindly shared their stories to help boost the campaign.

Baroness Estelle Morris
Chair of APS Support UK

2024 also saw the first APS global TV programme when Sky History TV broadcast Anne: the Forgotten Queen on its Sky History channels series 'Royal Autopsy': featuring our Medical Vice Chair, Professor Anisur Rahman. This programme explored Queen Anne's ill health and what modern medical experts now speculate could have been APS. Professor Rahman said: "It was really enthralling to work with Alice Roberts and her team, and our take home message at the end was how much better Queen Anne would have done if she had access to current treatment for obstetric APS. Indeed, she might well have had an heir which would have changed the course of British history – no Georgians, no Queen Victoria and ultimately no Charles III!".

We continue to support research projects through our patient group who are always happy to engage with online surveys and participate whenever possible. We were also involved with three national and international studies including a survey for the Rare Autoimmune Rheumatic Disease Alliance (RAIRDA), and we also collaborated on the review of the British Society of Haematology's guidelines on diagnosis and management of APS.

We continue to be both amazed and grateful for the many ways in which our supporters raise money and support the charity. It enables us to continue to raise awareness of APS, support and fund research and provide an important source of information and advice for APSs patients.

I would like to place on record my thanks to the APS Support UK team: Kate, Clare and Nancy whose work and commitment is central to what we are able to achieve. I would also like to thank my fellow trustees who give their time and expertise. It is very much appreciated.

We look forward to working with you over the next year.

Our Vision

A future where everyone with antiphospholipid syndrome (APS) is diagnosed early, treated appropriately and supported every step of the way.

Our Mission

APS Support UK aims to achieve earlier diagnosis and offer support to anyone affected by antiphospholipid syndrome (APS) through awareness, education and research.

Although we are a small charity, we punch well above our weight and have achieved much so far but there is much more to do. We will always do our utmost to help those affected by antiphospholipid syndrome.

Early diagnosis **saves lives**

Our Objectives

APS is a potentially life-threatening autoimmune disease that causes the blood to clot too quickly. The condition can cause fatal events such as strokes, heart attacks, blood clots in the lung and DVTs.

In pregnancy, APS is the most significant treatable cause of recurrent miscarriage and can increase the chance of stillbirth up to five times; it is also associated with other complications such as pre-eclampsia and premature births.

We aim to save and improve the lives of patients with antiphospholipid syndrome by achieving earlier diagnosis and the best possible treatment by:

- raising awareness of APS in the medical community
- offering information and understanding to anyone affected by APS
- funding and supporting research into APS

APS is a significantly under-recognised and under-diagnosed condition, so our charity is determined to raise the profile of APS wherever possible.

Public Benefit

The charity acknowledges its requirement to demonstrate clearly that it must have charitable purposes or 'aims' that are for the public benefit. Details of how the charity has achieved this are provided in the achievements and impact sections below. The directors confirm that they have paid due regard to the Charity Commission's guidance on public benefit before deciding which activities the charity should undertake.

ARE YOU AWARE OF APS?

Antiphospholipid syndrome (APS) is a life-threatening autoimmune condition that can cause strokes, heart attacks, DVTs and blood clots in the lung.

In pregnancy, APS is the most important treatable cause of recurrent miscarriage, and it is also associated with stillbirth, pre-eclampsia and premature babies.

1 IN 6 STROKES

under the age of 50 are caused by APS

1 IN 6 HEART ATTACKS

under the age of 50 are caused by APS

3 YEARS

is the average time it takes for a diagnosis of APS

34 YEARS

the average age a person is diagnosed with APS

3 MISCARRIAGES

before women are tested for APS

5 TIMES

the increased risk of stillbirth for a woman with APS

EARLY DIAGNOSIS

can prevent devastating consequences

LUPUS

is commonly associated with APS

Connect with us

@APSsupportUK

https://www.facebook.com/APSsupportUK/

APS Support UK

For people with antiphospholipid syndrome

aps-support.org.uk

0300 323 9943

COVID-19 Impact in 2024

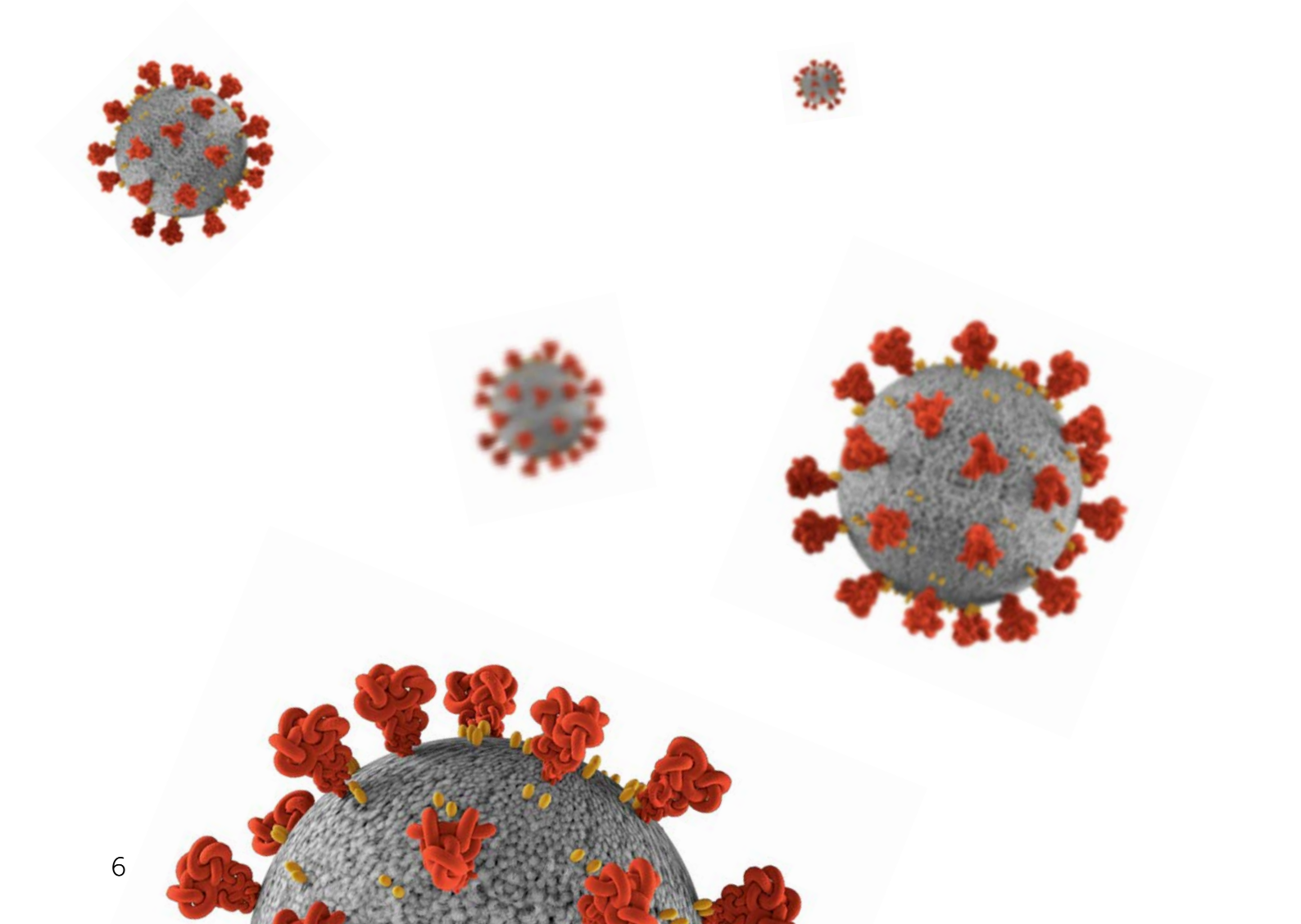
Since 2020, our charity has continually been impacted by the global COVID-19 pandemic and our services are still under great demand by our patient group.

Unlike many other healthcare charities, APS Support UK is still being affected by the pandemic for a number of reasons, most notably in connection with vaccines and the link between Covid and antiphospholipid antibodies.

With regard to COVID-19 vaccines, we are still being constantly asked whether certain vaccines are suitable for people with APS, following the changes in government guidelines regarding the AstraZeneca vaccine. This is mainly because the issue of suitability of vaccines for people with APS is still being investigated by the research community so, understandably, we receive many patient enquiries regarding vaccine safety.

Also, there is a growing body of evidence that may indicate that some vaccines caused people to develop APS, but much more research is needed before this theory can be proved. Coupled with this is the apparent link between transient antiphospholipid antibodies in people who develop COVID-19 and what this potentially means for patients; for example, a study published in December 2024 discusses the higher prevalence of antiphospholipid antibodies in patients with Covid-19: https://pubmed.ncbi.nlm.nih.gov/39638272. Again, a lot of research is taking place globally about this phenomenon, but more evidence is needed before any clear link can be established.

Consequently, it appears that our charity will continue to be impacted for the foreseeable future as more research unearths different aspects of the effects and links between COVID and APS.

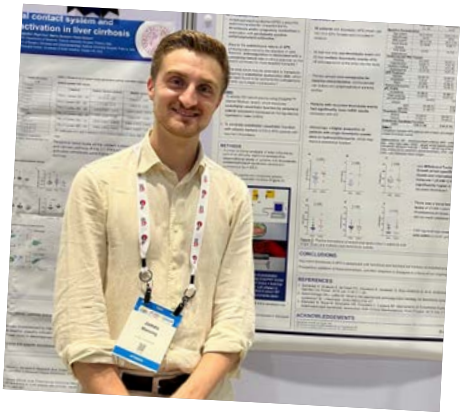


Charity objectives achieved in 2024

Raising awareness of APS in the medical community

James Manning at ISTH (International Society of Thrombosis and Haemostasis)

In June 2024, Dr James Manning travelled to Bangkok to attend the International Society on Thrombosis and Haemostasis (ISTH).The ISTH is the largest international medical conference dedicated to the field of blood clotting and bleeding, and attracts delegates from many of the world's leading medical institutions. APS Support UK awarded Dr Manning with a travel grant to enable him to travel to Thailand and present his research on APS and endothelial dysfunction. Dr Manning said: "Not only was the ISTH an excellent learning opportunity for me, but it also gave me the chance to hone my presentation skills. It can often be challenging for relatively junior medical trainees like myself to attend such meetings, but with the support of APS Support UK, this became much more accessible.' Dr Manning kindly wrote an article describing his work and presentation at the ISTH in our newsletter.



Dr James Manning

Dr Deepa Arachchillage for the British Society of Haematology

In April 2024, Dr Deepa Arachchillage (a doctor and scientist we have previously supported with research grants) invited our Medical Advisors to review the British Society of Haematology's guidelines on diagnosis and management of APS. Professors David D'Cruz and Anisur Rahman were able to schedule time to do this and made some pertinent suggestions which were included. Later in the year, Dr Arachchillage also requested us to support her application to join the NHS Commissioning Rare Disease Collaborative network for APS, which we were very happy to do.

Rare Autoimmune Rheumatic Disease Alliance

In May 2024, the non-profit organisation Rare Autoimmune Disease Alliance invited us to share a survey on our social media platforms to help them discover what patients think about the quality of their care, guidance and treatment for their rare autoimmune rheumatic disease and to identify gaps in care and influence for improvement where they are most needed. It was a pleasure to work with RAIRDA on this project and we were pleased to hear that they found the feedback from our patient group very useful.

Dr Deepa Arachchillage

Charity objectives achieved in 2024

Raising awareness of APS in the medical community

Dr Louise Nuttall from UCL

Dr Nuttall is a Research Assistant at UCL who has been working on a project that aimed to explore the language used around pregnancy loss, and the impact this language has on those with lived experience. In July 2024, Dr Nuttall invited us to share a survey she had designed with the goal of gaining insights into the views of people who have experienced pregnancy loss within the past three years. This collected data will be used to advise policymakers in the NHS and beyond. We shared the service via all our communication channels and Dr Nuttall thanked us for the excellent response from our patient group.

Presentation to the Faculty of Biology, Medicine and Health at the University of Manchester

One of our volunteer ambassadors, Yvonne Wren, is an APS Expert Patient and she once again kindly gave a talk entitled 'A Patient Journey – Living with Autoimmunity' to the Immunology post-graduate students at the Faculty of Biology, Medicine and Health at the University of Manchester in February 2024. Yvonne's talk was very well received, and she been invited back in 2025 possibly with the aim of filming her patient talk.

Royal College of APS midwives' course

Launched in 2022, the Royal College of Midwives i-learn APS course has been freely available to all members of the Royal College of Midwives via their online platform.

We are pleased to note that, by the end of 2024, 125 midwives had enrolled on the course and 79 had successfully completed the i-learning module. The RCM reported that the course continues to receive high feedback scores and evaluation from the participants; the comments are invariably constructive and include the following:

> "Extremely informative. Nice and simple to follow."

> "Extremely informative in a concise and logical order. I undertook this module to update and learn something new. Definitely achieved. Thank you."

> "The length of the module was perfect, not too long and overwhelmed with information. Really enjoyed it and learnt so much. Thank you."

Royal College of GPs online course

Thanks to our continued funding, the Royal College of GPs APS online course continued to be freely available to all health professionals throughout 2024. We have funded this course on the learning platform of the Royal College of GPs since 2017 (with updates from our Medical Advisers), and plan to continue to make this important online course free to access in the future.

By the end of 2024 the number of healthcare professionals who have enrolled in the course since it was launched is at 2622. During 2024 there were 373 new users and 147 of these completed all parts of the course.

The average score on course pre-assessment was 46% and this rose to 82% after course completion; this 37% knowledge increase indicates how valuable the course is when teaching healthcare professionals about APS.

The overall feedback score given by participants in star ratings during 2024 was 4/5. We are, therefore, very pleased to report that this course is still proving to be a very worthwhile educational tool.

How we achieved our objectives:

Offering information and understanding to anyone affected by APS

COVID-19 patient support

As with the last four years, 2024 saw an increase in the number of patient enquiries made to the charity, mainly related to the vaccine suitability for people with APS and, as ever, we did our utmost to support anyone who asked for assistance.

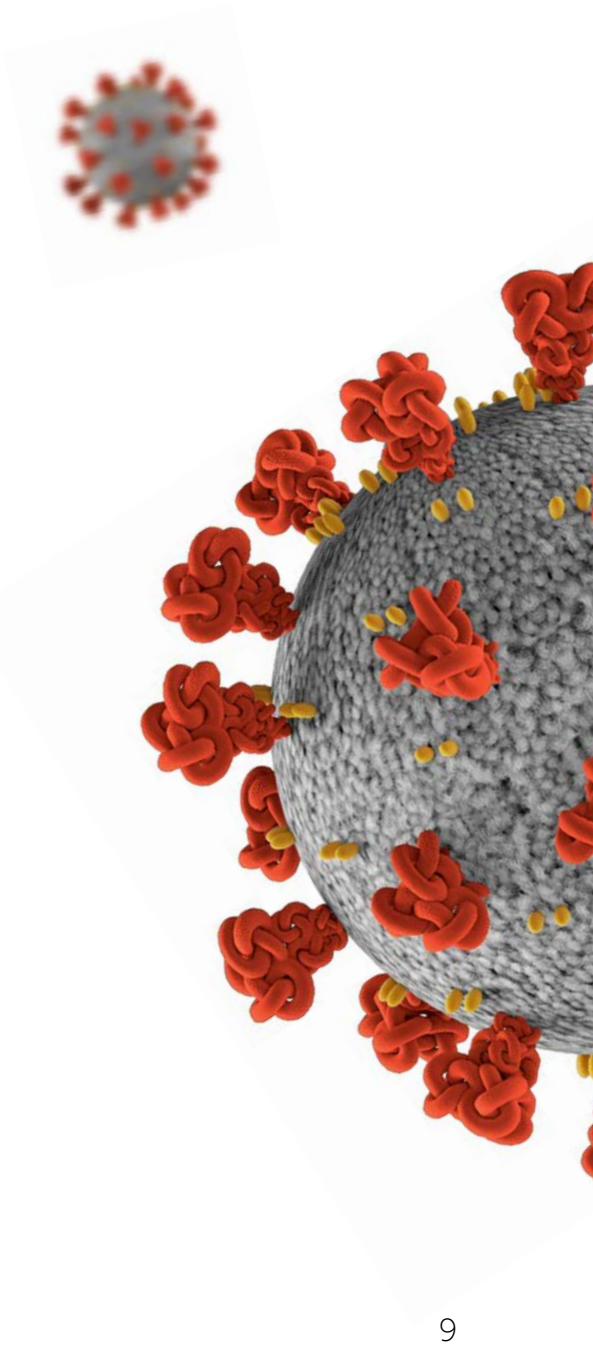
The following queries indicate a small sample of the types of questions we received:

> Should APS patients be called for the spring booster vaccine? - June 2024

> Have the covid boosters detrimentally affected anyone with APS? - September 2024

> I'm trying to understand if Pfizer is a safe option for me? - October 2024

Dr Louise Nuttall



How we achieved our objectives:

Offering information and understanding to anyone affected by APS

Baby Loss Certificates

The Department of Health and Social Care introduced a voluntary Certificate of Baby Loss in England to acknowledge babies lost before 24 weeks of pregnancy, as part of their Women's Health Strategy. This scheme was launched in February 2024, available to anyone who has suffered a pregnancy loss in memory of their baby, initially for losses since September 2018 with a plan to backdate further.

As APS is the most significant potentially treatable cause of recurrent miscarriage, the Department of Health and Social Care invited us to give feedback on this project directly; naturally, we endorsed this scheme and were happy to share the information via all our communication channels. This is very welcome news to many people in our APS community.

Baby Loss Awareness Week campaign

We have been involved in this national awareness campaign for over 15 years and there are now over 50 other charities involved, with SANDS and Tommy's Baby Charity as the lead charities. In 2024, the media coverage for the campaign was outstanding with the Wave of Light initiative reaching global proportions and patient stories appearing in all the national media outlets including the BBC and ITVX, plus lots of local news articles.

We created our own APS story campaign thanks to our brave patients and shared these throughout the week in October; we were pleased that the organisers thanked us directly on X (formerly known as Twitter) for all our efforts in sharing our Patient Stories and helping promote the campaign so productively.

Baby Loss Awareness Week

APS Awareness Month

APS Support UK works in partnership with other national patient organisations to raise awareness of APS annually during the month of June. We do this by creating and allowing others to share our daily infographics via our social media platforms on a variety of different aspects of APS and its symptoms.

Life Insurance for people with APS

We continued to partner with Cura Insurance throughout 2024 with the aim of helping people with APS potentially obtain life insurance policies. Cura Insurance is a company specialising in pre-existing medical conditions and understands the difficulty that many people with APS have with being offered insurance policies. APS is an unknown risk in the insurance world which can preclude patients from being offered cover.

As with previous years, to try and reach the largest audience possible, we promoted our webpage: https://aps-support.org.uk/self-help/living-with-aps/aps-and-life-insurance with a QR code on our social media platforms and also sent direct e-shots and included articles in our hard copy newsletters to those who wish to receive information in this format.

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How we achieved our objectives:

Funding and supporting research into APS

APS Support UK Research Fund

Our APS Research Fund is now in its sixth year, and, in 2024, we increased the grant amount available to applicants from £5,000 to up to £10,000 for research projects about antiphospholipid syndrome. We also continued to offer £1,000 grants to researchers presenting their work at international conferences.

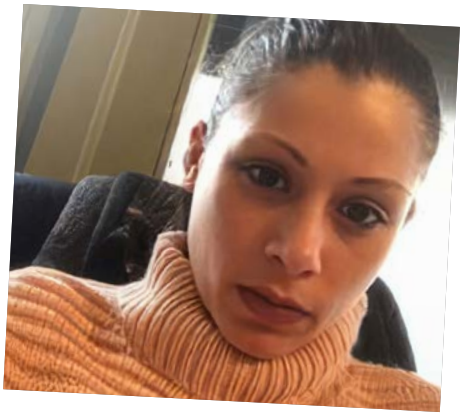
We received a grant application for £10,000 from Maria Efthymiou, Veronica Ventuerlli and Hannah Cohen from UCL for a project on: 'Delineating the importance of non-criteria IgA antiphospholipid antibodies (aPL): assessment of their prevalence and thrombogenic potential in APS with/without SLE'. This was approved by our Vice Medical Chairs and the grant awarded in October 2024; we very much look forward to seeing the outcome of this research.

Research by Maria Efthymiou and Ibrahim Tohidi-Esfahani

We funded a research project in 2022 after receiving a grant application from Dr Ibrahim Tohidi-Esfahani who wanted to run a project called: *'Complement activation in antiphospholipid syndrome patients with ischaemic stroke or other ischaemic brain injury: a therapeutic target?'.*

Based on the findings of this study and others, Dr Tohidi-Esfahani co-authored a groundbreaking paper in December 2024: *'Can Complement Activation be the missing link in antiphospholipid syndrome?:* https://pubmed.ncbi.nlm.nih.gov/38483257/.

We find it very encouraging that our seed funding is helping to drive research into the future treatment of APS.



Dr Maria Efthymiou

Dr Ibrahim Tohidi-Esfahani

How we achieved our objectives:

Funding and supporting research into APS

Survey by Reyhan Turan from London South Bank University

In December 2024, a final-year undergraduate student in the Division of Psychology at London South Bank University, Reyhan Turan, asked if our charity could help recruit participants for an online research survey they were planning.

Reyhan was conducting research for their dissertation titled *"Adults living with Chronic Pain: A Thematic Analysis of Psychological Coping Mechanisms and Quality of Life"* and asked if we could assist in identifying individuals who might be interested in participating in the study. The research aimed to gain a deeper understanding of the psychological coping mechanisms and quality of life for adults who live with chronic pain.

We felt this was a worthwhile project that patients would like to be involved in, so we shared Reyhan' information and survey link on our social media platforms. The appeal was very popular, and the maximum number of participants were recruited and Reyhan will be sharing the results with us once the examination board have marked the dissertation.

EST 1892 LSBU
London South Bank University

Our Impact in 2024

Our Impact in 2024

Website

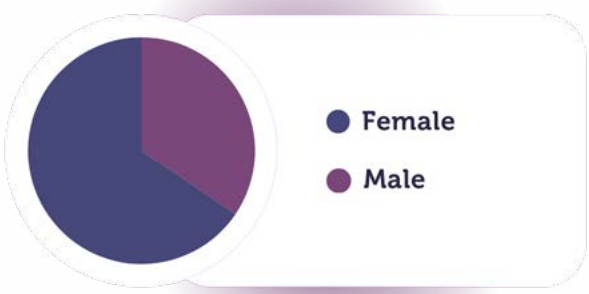
In 2024, our website was visited 294,830 times, with the highest number of visitors viewing the Symptoms, Pregnancy, and Brain information pages. These three sections alone accounted for over a third of all page visits, reflecting the continued demand for reliable and safe APS health information.

Most of our visitors accessed the website using mobile phones (72.9%), with desktop (24.9%) and tablet (2.3%) use following behind; interestingly, a small number of users also accessed our site via smart TVs.

295k page views

Geographically, the United Kingdom and the United States each accounted for around 36,000 users, with further engagement from Canada, Australia, South Africa, the Philippines and India.

In terms of demographics, 65.5% of our users were female and the largest age group was 25–34 years old, closely followed by those aged 35–44.



76k mobile users

We're pleased to see that the website continues to serve as a global hub for accurate, reliable and accessible APS information.

Our Impact in 2024

Social Media

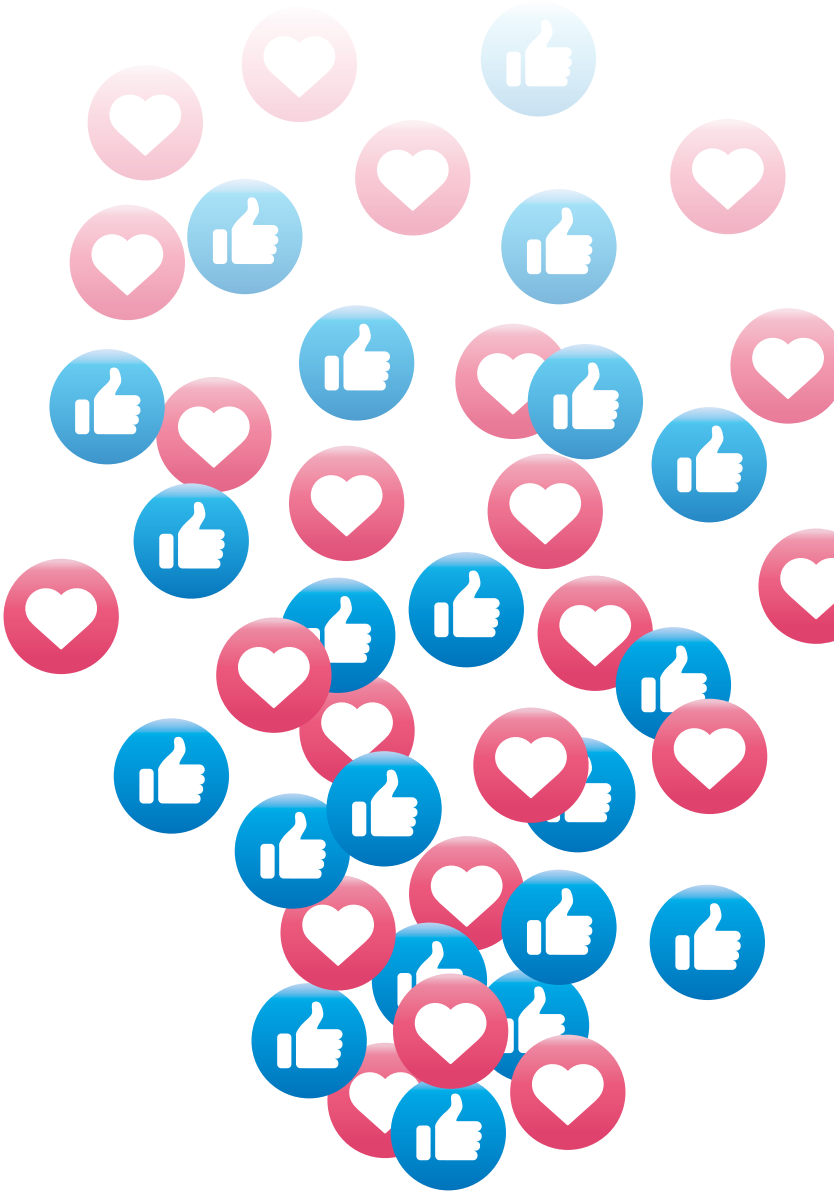
Our social media platforms remained a vital tool for community engagement in 2024, allowing us to share information, support and lived experiences with thousands of people affected by APS.

On Instagram, our account achieved a reach of 14,340, a 5.9% increase from the previous year. We also received 4,181 profile visits, which is up 8.2% on 2023, reflecting growing interest in our content and infographics.

On Facebook, our reach hit 87.3K, a remarkable 94% increase from 2023. We also gained 844 new followers (up 8.6%) and saw 16.8K page visits, marking a 47.3% rise from the previous year. Engagement with our posts remained strong throughout the year and we believe our social media presence continues to support people with APS.

87.3k reach
an increase of 94%

4.2k profile visits
an increase of 8.2%



Our Impact in 2024

Volunteers

We are very fortunate to have two world-leading APS experts as our Medical Vice-Chairs who write all our medical material, update the GP and midwife online course modules, help with complex enquiries and can contact their peers, if necessary, on specific APS subjects such as reviewing grant applications for our APS Research Fund.

We are extremely grateful to our charity ambassadors who give personal talks around the country to help raise awareness of APS, particularly Phil Godfrey, who continues to give talks to Rotary Clubs throughout the UK to raise awareness of APS. Phil continues to be a major fundraiser for our charity, and we are very grateful for his continued support and incredible efforts on behalf of APS patients in memory of his wife, Christine.

Another one of our volunteer ambassadors, Yvonne Wren, is an Expert Patient, and she regularly presents her talk *'A Patient Journey – Living with Autoimmunity'* to post-graduate students whenever possible.

We are also very grateful to all the wonderful volunteers who agreed to share their APS experiences on the Patient Stories section of our website: https://aps-support.org.uk/self-help/patient-stories and those who shared their Baby Loss stories for release in Baby Loss Awareness Month.

Expert Patient Yvonne Wren

In memory of Christine

Our Impact in 2024

Search Engine Optimisation and Google Ads campaign

Our Digital Media Marketing trustee, Chris Mansbridge, has continued to make significant improvements to the charity's SEO, so much so that APS Support UK is now usually ranked #1 in Google rankings when APS is entered as a search term.

We successfully applied for a $10,000 a month Google Grants for Non-profits which Chris Mansbridge successfully implemented. Due to the workload involved in creating and maintaining Google Ads, we placed an advert for a "paid-media volunteer" on the Reach Volunteering platform at the beginning of 2024. Following a number of applications, we were pleased to appoint Monika Baran to join the charity as a volunteer and manage our Google Ads campaigns.

Monika was the Head of Digital Marketing for an HR tech company and has been managing Google and LinkedIn ads, so has a very good understanding of advertising on other social media platforms.

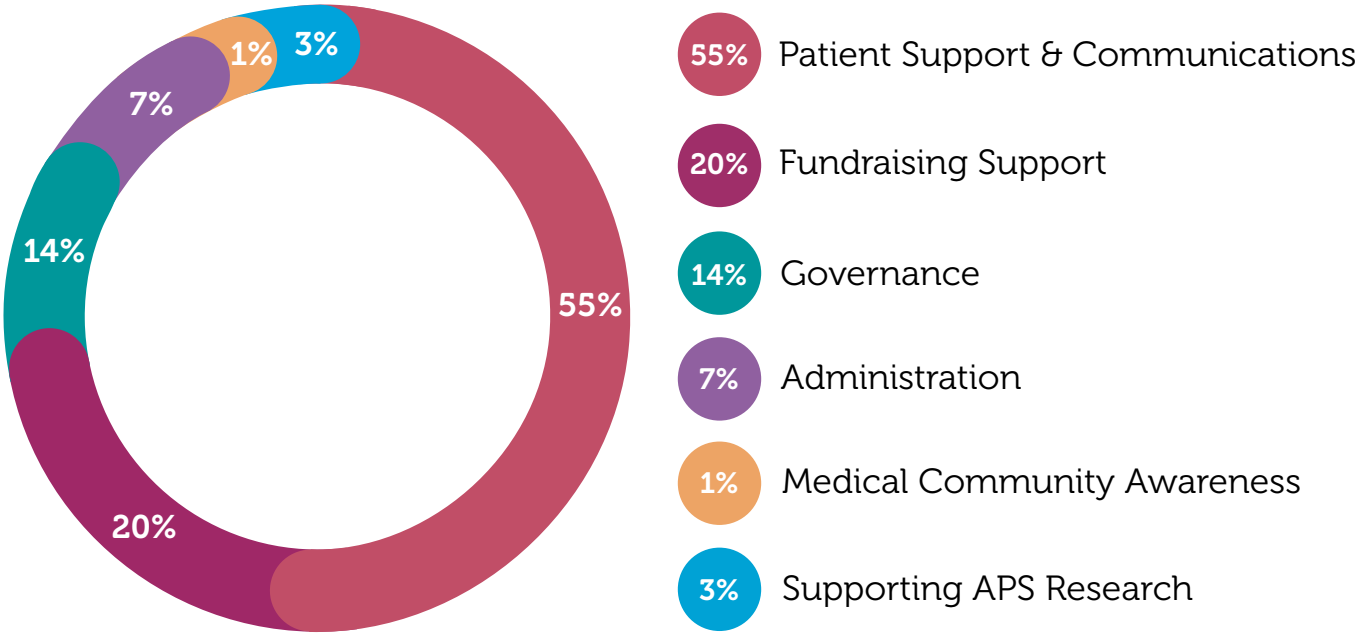
Throughout her career, she has been responsible for website SEO, working with teams and external agencies on various SEO strategies. Our Google Ad campaigns are doing well so far under Monika's supervision, and we look forward to reporting on the success of the campaigns in the future.

Supporting patients through charitable activities

We do not provide specific medical advice as we would be negligent in doing so; instead, we signpost and guide patients when they contact us, so they feel supported, less isolated and confused. We aim to make them feel part of the APS community by giving reliable information, understanding and assistance whenever we can.

To ensure that the charity's resources are spent wisely, our two employees record and log the time spent on charitable activities, and the results for 2024 are shown below:

Charity's staff activity breakdown 2024



Our Impact in 2024

APS in the news 2024

As usual, there were lots of stories in the local press and online platforms involving patients and their families who were sharing their APS experiences. The following articles all helped raise awareness of APS in the general public:

March 2024: Liam Justice appeared on Bridport News:

https://www.bridportnews.co.uk/news/24151005.liam-justice-gets-engaged-suffering-rare-blood-clots/

March 2024: Amy McSweeney appeared on Irish LM FM:

https://www.lmfm.ie/news/news-extra/23-year-old-stunned-to-discover-she-had-a-stroke/

May 2024: Sarah Heney appeared on Edinburgh Live:

https://www.edinburghlive.co.uk/news/edinburgh-news/edinburgh-mum-made-feel-like-29132664

July 2024: Megan Hetherington appeared on Wales Online:

https://www.walesonline.co.uk/news/real-life/ive-been-told-live-each-29564684

October 2024: Toni Bull who is one of our fundraisers and supporters appeared in the Herald Scotland:

https://www.heraldscotland.com/news/national/24647842.nurse-titanium-jaw-rare-medical-conditions-tackle-oxford-half/

We were really pleased when, in April 2024, an episode about Anne: the Forgotten Queen was broadcast on Sky History channels programme 'Royal Autopsy' featuring our Medical Vice Chair, Professor Anisur Rahman.

This programme explored Queen Anne's ill health and what modern medical experts now speculate could have been APS. Professor Rahman said: "It was really enthralling to work with Alice Roberts and her team, and our take home message at the end was how much better Queen Anne would have done if she had access to current treatment for obstetric APS. Indeed, she might well have had an heir which would have changed the course of British history – no Georgians, no Queen Victoria and ultimately no Charles III!".

We feel this national broadcast will have brought APS to the attention of the wider public and hope that awareness of APS keeps on increasing.

Collaboration

As we are a small charity, our impact is increased through collaboration with other charities, campaigns and organisations. We are grateful for the following organisations' generosity in sharing information and working with us during 2024:

- APS ACTION
- APS Foundation of America
- APS Foundation of Australia
- Baby Loss Awareness Week
- The British Society of Haematology
- Cura Life Insurance
- Different Strokes
- Eat on warfarin
- European Alliance of Associations for Rheumatology
- EURORDIS – Rare Diseases Europe
- LUPUS UK
- Mama Academy
- Manchester University Faculty of Biology, Medicine and Health
- Michigan University Medical School
- Prescription Charges Coalition
- RAIRDA – the Rare Autoimmune Rheumatic Disease Alliance
- Rosetrees Trust
- Royal College of GPs
- Royal College of Midwives
- Spanish APS Association
- Thrombosis UK
- Tommy's Baby Charity
- World Thrombosis Day

Thanks for all your help and support

As we look back on the remarkable year that was 2024, we want to express our heartfelt appreciation to our dedicated network of supporters, generous donors, volunteers, collaborators and passionate ambassadors.

Every one of you played a pivotal role in advancing the mission of APS Support UK and raising awareness of the condition; whether it was through your donations or fundraising, sharing your APS journeys, doctors and scientists providing expert medical advice or supporters and patients acting as ambassadors, your collective efforts have left an indelible mark on those affected by antiphospholipid syndrome.

It is with profound gratitude that we thank you for your staunch support. Your unwavering commitment has made a substantial difference in our fight against APS, and we are eager to embark on a brighter and yet another successful year 2025, with you by our side.

Queen Anne in Royal Autopsy

Professor Alice Roberts

Titanium Toni

Future plans for 2025

APS Clinical Nurse Specialist

We made considerable progress with the APS Clinical Nurse Specialist project in 2024 with the aim of having the nurse in place in 2025.

As this project involved bidding for grants from NHS Trusts, we employed an external consultant, Joe Kallarackal, to help us create a grant funding advert and job application form which we then advertise to our newly updated list of APS Specialists in haematology and obstetric clinics throughout the UK, plus our subscribers database; we also placed the advert on the front page of the website and posted on our social media channels.

This wide-ranging advertising approach seemed to work well as we had nine people/groups expressing interest in applying for the grant that Joe felt was a very successful result. We were pleased to receive three excellent grant applications from Leeds Teaching Hospital, Guy's and St Thomas' Hospital, London and a joint application from the Imperial and Royal Free Hospitals in London.

We held the Evaluation Meeting on 9th October 2024 and the panel members were: Joe Kallarackal, Professor Anisur Rahman, Jim Turner (Treasurer of APS Support UK) and Tiffany Martin, Matron for matron for Allergy, Rheumatology and Lupus from Guy's & St Thomas' Hospital. At the end of the meeting, the panel's clear winner was Leeds Teaching Hospital.

On recommendation by Joe Kallarackal, we employed a solicitor at Russell-Cooke to draw up the next legal and regulatory steps and are pleased to report that, at the end of 2024, Leeds Teaching Hospital are now in a position to begin advertising and recruiting for the role and we hope to see the APS Clinical Nurse Specialist in post in 2025.

PhD Studentship

We have been considering the best methods of spending funds wisely and have been exploring the possibility of offering a 3-year PhD studentship in the field of APS. Through our Medical Vice Chair, Professor Anisur Rahman, we have been liaising with the Rosetrees Trust to explore whether they would be willing to offer a jointly funded PhD Studentship.

We feel this is the best solution as the Rosetrees Trust has considerable experience in administering this type of scholarship and would, therefore, be able to establish the infrastructure of the course as well as the fact that the full cost of a three year studentship would be beyond our means.

Fortunately, the Rosetrees Trust have been very interested in the scheme and kindly offered to co-fund this scheme. We are planning to promote the funding round in the autumn of 2025 and will help advertise if through all our communication channels.

New website

We are continuing to develop our new website as planned and it is coming on very well. The current one is over ten years old, and it is not possible to add in plug-ins and other media easily, which is an exciting area we have been working on. We are hoping to have the new site launched in the next couple of years, but this is a huge project as the whole content has to be checked and validated by medical professionals too.

APS Research Fund awards

We intend to continue offering small grants again in 2025 and will be making the application process available on our website when it opens. As usual, we will be advertising the grants through all our communications channels. As we have not had many applications in the last few years and charity funds are doing well, we may consider increasing the amount from £10,000 up to a maximum of £20,000 in 2025, but this has yet to be decided.

Legal and Administrative Information

The Trustees present their final report and the audited financial statements for the year ended 31 December 2024.

The legal and administrative information set out below forms part of this report. The financial statements comply with current statutory requirements, the Memorandum and Articles of Association, the requirements of the Charities Act 2011, the Charities SORP (FRS 102) and the Companies Act 2006.

Charity Registration Number:	1138116
Company Registration Number:	07268671
Date of Incorporation:	2010
Financial Year:	1st January 2024 - 31st December 2024
Registered Office:	The Orchard White Hart Lane Basingstoke Hampshire RG21 4AF
Trustees/Directors of the Organisation:	Baroness Morris of Yardley (Chair) Dr John Wolffe Professor David D'Cruz Professor Anisur Rahman Mr James Turner Mr Christopher Mansbridge
Bankers:	NatWest Lambeth North Branch 91 Westminster Bridge Road London SE1 7ZB
Independent Examiner:	Knight Goodhead Limited 7 Bournemouth Road, Chandler's Ford, Eastleigh, Hampshire, S053 3DA

Governance and Management

Governing Document

The charity operates under a Memorandum and Articles of Association.

Appointment, retirement and training of the Trustees

When a vacancy occurs on the Board of Trustees, the board will take the opportunity to review the skill sets of trustees to identify specific skill sets that would strengthen the Board's overall effectiveness. New trustees are recruited via our communication channels or professional organisations such as Reach.

Governance of the Charity

The Board of Trustees meets three times a year to provide strategic direction and areas of activity for the charity.

Day-to-day operations and administration are delegated to the Management Team to provide regular reports to the trustees on performance and operations.

Financial Review

Statement of responsibilities of the trustees

The trustees are responsible for preparing the annual report and the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice (UK GAAP).

The trustees are required to prepare the annual report and financial statements for each financial year, which give a true and fair view of the state of affairs of the charitable company and of its incoming resources and application of resources, including income and expenditure, for the period. In preparing those financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on a going concern basis unless it is inappropriate to presume that the charity will continue operation.

The trustees are responsible for keeping adequate accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the financial statements comply with the Companies Act 2006. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies, and complies with the charity's governing document and The Statement of Recommended Practice: Accounting and Reporting by Charities using FRS 102.

Results for the Year

For the financial year ended 31 December 2024, the charity made a surplus of £18,699 (2023: £92,184). Income totalled £114,900 (2023: £172,332), with expenditure of £96,201 (2023: £80,148).

Total funds at 31 December 2024 are £398,507 (2023: £379,808), of which £203,000 (2023: £93,000) relate to designated funds, with £40,214 (2023: £44,753) relating to restricted funds.

£73,000 of designated funds (2023: £73,000) relate to the designated reserve explained in the reserve policy. General funds total £155,293 (2023: £242,052). The trustees continue to keep the level of reserves under close review to ensure the needs of the charity can be met.

Reserves Policy

The trustees decided to introduce a designated reserve in the annual accounts for 2017 onwards. The reserve will protect the charity from the risk of unforeseen emergencies or other unexpected need for funds and illustrates to trustees, donors, creditors, employees, beneficiaries and others that the charity is adequately financially equipped to meet its existing and planned commitments and obligations.

Independent examiner's report to the trustees on the unaudited accounts of Hughes Syndrome Foundation

I report to the charity trustees on my examination of the accounts of the company for the year ended 31 December 2024, which are set out on pages 23 to 31.

Responsibilities and basis of report

As the charity's trustees (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 (the "2006 Act").

Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 (the '2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's report

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those accounting records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective October 2019).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

J E Harris FCCA
Knight Goodhead Limited
Chartered Accountants
7 Bournemouth Road
Chandler's Ford, Eastleigh
Hampshire SO53 3DA

Statement

Financial Activities for the year ended 31st December 2024

Including Income and Expenditure Account

INCOMING RESOURCES

	Notes	Unrestricted Funds	Restricted Funds	2024 TOTAL	2023 TOTAL
Donations and legacies		£63,455	£10,914	£74,369	£129,775
Charitable activities		£32,800	£620	£33,420	£38,238
Investment income		£7,090	-	£7,090	£4,271
Other income		£21	-	£21	£48
TOTAL INCOME	**3**	**£103,366**	**£11,534**	**£114,900**	**£172,332**

EXPENDITURE

	Notes	Unrestricted Funds	Restricted Funds	2024 TOTAL	2023 TOTAL
Raising funds		£4,110	-	£4,110	£2,167
Charitable activities		£76,015	£16,076	£92,091	£77,981
TOTAL EXPENDITURE	**4**	**£80,125**	**£16,076**	**£96,201**	**£80,148**

NET INCOME / (EXPENDITURE) FOR THE PERIOD

	Notes	Unrestricted Funds	Restricted Funds	2024 TOTAL	2023 TOTAL
TOTAL NET INCOME		**£23,241**	**(£4,542)**	**£18,699**	**£92,184**

FUNDS

	Notes	Unrestricted Funds	Restricted Funds	2024 TOTAL	2023 TOTAL
Funds at 1 January 2024		£335,052	£44,756	£379,808	£287,624
FUNDS AT 31 December 2024	**7**	**£358,293**	**£40,214**	**£398,507**	**£379,808**

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 6 to the financial statements.

Comparative statement of financial activites year ended 31 December 2023

Including Income and Expenditure Account

INCOME

	Notes	Unrestricted Funds	Restricted Funds	2023 Total
Donations and legacies		£128,492	£1,283	£129,775
Charitable activities		£37,609	£629	£38,238
Investment income		£4,271	-	£4,271
Other income		£48	-	£48
TOTAL INCOME	**3**	**£170,420**	**£1,912**	**£172,332**

EXPENDITURE

	Notes	Unrestricted Funds	Restricted Funds	2023 Total
Raising funds		£2,167	-	£2,167
Charitable activities		£70,643	£7,338	£77,981
TOTAL EXPENDITURE	**4**	**£72,810**	**£7,338**	**£80,148**

NET INCOME / EXPENDITURE FOR THE PERIOD

	Notes	Unrestricted Funds	Restricted Funds	2023 Total
NET INCOME / EXPENDITURE FOR THE PERIOD		**£97,610**	**(£5,426)**	**£92,184**

FUNDS

	Notes	Unrestricted Funds	Restricted Funds	2023 Total
Funds at 1 January 2023		£237,442	£50,182	£287,624
FUNDS AT 31 December 2023	**7**	**£335,052**	**£44,756**	**£379,808**

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above.

Balance sheet as at 31 December 2024

CURRENT ASSETS

	Notes	2024		2023	
Debtors	6	£7,634		£8,381	
Cash at bank and in hand	**7**	£403,728		£372,844	
		£411,362		**£381,225**	

CREDITORS

	Notes	2024		2023	
Amounts falling due within one year Accruals		(£12,855)		(£1,417)	
NET ASSETS	**10**		**£398,507**		**£379,808**

FUNDS

	Notes	2024		2023	
Restricted funds	**8**		£40,214		£44,756
Unrestricted funds			-		-
General funds	**8**		£155,293		£242,052
Designated funds	**8**		£203,000		£93,000
TOTAL FUNDS			**£398,507**		**£379,808**

For the financial period ended 31 December 2024, the company was entitled to exemption from audit under section 477 Companies Act 2006; and no notice has been deposited under section 476. The directors acknowledge their responsibilities for ensuring that the company keeps accounting records, which comply with section 386, and preparing accounts, which give a true and fair view of the state of affairs of the company as at the end of the year and of its income and expenditure for the financial year, in accordance with the requirements of section 394 and 395, and which otherwise comply with the requirements of the Companies Act 2006 relating to accounts, so far as applicable to the company.

The accounts are prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by the board of trustees on 23/09/2025 and signed on its behalf by:

James Turner
Trustee

Notes to the accounts for the year ended 31 December 2024

1. ACCOUNTING POLICIES

a) Accounting convention

The financial statements have been prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with FRS 102 (effective 1 January 2019), and the Companies Act 2006.

The charity meets the definition of the public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note.

The accounts have been prepared on the going concern basis. There are no material uncertainties about the charity's ability to continue.

b) Income

Income is recognised in the statement of financial activities in the year in which it is receivable.

Grants and donations are only included in the statement of financial activities when the charity has unconditional entitlement to the resources.

Income from tax reclaims are included in the statement of financial activities at the same time as the Investment income is included in the accounts when receivable.

c) Expenditure

Expenditure is recognised in the period in which they are incurred. Resources expended include attributable VAT which cannot be recovered.

d) Fund accounting

Funds held by the charity are either:

Unrestricted general funds

Funds which can be used in accordance with the charitable objects at the discretion of the trustees.

Designated funds

Funds which are set aside for specific purposes by the trustees to be used in accordance with the charitable objects.

Restricted funds

Funds that can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purpose.

e) Tangible fixed assets

Fixed assets are capitalised where the purchase price exceeds £1,000. Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life.

2. LEGAL STATUS

The charity is a company limited by guarantee and has no share capital. The charitable company was incorporated on 1 June 2010 in England and Wales and was registered on 17 September 2010 with the Charity Commission in England and Wales. The charity is a public benefit entity.

The registered office of the charitable company is The Orchard, White Hart Lane, Basingstoke, Hampshire, RG21 4AF.

Notes to the accounts for the year ended 31 December 2024

3. INCOME

Donations & Legacies	Unrestricted Funds	Restricted Funds	2024 TOTAL	2023 TOTAL
Donations	£41,495	£10,740	£52,235	£47,757
Legacies	£3,000	-	£3,000	£76,399
Gift aid recoverable	£18,960	174	£19,134	£5,619
TOTAL	**£63,455**	**£10,914**	**£74,369**	**£129,775**

Charitable activities	Unrestricted Funds	Restricted Funds	2024 TOTAL	2023 TOTAL
Fundraising income	£21,429	£620	£22,049	£28,048
Membership renewals	£11,371	-	£11,371	£10,190
TOTAL	**£32,800**	**£620**	**£33,420**	**£38,238**

Investment Income	Unrestricted Funds	Restricted Funds	2024 TOTAL	2023 TOTAL
Bank Interest	£7,090	-	£7,090	£4,271
TOTAL	**£7,090**	**-**	**£7,090**	**£4,271**

Other Income	Unrestricted Funds	Restricted Funds	2024 TOTAL	2023 TOTAL
Sundry Income	£21	-	£21	£48
TOTAL	**£21**	**-**	**£21**	**£48**

	Unrestricted Funds	Restricted Funds	2024 TOTAL	2023 TOTAL
TOTAL INCOME	**£103,366**	**£11,534**	**£114,900**	**£172,332**

Notes to the accounts for the year ended 31 December 2024

4. EXPENDITURE

Raising funds	Unrestricted Funds	Restricted Funds	2024 TOTAL	2023 TOTAL
Fundraising costs	£4,110	-	£4,110	£2,167
TOTAL	**£4,110**	**-**	**£4,110**	**£2,167**

Charitable activities	Unrestricted Funds	Restricted Funds	2024 TOTAL	2023 TOTAL
Staff costs	£54,660	-	£54,660	£49,304
Insurance costs	£446	-	£446	£426
Office costs	£2,360	-	£2,360	£2,104
Raising awareness	£12,639	-	£12,639	£15,203
Rent	£4,104	-	£4,104	£4,104
Legal and professional fees	£368	-	£368	£360
Accountancy	£1,438	-	£1,438	£1,477
Grants paid	-	£11,000	£11,000	£5,000
APS Nurse Specialist Project	-	£5,076	£5,076	-
Bank charges	-	-	-	£3
TOTAL	**£76,015**	**£16,076**	**£92,091**	**£77,981**

	Unrestricted Funds	Restricted Funds	2024 TOTAL	2023 TOTAL
TOTAL EXPENDITURE	**£80,125**	**£16,076**	**£96,201**	**£80,148**

The independent examination fee included in accountancy amounted to £1,438 (2023: £1,477).
Grants of £nil (2023: £nil) were paid as part of the Louise Gergel Fellowship Project.
Grants of £10,000 (2023: £5,000) were paid to University College London

Notes to the financial statements for the year ended 31st December 2024

5. EMPLOYED STAFF COSTS AND NUMBERS

	2024	2023
Salaries and wages	£53,068	£47,868
Pension	£1,592	£1,436
TOTAL	**£54,660**	**£49,304**

No employee earned more than £60,000 during this or the prior period. The total number of employees during the period was 2 (2023: 2).

Key management were paid remuneration totalling £46,792 (2023: £44,889).

No trustee received any remuneration during this or the prior period.

Trustees' indemnity insurance of £34 (2023: £26) for the Board of Trustees was paid during the year.

6. DEBTORS

	2024	2023
Gift aid recoverable	£6,253	£7,036
Prepayments	£1,381	£1,345
TOTAL	**£7,634**	**£8,381**

7. CASH AT BANK AND IN HAND

Bank balances are held as follows:

	2024	2023
NatWest current account	£78,425	£56,567
NatWest deposit account	£50,172	£49,455
Shawbrook bank	£81,790	£80,781
Cambridge and Counties	£89,003	£85,159
Earl Shilton	£80,803	£80,000
Louise Gergel account	£21,003	£20,649
PayPal	£2,532	£233
TOTAL	**£403,728**	**£372,844**

Notes to the accounts for the year ended 31 December 2024

8. MOVEMENT IN FUNDS

Restricted funds	At 1 January 2024	Income	Expenditure	Transfers	At 31 December 2024
Louise Gergel Fellowship	£20,649	£354	-	-	£21,003
Research and Projects Fund	£15,107	£1,180	(£11,000)	-	£5,287
APS Research Fund	£9,000	-	-	-	£9,000
Nurse Specialist Project	-	£10,000	(£5,076)	-	£4,924
TOTAL	**£44,756**	**£11,534**	**(£16,076)**	**-**	**£40,214**

Designated funds	At 1 January 2024	Income	Expenditure	Transfers	At 31 December 2024
Research and Projects fund	£20,000	-	-	-	£20,000
Designated reserve fund	£73,000	-	-	-	£73,000
Nurse Specialist Project	-	-	-	£60,000	£60,000
PhD Studentship Grants Award	-	-	-	£50,000	£50,000
TOTAL	**£93,000**	**-**	**-**	**£110,000**	**£203,000**

Unrestricted funds	At 1 January 2024	Income	Expenditure	Transfers	At 31 December 2024
General funds	**£242,052**	**£103,366**	**(£80,125)**	**(£110,000)**	**£155,293**

	At 1 January 2024	Income	Expenditure	At 31 December 2024
TOTAL FUNDS	**£379,808**	**£114,900**	**(£96,201)**	**£398,507**

Notes to the accounts for the year ended 31 December 2024

8. MOVEMENT IN FUNDS - PRIOR YEAR FUNDS MOVEMENTS

Restricted funds	At 1 January 2023	Income	Expenditure	At 31 December 2023
Louise Gergel Fellowship	£19,369	£1,283	(£3)	£20,649
Research and Projects Fund	£19,478	£629	(£5,000)	£15,107
APS Research Fund	£9,000	-	-	£9,000
Digital Media Assistant	£2,335	-	(£2,335)	-
TOTAL	**£50,182**	**£1,912**	**(£7,338)**	**£44,756**

Designated funds	At 1 January 2023	Income	Expenditure	At 31 December 2023
Research and Projects fund	£20,000	-	-	£20,000
Designated reserve fund	£73,000	-	-	£73,000
TOTAL	**£93,000**	**-**	**-**	**£93,000**

Unrestricted funds	At 1 January 2023	Income	Expenditure	At 31 December 2023
General funds	**£144,442**	**£170,420**	**(£72,810)**	**£242,052**

	At 1 January 2023	Income	Expenditure	At 31 December 2023
TOTAL FUNDS	**£287,624**	**£172,332**	**(£80,148)**	**£379,808**

Notes to the accounts for the year ended 31 December 2024

8. MOVEMENT IN FUNDS

RESTRICTED FUNDS

Louise Gergel Fellowship
The Louise Gergel Fellowship is a dedicated family memorial fundraising sub-committee who raise funds for medical research and bursaries only.

Research and Projects Fund
The Research and Projects Fund is for medical research and specific projects such as online APS courses for healthcare staff and patient initiative such as conferences etc.

APS Research Fund
One of our key aims is to support research into antiphospholipid syndrome (APS) and we have committed over £543,000 to-date into research we believe will have a real impact on the APS community. APS Support UK is a grant making charity recognised by the National Institute for Health Research (NIHR) as a non-commercial partner funding research of clear value to the NHS as a result of open competition with high quality peer review. We aim to offer awards of up to £10,000 to APS-specific research projects on a yearly basis.

Nurse Specialist Project
The APS Clinical Nurse Specialist role is being set up with the aim of creating a service within an NHS clinic to provide support and advice specifically for patients with APS; for example on subjects like symptom control, anticoagulation and vaccinations.

DESIGNATED FUNDS

Designated Reserve Fund
This reserve protects the charity from the risk of unforeseen emergency or other unexpected need of funds and illustrates to Trustees, Donors, Creditors, Employees, Beneficiaries and others that the charity is adequately financially equipped to meet its existing and planned commitments and obligations.

Research and Projects Fund
The Research and Projects Fund is for medical research and specific projects such as online APS courses for healthcare staff and patient initiative such as conferences etc.

APS Research Fund
One of our key aims is to support research into antiphospholipid syndrome (APS) and we have committed over £543,000 to-date into research we believe will have a real impact on the APS community. APS Support UK is a grant making charity recognised by the National Institute for Health Research (NIHR) as a non-commercial partner funding research of clear value to the NHS as a result of open competition with high quality peer review. We aim to offer awards of up to £10,000 to APS-specific research projects on a yearly basis.

Nurse Specialist Project
The APS Clinical Nurse Specialist role is being set up with the aim of creating a service within an NHS clinic to provide support and advice specifically for patients with APS; for example on subjects like symptom control, anticoagulation and vaccinations.

PhD Studentship Grants Award
The Rosetrees PhD Reserve fund is for our contribution to the PhD Studentship in the area of APS being jointly funded by APS Support UK and the Rosetrees Trust across 3 years, planned to commence in 2025.

Notes to the accounts for the year ended 31 December 2024

9. RELATED PARTY TRANSACTIONS

During this year and the prior year, no trustees were reimbursed expenses incurred on behalf of the charity.

10. ANALYSIS OF NET ASSETS BETWEEN FUNDS

2024	Restricted funds	Designated funds	Unrestricted funds	2024 Total funds
Current assets	£40,214	£203,000	£168,148	£411,362
Current liabilities	-	-	(£12,855)	(£12,855)
NET ASSETS	**£40,214**	**£203,000**	**£155,293**	**£398,507**

2023	Restricted funds	Designated funds	Unrestricted funds	2023 Total funds
Current assets	£44,756	£93,000	£243,469	£381,225
Current liabilities	-	-	(£1,417)	(£1,417)
NET ASSETS	**£44,756**	**£93,000**	**£242,052**	**£379,808**