

HUGHES SYNDROME FOUNDATION

England & Wales · Charity number 1138116

Details

Other names	APS SUPPORT UK
Status	Registered
Legal form	Charitable company
Company number	07268671
Registered	2010-09-17
Register	View on the Charity Commission register

Contact

Address	The Orchard White Hart Lane Basingstoke Hampshire RG21 4AF
Phone	03003239943
Email	info@aps-support.org.uk
Website	www.aps-support.org.uk

Activities

Objects: THE COMPANY'S OBJECTS ARE SPECIFICALLY RESTRICTED TO THE RELIEF OF SICKNESS AND THE PROTECTION AND PRESERVATION OF PUBLIC HEALTH, IN PARTICULAR BUT NOT EXCLUSIVELY BY FUNDING RESEARCH INTO HUGHES SYNDROME (ANTIPHOSPHOLIPID SYNDROME) AND BY ADVANCING PUBLIC AND MEDIA UNDERSTANDING OF THE CAUSES AND PROPER TREATMENT OF HUGHES SYNDROME.

Activities: We aim to achieve earlier diagnosis and better treatment for people with antiphospholipid syndrome (APS). We support anyone affected by APS; provide education and awareness within the medical profession; raise awareness of APS in the general public and raise funds to provide support, education and research.

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£114,900	£96,201	-	-
2023-12-31	£172,332	£80,148	-	-
2022-12-31	£91,541	£77,692	-	-
2021-12-31	£128,035	£66,274	-	-
2020-12-31	£127,590	£92,020	-	-

Trustees

Name	Role	Appointed
BARONESS ESTELLE MORRIS	Chair	2012-03-05
Christopher James Mansbridge		2020-01-01
DR WOLFFE		
Ekta Fors		2025-11-12
James Turner		2018-05-04
PROFESSOR D'CRUZ		
Professor Anisur Rahman		2015-05-01

Accounts



APS Support UK

For people with antiphospholipid syndrome



Another Kittwalk, same big heart



Falling for a good cause



From start line to support



Teeing off "Fore" APS

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 APS 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.



Phil Godfrey

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

↘ @APSupportUK 

<https://www.facebook.com/APSupportUK/> 

COVID-19 Impact in 2024

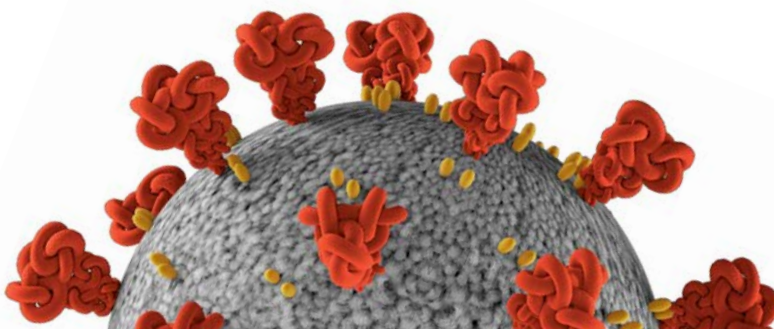
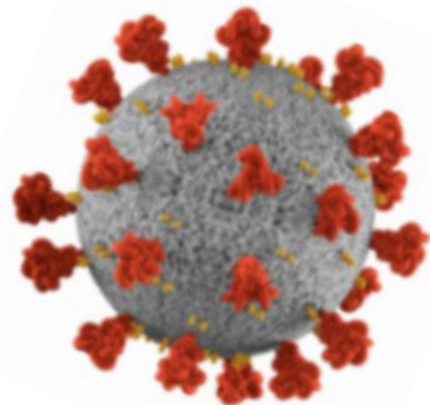
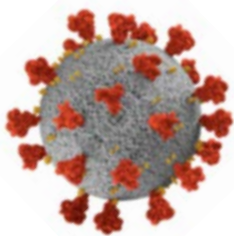
Since 2020, our charity has continually been impacted by the global COVID-19 pandemic and our services are still under great demand by our patient group.

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.

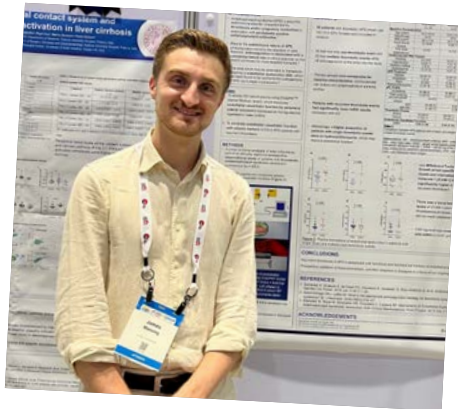


Charity objectives achieved in 2024

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.



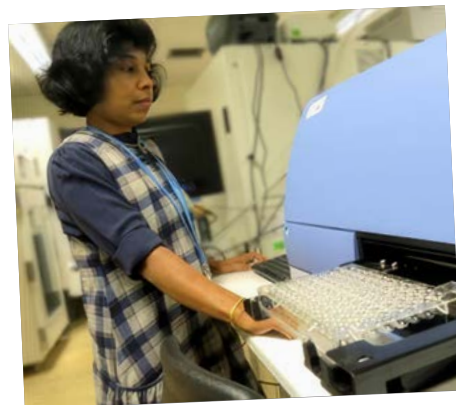
Dr James Manning

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:

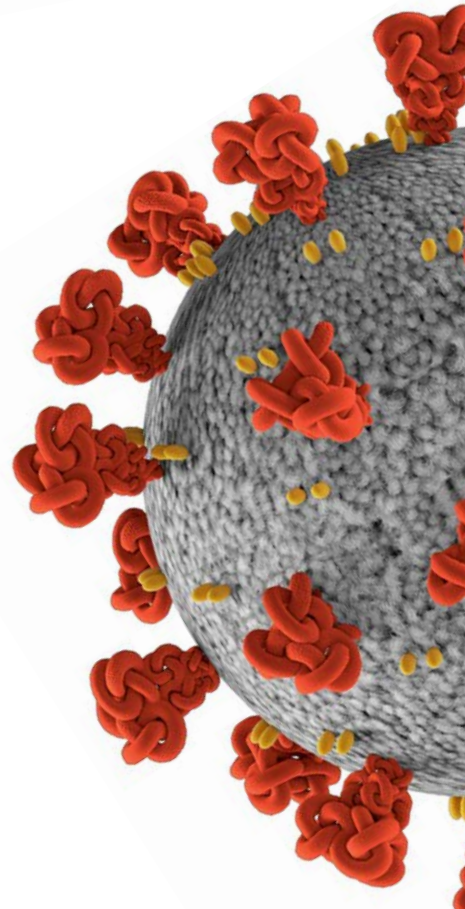
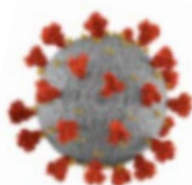
“ Should APS patients be called for the spring booster vaccine? ” - June 2024

“ 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.

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.



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.

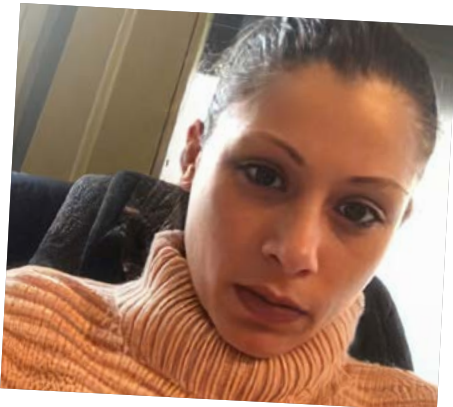
We received a grant application for £10,000 from Maria Efthymiou, Veronica Ventuerlli and Hannah Cohen from UCL for a project on: 'Delineating the importance of non-criteria IgA antiphospholipid antibodies (aPL): assessment of their prevalence and thrombogenic potential in APS with/without SLE'. This 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's 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.



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.

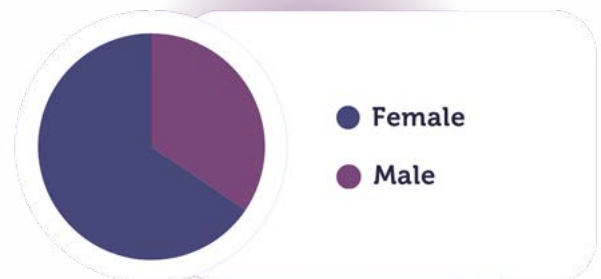
Most of our visitors accessed the website using mobile phones (72.9%), with desktop (24.9%) and tablet (2.3%) use following behind; interestingly, a small number of users also accessed our site via smart TVs.



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.

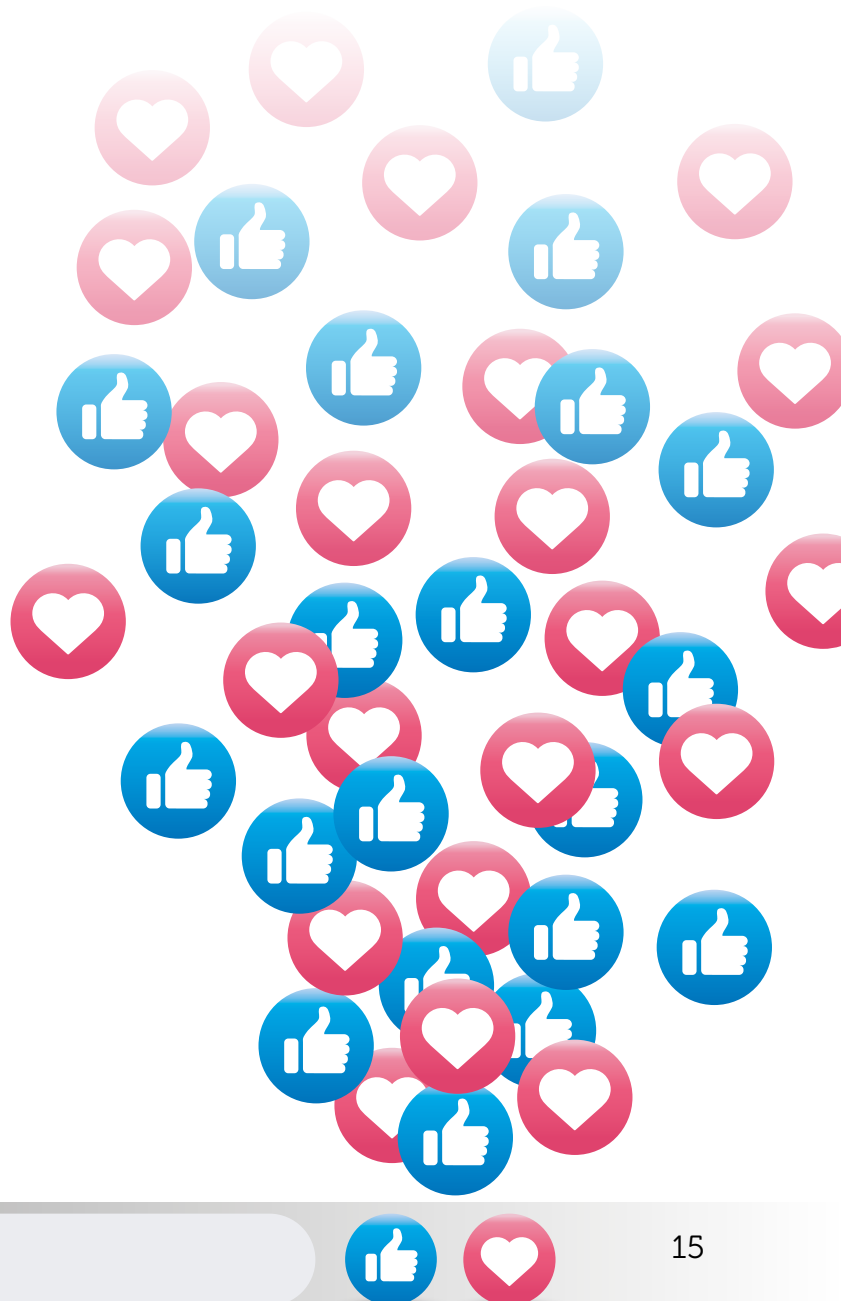
On Facebook, our reach hit 87.3K, a remarkable 94% increase from 2023. We also gained 844 new followers (up 8.6%) and saw 16.8K page visits, marking a 47.3% rise from the previous year. Engagement with our posts remained strong throughout the year and we believe our social media presence continues to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



4.2k profile visits
an increase of 8.2%



87.3k reach
an increase of 94%



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.



In memory of Christine



Expert Patient Yvonne Wren

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.

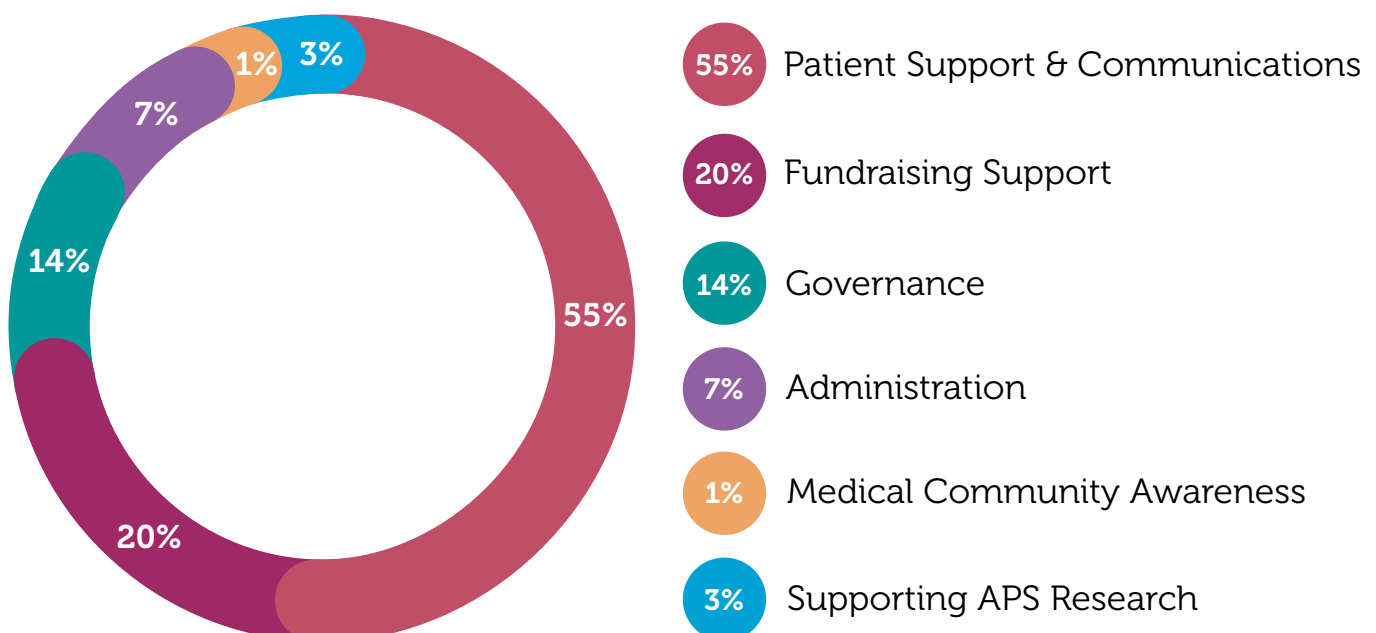
Throughout her career, she has been responsible for website SEO, working with teams and external agencies on various SEO strategies. Our Google Ad campaigns are doing well so far under Monika's supervision, and we look forward to reporting on the success of the campaigns in the future.

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 Alike Roberts



Titanium Toni

THANK YOU

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 activities 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

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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

Accounts



APS Support UK

For people with antiphospholipid syndrome



APS ally Andy Tang



Joe rocks a kilt!



In memory of Annie Tang



Mindfulness meets charity with Dipan!

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.

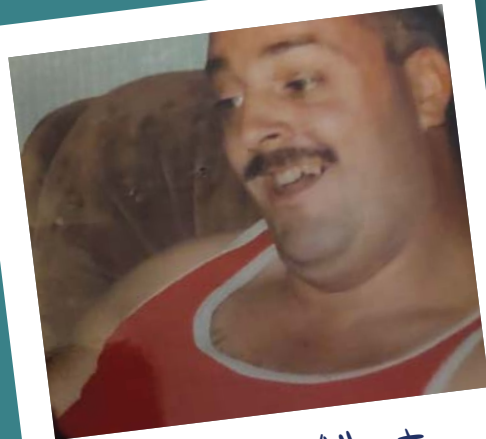
As of yet, we simply don't know why people develop APS, why some patients go on to have blood clots while others don't, why some women (but not all) have pregnancy problems and why some people are affected by symptoms more than others – vital research is needed before we can answer these questions.

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.



Graeme with Mum



In memory of Albert

Introduction and Message from the Chair

We are pleased to present the APS Support UK Annual Report for 2023 and would like to thank everyone who has supported and collaborated with our charity throughout this year.

We have continued to focus on supporting research and were delighted to be involved in five national and international projects, including a PhD studentship whose work focuses on a self-management application for people with primary antiphospholipid syndrome. We have also supported a study about APS diagnostic journeys and how they can be improved.

We were particularly pleased to be involved with the development of a European Alliance of Associations for Rheumatology (EULAR) disease activity index for APS as this will be the first of its kind, and we are also looking forward to sharing the results of the Michigan University group's study on APS patients' experiences, priorities and concerns surrounding pregnancy.

None of these projects would have been possible without the participation of our APS patient group and we would like to extend our thanks to everyone who responded.

It was very rewarding to be involved in a new initiative, established by APS ACTION. This network of internationally renowned physicians and scientists is working to find a cure for antiphospholipid syndrome and an APS Action Patients' Engagement Workshop has been established to bring patient groups around the world together to help guide the scientists' priorities. We look forward to continuing working with this group over the coming years.



Baroness Estelle Morris
Chair of APS Support UK

Our small grants awards scheme continues to support researchers, and we would like to thank Professor Beverley Hunt OBE for her help in reviewing the winning application as part of our Peer Review Panel.

We are constantly amazed by the range of activities our supporters take part in to raise funds for the charity. This means that we can continue to support those affected by APS and contribute to future research. In 2023, we were very fortunate to receive two legacies from Nina Ballard and Frances Simner which means the charity is very financially stable going into 2024.

Together with the legacy we received from Arthur Ogden, we are now able to consider increasing the amount we award to applicants in our grant making programme and have taken the first steps in funding two new initiatives; an APS Nurse Specialist based in an NHS hospital and a 4-year PhD studentship. Clearly, we have a lot of work to do in 2024, but we relish the challenge and look forward to, hopefully, reporting progress on these projects.

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, and to the trustees who give generously of their time and expertise.

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



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; we always do our utmost to help those affected by antiphospholipid syndrome (APS).

Early diagnosis **saves lives**

Our Objectives

APS is a life-threatening autoimmune disease that causes the blood to clot too quickly. The condition can cause potentially 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 section below. The directors confirm that they have paid due regard to the Charity Commission guidance on public benefit before deciding which activities the charity should undertake.



Phil Godfrey

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

↪ @APSupportUK 

<https://www.facebook.com/APSupportUK/> 



APS Support UK
For people with antiphospholipid syndrome

aps-support.org.uk
0300 323 9943

Registered charity 1138116. Copyright 2018

COVID-19 Impact in 2023

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. 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.

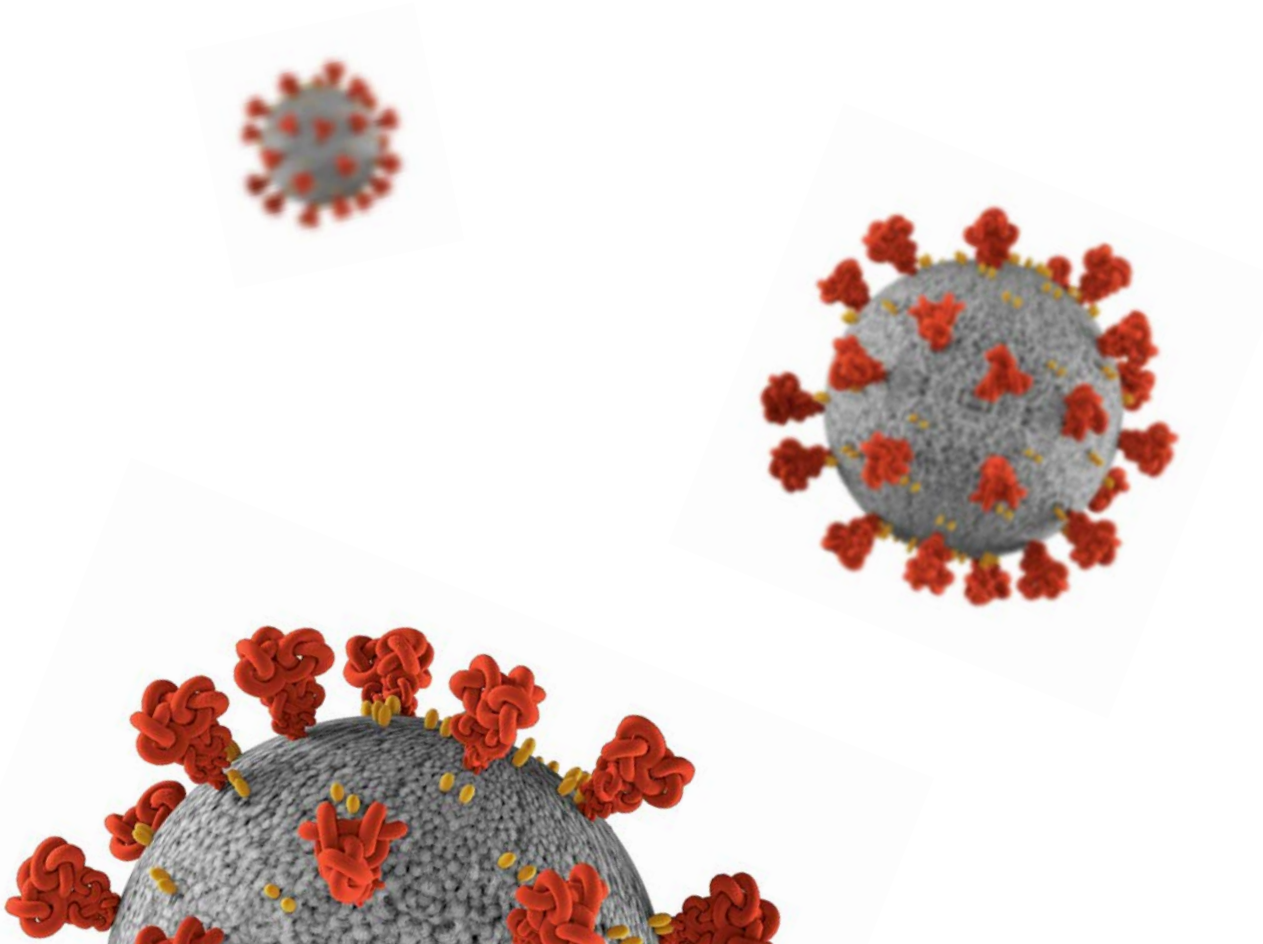
The other reasons our charity is still being affected by the pandemic is the apparent link between antiphospholipid antibodies and COVID-19 and what this potentially means for patients.

For example, researchers published an article in the journal Rheumatology in May 2023 that found that, compared with the general population, patients with rare autoimmune rheumatic diseases (including APS) have more than a 2-fold increased risk for COVID-19-related death: <https://www.rheumatologyadvisor.com/news/risk-for-covid-19-related-death-elevated-in-rare-autoimmune-rheumatic-diseases/>

Additionally, there is an apparent link between transient antiphospholipid antibodies and COVID-19 in the general population who were hospitalised with COVID-19. For example, a study published in October 2023 found that a “significant proportion of COVID-19 patients with oxygen demand were autoantibody-positive, and autoantibodies persisted for several months after symptom onset. Whether these autoantibodies are related to long-term sequelae in COVID-19 patients requires further investigation”: <https://pubmed.ncbi.nlm.nih.gov/37845706/>

From these studies 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.

Overall, 2023 was yet another busy year for APS Support UK as we continued to deal with a large increase in workload due to COVID-19 enquiries and the dissemination of COVID-related research articles to the APS community.



Charity objectives achieved in 2023

Raising awareness of APS in the medical community

Contribution and review of the national Tommy's Baby Charity website content

In April 2023, Tommy's, the pregnancy and baby charity, asked us to review and contribute to the information on their website regarding APS. Our Medical Advisors, Professors David D'Cruz and Anisur Rahman, kindly updated and commented on the content and worked collaboratively with Tommy's to provide a new webpage which can be viewed here: <https://www.tommys.org/pregnancy-information/pregnancy-complications/antiphospholipid-syndrome-aps>. Tommy's also now signpost APS Support UK's website from their main page.

APS ACTION Patients Engagement workgroup

The international group, APS ACTION, invited patient groups around the world to take part in a global meeting in April 2023 that also included 7 doctors (over 30 doctors are involved with the whole project, but not all could attend the online meeting).

The patient groups who met were APS Support UK, the APS Foundation of America and the APS Group of Australia. It was a positive initial meeting, and the Working Group is committed to establishing a strong partnership and having a global impact. Our charity provided the committee with the details of other national APS groups, so the next meeting should have more country participants. We also discussed creating a top 10 priority APS list similar to those adopted by the James Lind Trust who we have worked with in the past.



Dr Thomas McDonnell

Dr Thomas McDonnell research achievements

We have awarded Dr Thomas McDonnell a number of research grants in the past, so we were very pleased to learn that he had won the Garrod Award at the British Society of Rheumatology in April 2023.

Furthermore, in May 2023, Dr McDonnell was also awarded the Emerging Leaders Prize from the Medical Research Foundation and was awarded a grant of £20,000 to continue his research into APS. The MRF produced this video of Thomas which we shared on our social media channels with their permission: <https://twitter.com/MedResFdn/status/1613867333528739841>

It is very gratifying to witness the researchers we have supported over the years making significant contributions to the APS research community. Dr McDonnell's work is clearly making a tangible difference in advancing our understanding and treatment of APS.

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 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 2023.

This year, Yvonne was finally able to visit in person rather than relying on Zoom as in the last few years, and you can see Tweet from the University of Manchester thanking Yvonne for her "fantastic and thought-provoking talk" here: https://twitter.com/UoM_PGT_Immuno/status/1625543315079806999

Tommy's

The pregnancy and baby charity

Charity objectives achieved in 2023

Raising awareness of APS in the medical community

Royal College of Midwives APS course

Since its launch in 2022, the Royal College of Midwives i-learn course continued to be available throughout 2023 to all the members of the Royal College of Midwives.

As of February 2023, 49 midwives had enrolled, 37 had completed 100% of the i-Learning module and 34 had evaluated and claimed a certificate. The RCM reported that the course is receiving very positive evaluation reports.



Royal College
of Midwives
i-learn

Royal College of GPs online course

Thanks to our continued funding, the Royal College of GPs APS online course was available to health professionals throughout 2023. We have funded this course on the learning platform of the Royal College of GPs since 2017 (with updates), and hope to continue to make it free to all healthcare professionals to access in the future.

By the third quarter of 2023, almost 1200 healthcare professionals have taken and completed this course with an improvement of approximately 40% in their knowledge; we are pleased that this is still proving to be a very worthwhile educational tool.



Royal College of
General Practitioners

APS | ACTION 

How we achieved our objectives:

Offering information and understanding to anyone affected by APS

COVID-19 patient support

As with the last three years, 2023 saw an increase in the number of patient enquiries made to the charity, mainly related to the vaccines, and we did our utmost to support anyone who asked for assistance.

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

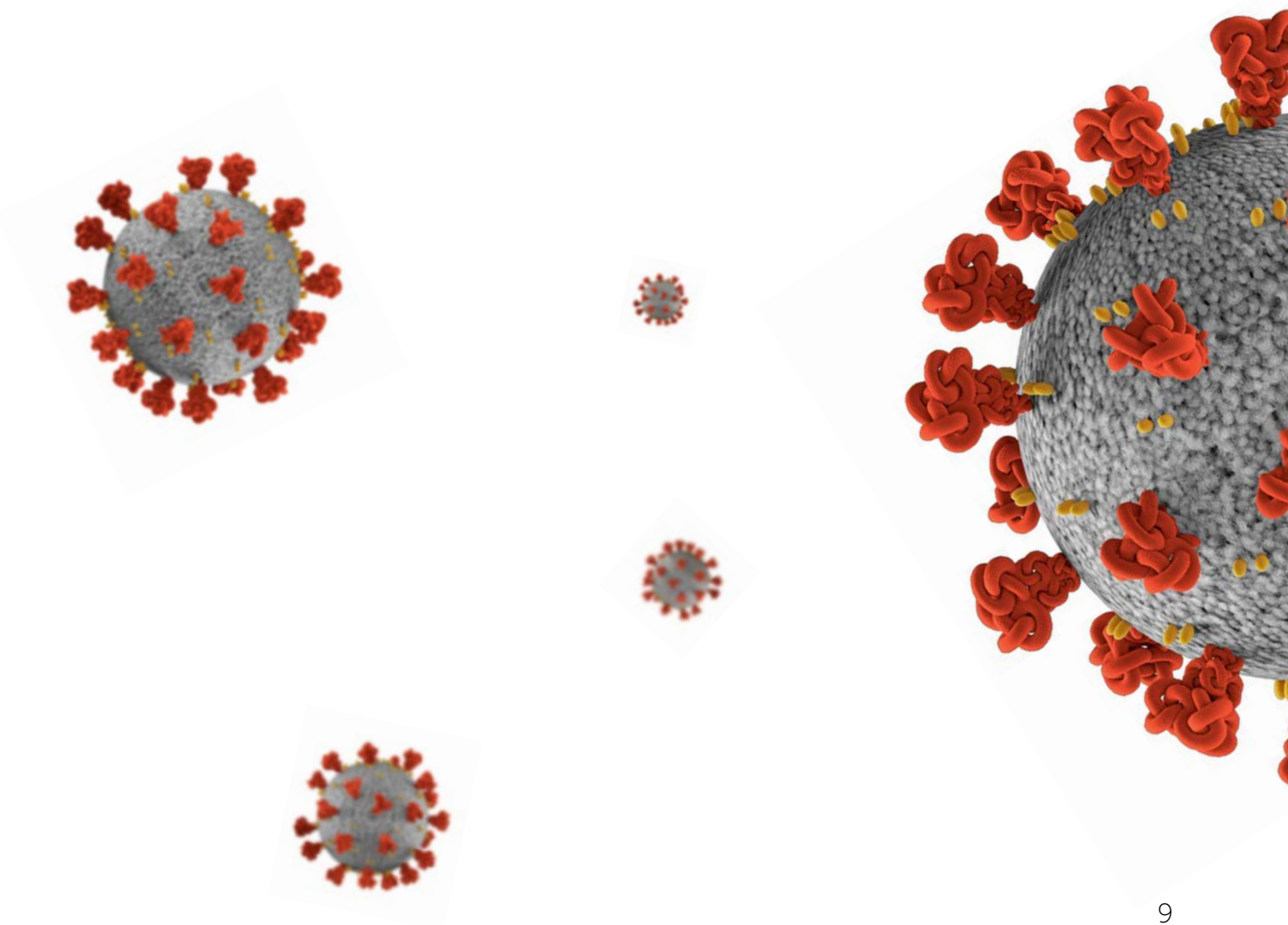
“Do people with APS qualify to get COVID tests sent out from the government?” - March 2023

“Both mum and myself have APS. She’s been told by her GP that Moderna vaccines are contraindicated in APS patients. Do you know if this is true?” - April 2023

“Are all the available Covid vaccinations suitable for patients with APS?” - May 2023

“Do you know if there is any research saying that Covid vaccine does not give APS for patients? There is this patient here in Brazil that claims her doctor is certain that her APS was caused by the Covid vaccine.” - July 2023

“Hi, what is the advice on Covid boosters when you have APS?” - October 2023



How we achieved our objectives:

Offering information and understanding to anyone affected by APS

Baby Loss Certificates

We were directly contacted by the Department of Health and Social Care regarding the launch of the proposed Baby Loss Certificates. The government is planning to provide these certificates to anyone who has suffered a pregnancy loss in memory of their baby. We endorsed this project, gave feedback as requested and shared the information on all our communication channels.

Baby Loss Awareness Week campaign

We have been involved in this national campaign for over ten years and there are now over 50 other charities involved, with SANDS and Tommy's Baby Charity as the lead groups. This year, we took a more active role by changing the banners on our social medial channels to 'pink and blue' and encouraged the APS community to join the 'Wave of Light' where families across the world light a candle to remember all the babies that have died too soon.

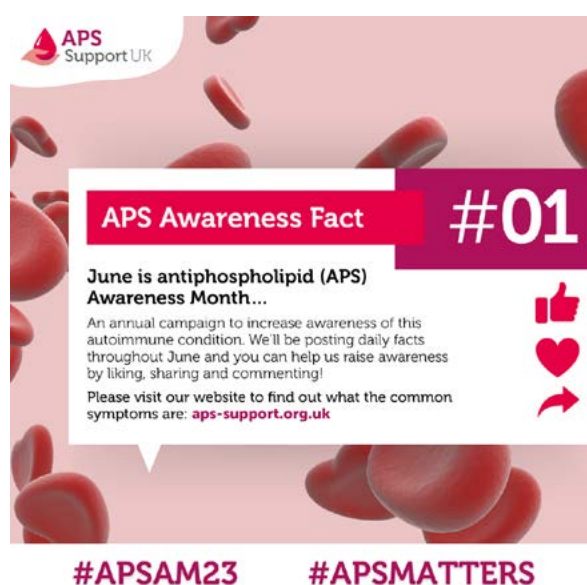


APS Awareness Month

APS Support UK works in partnership with other national patient organisations to raise awareness of APS 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 in 2023 with the aim of helping people with APS obtain life insurance policies; Cura Insurance is a company specialising in pre-existing medical conditions. 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.



How we achieved our objectives:

Funding and supporting research into APS

APS Support UK Research Fund

Our APS Research Fund is now in its fifth year. This fund offers small grants of up to £5,000 for research projects and travel awards specifically concentrating on antiphospholipid syndrome.

In 2023 we were, again, in a financial position to offer small grants to researchers, so we promoted the research applications on our website via our social media and direct communication channels early in the year.

As with the last three years, we extended the closing date from 15th April 2023 to 15th June 2023 due to the pressures caused by the pandemic. All applicants were asked to submit additional information on how the COVID-19 pandemic might affect their research proposal and whether they would still be able to conduct the research as outlined in their applications.

As with previous years following the pandemic and the subsequent effect on the UK research community, we only received one grant application in 2023 and, this year, we awarded £4,816.80 to:

- Dr Thomas McDonnell and Dr Hannah Bradford from University College London to work on their project entitled: Dissecting the significance of a novel complement producing monocyte subset in patients with APS/SLE overlap syndrome

The applications are usually evaluated by our charity's Medical Vice Chairs, Professors David D'Cruz and Anisur Rahman but, because this application came from colleagues in Professor Rahman's unit, we sent the application to our Peer Review Panel where it was kindly reviewed in an evaluation form by Professor Beverley Hunt OBE.

Self-management app for people with APS

We have been liaising with Drs Heide Lempp and Lindsay Bearn for the past five years as they tried to get their project Co-designing a self-management intervention for people with primary antiphospholipid syndrome launched. In the summer of 2023, we were delighted to learn that they had been awarded a grant for a full-time 3-year PhD studentship.

The project should prove to be a success with patients as well as researchers and will focus on creating a free application where people can record information about their symptoms and daily living. Our charity will be working with the researchers on this project, helping disseminate surveys and providing a link to our patient group.

Michigan (US) APS programme

We were approached by Drs Jason Knight and Ray Zu from the Michigan University group who asked if we would be able to help recruit patients from the APS community in the UK into a new research project they were establishing.

This is a new type of research where patients 'as partners' are included in projects at the very beginning by identifying what patients want researchers to study, and at the very end by sharing the study results. This type of research aims to understand and develop solutions to meet APS patients' needs beyond medications.

This particular virtual research project aimed to understand experiences, priorities and concerns surrounding pregnancy for individuals diagnosed with APS. We invited our patient group to be involved via our communication channels and, if they wanted to participate, they were asked to complete surveys about personal and medical information, including history with APS and pregnancy.

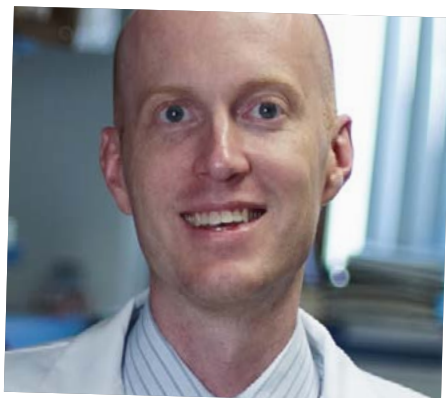
The recruitment went well, and the Michigan Group told us that they had "succeeded in obtaining surveys from 70 participants, 7 of whom found our study through you" and they thanked us and our patient group for all their help. They will be sharing the results once they have analysed them.

How we achieved our objectives:

Funding and supporting research into APS

Development and Validation of a EULAR disease activity index

Maria Tektonidou, Professor of Rheumatology at the University of Athens, is chairing this new European Alliance of Associations for Rheumatology (EULAR) task force and requested that we email our professional contacts and ask them to complete their survey. We did so by sending a direct communication to the rheumatologists on our APS professionals database who seemed happy to complete the survey.



Jason Scott Knight, MD, PhD

Swansea University Research project

PhD researcher, Rupert Harwood, asked if we could help recruit patients for this study about APS diagnostic journeys and how they can be approved. His study is going to be based on the original research we worked on with Dr Peter Donan and Mary McDonald in 2009: <https://pubmed.ncbi.nlm.nih.gov/19455365/>

We shared Rupert's survey through our communication channels and the APS patient responses were overwhelming, so much so that this research will be developed further. Rupert kindly agreed that he will write an article summarising the findings in our newsletter next year.



Professor Lindsay Bearn



Yu (Ray) Zuo, MD, MSc

Our Impact in 2023



Our Impact in 2023

Website

In 2023, we had 136% increase in page views. Interestingly, we had 43k users from the United States compared with 35k from the United Kingdom. In terms of demographics, the majority of visits were from female users aged between 25-34.

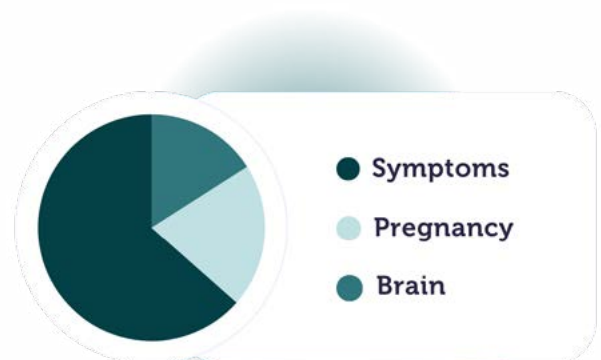
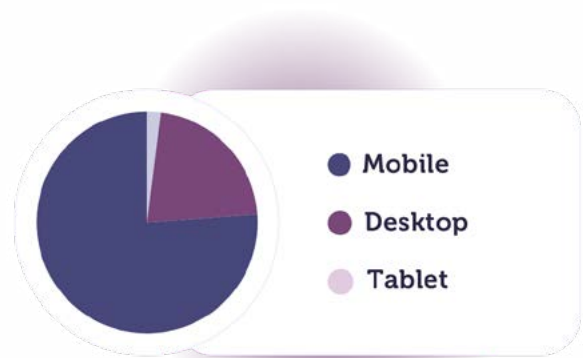
136% increase in page views

Our website is accessed by just over 95k users via their mobile phone, while approximately 27k viewed it on their desktop computer. 2.5k users access our website on a tablet and some even used their smart TV!

The most popular views in 2023 were the Symptoms, Pregnancy and Brain pages, which made up...

28% of all website visits

We are reassured that our website continues to be viewed, both nationally and internationally, as a trustworthy, timely and reliable source of APS information.



Our Impact in 2023

Social Media

Our social media platforms continued to do well in 2023, and we posted daily articles offering information and hope to the APS community via Facebook, X (Twitter) and Instagram. These posts receive lots of visitor comments and provide us with a way to communicate directly and regularly with people who are affected by APS; in turn, this allows us to gauge what is important to the community and which topics we need to focus on.

Throughout 2023, we received 990 new follows on Facebook, an increase of 28% compared to the previous year; our Facebook reach was an incredible 114.8K, an impressive rise of 377%. Our Facebook page visits were 35.5K, a huge 638% increase from 2022.

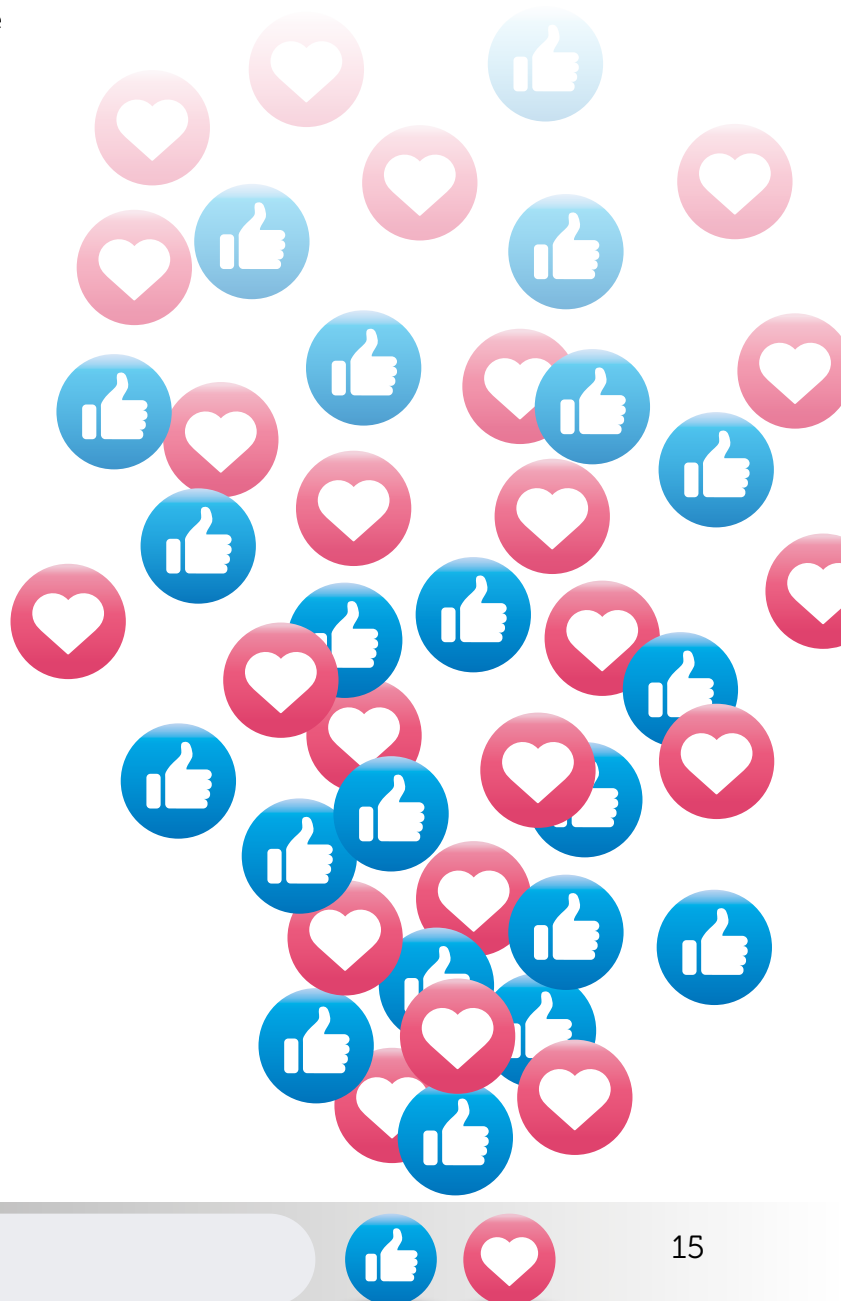
We were pleased to note that, this year, our Instagram account achieved a reach of 14.3K, an increase of 277% from the previous year. We also received 4.2K profile visits, an increase of 626%.



14.3k reach
an increase of 277%



35.5k page visits
an increase of 638%



Our Impact in 2023

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; for example, this year, we called upon the expert opinion of Professor Beverley Hunt OBE to review the APS Research Fund application.

As we have fostered good collaborative connections with other charities, teaching hospitals and leading APS experts, we can call on their professional help when needed; for example, Thrombosis UK and LUPUS UK generously continue to share their information and resources with our charity.

We are also 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.



Alex and Annie



Lydia Goodall

Our Impact in 2023

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.

After Chris Mansbridge, successfully applied for a \$10,000-a-month Google Grant for Non-profits, we have been busy trying to spend this amount every month on Google Ads campaigns. We developed two on associated search topics such as 'miscarriage' and 'blood clots' but felt that we now needed extra help in this specialist area.

We, therefore, created an advert for a "paid-media volunteer" which will be placed on the Reach Volunteering platform in 2024, and we hope to appoint someone to this new role as soon as possible.

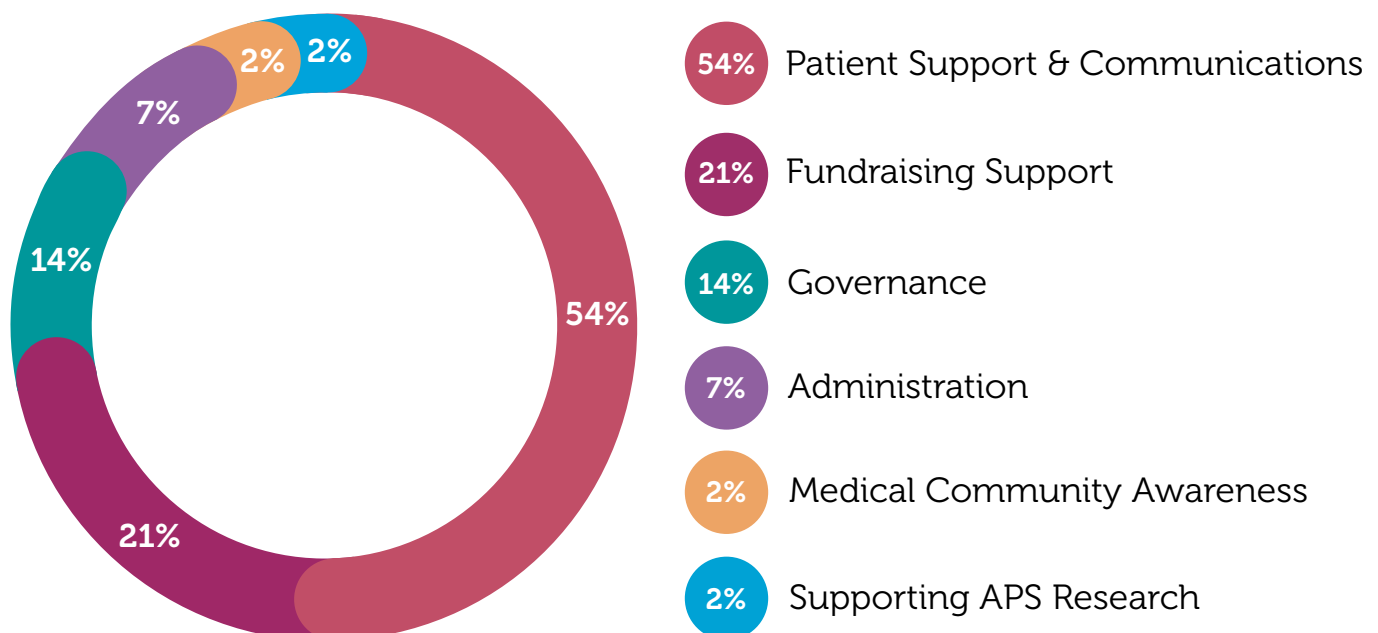
activities

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

As with previous years, COVID-19 enquiries took up a lot of our resources in terms of offering patient support. We were also able to disseminate research surveys to the APS patient community which assisted scientists with a number of important projects.

To ensure that the charity's resources are spent wisely, our employees record and log the time spent on charitable activities, and the results for 2023 are shown below:

Charity's staff activity breakdown 2023



Supporting patients through charitable

Our Impact in 2023

APS in the news 2023

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, such as: <https://www.aberdeenlive.news/news/aberdeen-news/family-beloved-aberdeen-vet-who-8304191>

There were also a number of APS-related articles in the national news throughout 2023, including an article about our Patient Expert, Yvonne Wren, published in Walking World in February regarding her walk along the Thames Path National Trail to raise money and awareness of APS: <https://www.walkingworld.com/Articles/Newsletter/Newsletter-archive/February-2023.aspx>

We were contacted by Phoenix Research in September 2023 asking if we could find an APS expert to appear on a TV programme with Professor Alice Roberts on Sky History called 'Royal Autopsy'. This is because there is a possible link between Queen Anne and APS as she had a large number of miscarriages and was unwell throughout her life. Our Medical Vice Chair, Professor Anisur Rahman, kindly agreed to film part of the programme at his clinic in University Hospital London and the programme is due to be broadcast in April 2024.



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 2023:

- [APS ACTION](#)
- [APS Foundation of America](#)
- [APS Foundation of Australia](#)
- [Baby Loss Awareness Week](#)
- [Cura Life Insurance](#)
- [Different Strokes](#)
- [Eat on warfarin](#)
- [European Alliance of Associations for Rheumatology](#)
- [EURORDIS – Rare Diseases Europe](#)
- [German APS Support Group](#)
- [LUPUS UK](#)
- [Mama Academy](#)
- The [University Manchester Faculty of Biology, Medicine and Health](#)
- [Michigan University Medical School](#)
- [Philippines APS Support Group](#)
- [Prescription Charges Coalition](#)
- [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 2023, 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 financial contributions, sharing your APS journeys, providing expert medical advice or 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 2024, with you by our side.



Professor Maria Tektonidou



Professor Heidi Lempp



Claire conquers the Cayman Islands

THANK YOU

Future plans for 2024

APS Nurse Specialist

In January 2022 we reached out to the APS community to ask patients how they would like to spend the legacy of £60,000 that was kindly left by the estate of Arthur Ogden. From the online survey, the majority of respondents voted that we fund the salary of a nurse specialist for a year.

As the trustee who would have managed this project, Mike Shipley, sadly died in July 2022 it was agreed that we should find a suitably experienced person who can help us create this service within the NHS. We did this in 2023 by using professional contacts via our trustees and have now set up a meeting with JK Consultancy in February 2024 with the aim of getting this project started in 2024.

PhD Studentship

Due to the stability of the charity funds, we are considering funding a 4-year PhD studentship in APS research. As the average yearly stipend is around £22,000-£25,000, it may be that we will not be able to fully fund the PhD studentship ourselves, so we have agreed that we should research and approach other charities or bodies in 2024 that may be willing to part or co-fund the studentship with us.

New website

We have been developing 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 and the whole content has to be checked and validated too.

APS Research Fund awards

We intend to continue offering small grants again in 2024 and will be making the application process available on our website at the beginning of the year with a deadline of 15th April 2024. We be advertising the grants through all our communications channels. As we have not had many applications in the last few years, we may consider increasing the amount from £5,000 to £10,000 in 2024.



Dr Ibrahim Tahidi-Esfahani



Dr Hannah Bradford

Legal and Administrative Information

The Trustees present their final report and the audited financial statements for the year ended 31 December 2023.

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 2023 - 31st December 2023

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 in 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.

So far as the trustees are aware, there is no relevant audit information (information needed by the company's auditors in connection with preparing their report) of which the company's auditors are unaware. Each trustee has taken all the steps that they ought to have taken as a trustee in order to make themselves aware of any relevant audit information and to establish that the company's auditors are aware of that information.

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 2023, the charity made a surplus of £92,184 (2022: £13,849). Income totalled £172,332 (2022: £91,541), with expenditure of £80,148 (2022: £77,692).

Total funds at 31 December 2023 are £379,808 (2022: £287,624), of which £93,000 (2022: £93,000) relate to designated funds, with £44,756 (2022: £50,182) relating to restricted funds. £73,000 of designated funds (2022: £73,000) relate to the designated reserve explained in the reserve policy. General funds total £242,052 (2022: £144,442). 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.

The trustees acknowledge their general legal duty to spend income within a reasonable time of receipt and to do so in the charity's best interest, and hence it is not the charity's policy to hold excessive reserves above and beyond those that are prudent. Our reserve policy is in accordance with the provisions of CC19.

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 2023, 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).

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 2023

Including Income and Expenditure Account

INCOMING RESOURCES

	Notes	Unrestricted Funds	Restricted Funds	2023 TOTAL	2022 TOTAL
Donations and legacies		£128,492	£1,283	£129,775	£59,996
Charitable activities		£37,609	£629	£38,238	£29,998
Investment income		£4,271	-	£4,271	£1,529
Other income		£48	-	£48	£18
TOTAL INCOME	3	£170,420	£1,912	£172,332	£91,541

EXPENDITURE

	Notes	Unrestricted Funds	Restricted Funds	2023 TOTAL	2022 TOTAL
Raising funds		£2,167	-	£2,167	£2,582
Charitable activities		£70,643	£7,338	£77,981	£75,110
TOTAL EXPENDITURE	4	£72,810	£7,338	£80,148	£77,692

NET INCOME / (EXPENDITURE) FOR THE PERIOD

	Notes	Unrestricted Funds	Restricted Funds	2023 TOTAL	2022 TOTAL
TOTAL NET INCOME		£97,610	(£5,426)	£92,184	£13,849

FUNDS

	Notes	Unrestricted Funds	Restricted Funds	2023 TOTAL	2022 TOTAL
Funds at 1 January 2023		£237,442	£50,182	£287,624	£273,775
FUNDS AT 31 December 2023	7	£335,052	£44,756	£379,808	£287,624

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 activities year ended 31 December 2022

Including Income and Expenditure Account

INCOME

	Notes	Unrestricted Funds	Restricted Funds	2022 Total
Donations and legacies		£55,166	£4,830	£59,996
Charitable activities		£28,718	£1,280	£29,998
Investment income		£1,529	-	£1,529
Other income		£18	-	£18
TOTAL INCOME	3	£85,431	£6,110	£91,541

EXPENDITURE

	Notes	Unrestricted Funds	Restricted Funds	2022 Total
Raising funds		£2,582	-	£2,582
Charitable activities		£58,519	£16,591	£75,110
TOTAL EXPENDITURE	4	£61,101	£16,591	£77,692

NET INCOME / EXPENDITURE FOR THE PERIOD

	Notes	Unrestricted Funds	Restricted Funds	2022 Total
NET INCOME / EXPENDITURE FOR THE PERIOD		£24,330	(£10,481)	£13,849

FUNDS

	Notes	Unrestricted Funds	Restricted Funds	2022 Total
Funds at 1 January 2022		£213,112	£60,663	£273,775
FUNDS AT 31 December 2022	7	£237,442	£50,182	£287,624

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 2023

CURRENT ASSETS

	Notes	2023		2022	
Debtors	6	£8,381		£6,750	
Cash at bank and in hand	7	£372,844		£282,171	
		£381,225		£288,921	

CREDITORS

	Notes	2023		2022	
Amounts falling due within one year Accruals		(£1,417)		(£1,207)	
NET ASSETS	10		£379,808		£287,624

FUNDS

	Notes	2023		2022	
Restricted funds	8		£44,756		£50,182
Unrestricted funds					
General funds	8		£242,052		£144,442
Designated funds	8		£93,000		£93,000
TOTAL FUNDS			£379,808		£287,624

For the financial period ended 31 December 2023, 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 and signed on its behalf by:

James Turner
Trustee

Notes to the accounts for the year ended 31 December 2023

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 gift to which they relate.

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 2023

3. INCOME

Donations & Legacies	Unrestricted Funds	Restricted Funds	2023 TOTAL	2022 TOTAL
Donations	£46,474	£1,283	£47,757	£56,505
Legacies	£76,399	-	£76,399	£1,000
Gift aid recoverable	£5,619	-	£5,619	£2,491
TOTAL	£128,492	£1,283	£129,775	£59,996

Charitable activities	Unrestricted Funds	Restricted Funds	2023 TOTAL	2022 TOTAL
Fundraising income	£27,419	£629	£28,048	£19,981
Membership renewals	£10,190	-	£10,190	£10,017
TOTAL	£37,609	£629	£38,238	£29,998

Investment Income	Unrestricted Funds	Restricted Funds	2023 TOTAL	2022 TOTAL
Bank Interest	£4,271	-	£4,271	£1,529
TOTAL	£4,271	-	£4,271	£1,529

Other Income	Unrestricted Funds	Restricted Funds	2023 TOTAL	2022 TOTAL
Sundry Income	£48	-	£48	£18
TOTAL	£48	-	£48	£18

	Unrestricted Funds	Restricted Funds	2023 TOTAL	2022 TOTAL
TOTAL INCOME	£170,420	£1,912	£172,332	£91,541

Notes to the accounts for the year ended 31 December 2023

4. EXPENDITURE

Raising funds	Unrestricted Funds	Restricted Funds	2023 TOTAL	2022 TOTAL
Fundraising costs	£2,167	-	£2,167	£2,582
TOTAL	£2,167	-	£2,167	£2,582

Charitable activities	Unrestricted Funds	Restricted Funds	2023 TOTAL	2022 TOTAL
Staff costs	£49,304	-	£49,304	£46,927
Insurance costs	£426	-	£426	£680
Office costs	£2,104	-	£2,104	£1,956
Raising awareness	£12,868	£2,335	£15,203	£13,454
Rent	£4,104	-	£4,104	£4,104
Legal and professional fees	£360	-	£360	£571
Accountancy	£1,477	-	£1,477	£1,387
Grants paid	-	£5,000	£5,000	£6,000
Bank charges	-	£3	£3	£31
TOTAL	£70,643	£7,338	£77,981	£75,110

	Unrestricted Funds	Restricted Funds	2023 TOTAL	2022 TOTAL
TOTAL EXPENDITURE	£72,810	£7,338	£80,148	£77,692

The independent examination fee included in accountancy amounted to £1,417 (2022: £1,387).

Grants of £nil (2022: £nil) were paid as part of the Louise Gergel Fellowship Project.

Grants of £5,000 were paid to University College London (2022: £6,000 to the Royal College of General Practitioners).

Notes to the financial statements for the year ended 31st December 2023

5. EMPLOYED STAFF COSTS AND NUMBERS

	2023 TOTAL	2022 TOTAL
Salaries and wages	£47,868	£44,985
Social security costs	-	£590
Pension	£1,436	£1,352
TOTAL	£49,304	£46,927

No employee earned more than £60,000 during this or the prior period. The total number of employees during the period was 2 (2022: 2).

Key management were paid remuneration totalling £44,889 (2022: £42,850).

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

Trustees' indemnity insurance of £228 (2022: £228) for the Board of Trustees was paid during the year.

6. DEBTORS

	2023 TOTAL	2022 TOTAL
Gift aid recoverable	£7,036	£6,750
Prepayments	£1,345	-
TOTAL	£8,381	£6,750

7. CASH AT BANK AND IN HAND

Bank balances are held as follows:

	2023	2022
NatWest current account	£56,567	£56,929
NatWest deposit account	£49,455	£32,628
Shawbrook bank	£80,781	£30,561
Cambridge and Counties	£85,159	£82,046
Hampshire Bank	-	£60,298
Earl Shilton	£80,000	-
Louise Gergel account	£20,649	£19,369
PayPal	£233	£340
TOTAL	£372,844	£282,171

Notes to the accounts for the year ended 31 December 2023

8. MOVEMENT IN FUNDS

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

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 initiatives 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 £5,000 to APS-specific research projects on a yearly basis.

Digital Media Assistant

This fund represents monies received to engage a digital media assistant to oversee the social media presence and search engine optimisation of the charity.

Notes to the accounts for the year ended 31 December 2022

8. MOVEMENT IN FUNDS - PRIOR YEAR FUNDS MOVEMENTS

Restricted funds	At 1 January 2022	Income	Expenditure	At 31 December 2022
Louise Gergel Fellowship	£19,120	£280	(£31)	£19,369
Research and Projects Fund	£23,648	£1,830	(£6,000)	£19,478
APS Research Fund	£5,000	£4,000	-	£9,000
Digital Media Assistant	£12,895	-	(£10,560)	£2,335
TOTAL	£60,663	£6,110	(£16,591)	£50,182

Designated funds	At 1 January 2022	Income	Expenditure	At 31 December 2022
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 2022	Income	Expenditure	At 31 December 2022
General funds	£120,112	£85,431	(£61,101)	£144,442

	At 1 January 2022	Income	Expenditure	At 31 December 2022
TOTAL FUNDS	£273,775	£91,541	(£77,692)	£287,624

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.

Notes to the accounts for the year ended 31 December 2023

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

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

2022	Restricted funds	Designated funds	Unrestricted funds	2022 Total funds
Current assets	£50,182	£93,000	£145,739	£288,921
Current liabilities	-	-	(£1,297)	(£1,297)
NET ASSETS	£50,182	£93,000	£144,442	£287,624

Accounts



APS Support UK

For people with antiphospholipid syndrome



Sarah steps up for APS



Crazy hair for APS care!



In memory of Craig



Hyjek sisters run Brighton

Overview

Antiphospholipid syndrome (APS) is a 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.



Amy and Macushla



In Memory of Carol

Introduction and Message from the Chair

We are pleased to present the Annual Report for 2022. Although patient enquiries about the pandemic continue to stretch the charity, it has been a slightly calmer year for APS Support UK compared to the two previous years which were the busiest in our charity's history.

This year we have been able to focus more on raising awareness amongst the medical profession and the public and we are delighted to have been able to continue with our small grants awards.

The learning modules which the charity has funded and developed, working alongside the Royal College of GPs and the Royal College of Midwives, continue to be popular and make a real impact in raising awareness of APS within the medical profession. Our aim is that initiatives like these will contribute to reducing the time that people often have to wait for a diagnosis.

We have been pleased to be able to continue with our small grants programme throughout the pandemic. Many of the researchers who are awarded grants are at the start of their career and although the amounts of money are relatively small, they can make a real difference to both the researcher and the knowledge we have about APS.

We can also report a growing involvement with national and international research as a number of scientific teams ask to connect to our patient group. This year, this has included requests from EULAR, the European Alliance of Associations for Rheumatology; EURORDIS – the Rare Diseases Group for Europe; and ERN-ReCONNET - the European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases. In this way, we can play an important role in research that hopefully will lead to improved treatment of the condition.

All this is only possible because of the activities of our supporters, and we continue to be both amazed and grateful for the many ways in which they raise funds and help to raise awareness. We continue to distribute our newsletter online and this year have increased our presence on social media as well as improved the way our website works. We hope to build on this in the coming year.

We lost two members of the charity's board of trustees in 2022 when Andrew Pearson retired due to ill-health in January and Mike Shipley, sadly, passed away in July. We are confident that our board still has a wide skillset, but we will be looking to recruit trustees with relevant qualifications in the future. I am immensely grateful to all the trustees. Their experience and expertise are invaluable to the work of the charity, and they give generously of their time and knowledge.

I would also like to place on record my thanks to the APS Support UK team: Kate, Claire and Nancy whose work and commitment is central to what we are able to achieve.

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



A handwritten signature in blue ink, which appears to read 'Estelle'.

Baroness Estelle Morris
Chair of APS Support UK

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; we always do our utmost to help those affected by antiphospholipid syndrome (APS).

Early diagnosis **saves lives**

Our Objectives

APS is a life-threatening autoimmune disease that causes the blood to clot too quickly. The condition can cause potentially 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
- 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 section below. The directors confirm that they have paid due regard to the Charity Commission guidance on public benefit before deciding which activities the charity should undertake.



Phil Godfrey

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 lungs.

In pregnancy, APS is the most important treatable cause of recurrent miscarriage, and it 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

COVID-19 Impact in 2022

As with 2020 and 2021, our charity continued to be impacted by the global COVID-19 pandemic, particularly in the first quarter of the year. Although restrictions in the UK were mainly lifted by March, our charity's resources continued to be stretched mainly due to patient enquiries predominantly regarding vaccines, the suitability of antivirals and the reasons why antiphospholipid antibodies are associated with COVID and what this means for patients.

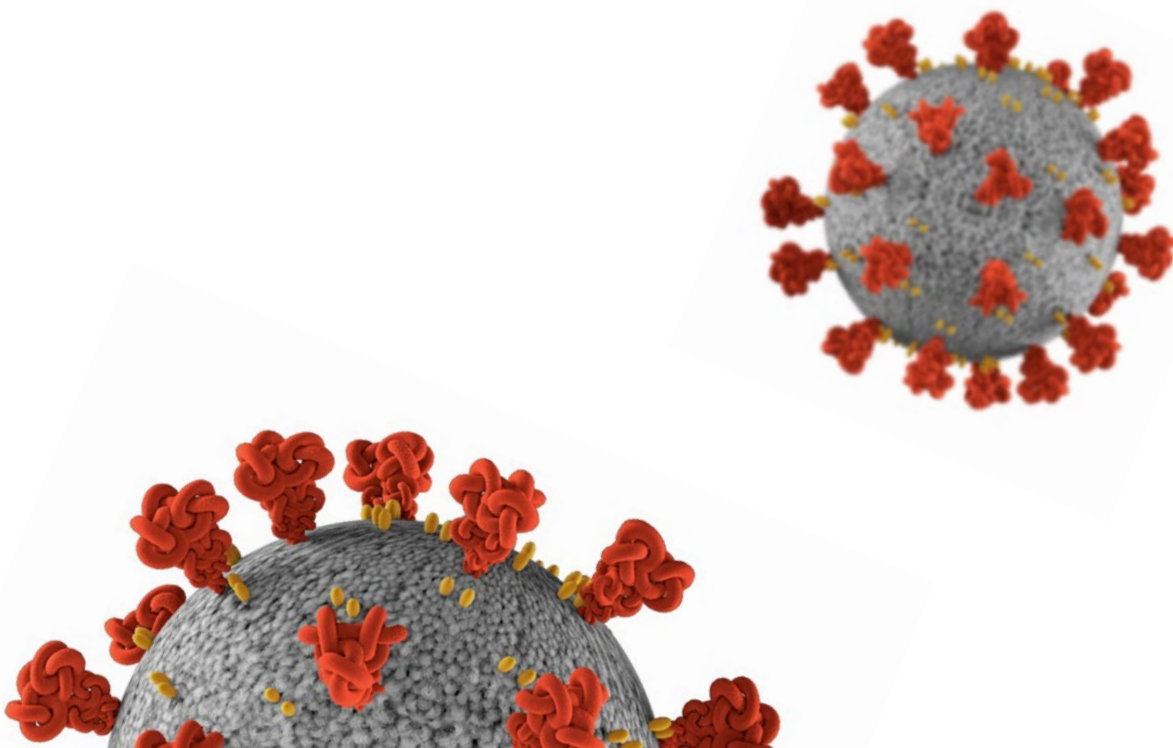
Fortunately, several scientific papers about APS and COVID were published in 2022 which made it clear the international research community is prioritising this subject; this helped us allay some of the worries of the APS community and reassured people that they are not being ignored.

For example: researchers at Michigan Medicine and the National Heart, Lung, and Blood Institute studied the blood samples of nearly 250 patients hospitalized for COVID-19: <https://www.michiganmedicine.org/health-lab/rogue-antibodies-make-cells-sticky-trigger-blood-clots-covid-19-patients>.

While another group of scientists found that patients with triple-positive thrombotic APS did not suffer from severe COVID-19 outcomes and, more importantly, the COVID-19 vaccine was well tolerated. The authors concluded that "these data may reassure patients and physicians and contribute to reducing hesitancy in unvaccinated patients": <https://pubmed.ncbi.nlm.nih.gov/35412604/>.

This research was supported by another scientific paper, published in the Rheumatology Oxford, that found "the COVID-19 vaccine does not increase the risk for prothrombotic antibody-induced thrombotic events among patients with antiphospholipid syndrome (APS)": <https://www.rheumatologyadvisor.com/home/general-rheumatology/covid-19-vaccine-does-not-raise-thrombotic-risk-in-antiphospholipid-syndrome/>.

Overall, 2022 was yet another very busy year for APS Support UK as we continued to deal with large increase in workload due to COVID-19 enquiries and the dissemination of COVID-related research articles to the APS community.



Charity objectives achieved in 2022

Raising awareness of APS in the medical community

British Society of Haematology new guidelines

We were contacted by the British Society of Haematology (BSH) in January 2022 who asked us to review the draft Guidelines for Thrombophilia Testing and accompanying appendix that are now included the new BSH guidelines. Our Medical Advisors agreed to do this pro bono work because they felt that the draft was very useful and would be beneficial to people with APS; they noted that the guidelines were extremely clear about when people should be tested for antiphospholipid antibodies.

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

One of our volunteer ambassadors, Yvonne Wren, is an Expert Patient and she kindly gave a talk entitled 'A Patient Journey – Living with Autoimmunity' to the post-graduate students at the Faculty of Biology, Medicine and Health at Manchester University in February 2022. As with the previous year, Yvonne could not visit in person due to the pandemic, so it was conducted via Zoom. The feedback from the course leader, Nicholas Barnes, who is a Lecturer in Healthcare Science (Clinical Immunology) at Manchester University, was excellent and Yvonne has been invited back to give another talk in 2023.

Royal College of Midwives' APS course

Following on from our progress with this project in 2021, we were delighted that the APS module was the first online course to be launched on the new Royal College of Midwives' i-learn platform. It was launched in July 2022 and was the RCM's 'course of the month'.

The course is accessible to all members of the Royal College of Midwives, and we have a page on our website describing our partnership with the RCM, and the benefits of the course for both midwives and patients. We will monitor the uptake during 2023.

Contribution and review of MedlinePlus Genetics website content

In February 2022, we were contacted by MedlinePlus as they had recently teamed up with Genetic Alliance, which is an information resource developed and maintained by the National Library of Medicine. The goal of this collaboration is to review and suggest updates to the genetics information available on the MedlinePlus website.

MedlinePlus is now the new home of Genetics Home Reference. The content from Genetics Home Reference is featured in a new section called MedlinePlus Genetics. The merger adds more than 1,300 genetic conditions summaries to MedlinePlus; another section on MedlinePlus contains pages about a variety of health topics, including genetic conditions.

Medline Plus reached out to APS Support UK because they wanted our help to review the content for their description of antiphospholipid syndrome, which we did and then shared via our communication channels. The new content can be viewed here: <https://medlineplus.gov/genetics/condition/antiphospholipid-syndrome/>.

Charity objectives achieved in 2022

Raising awareness of APS in the medical community

Royal College of GPs online course

As mentioned in the Future Plans of our 2021 Annual Report, the trustees agreed to assess whether the charity should continue to fund the online course for GPs. We have funded this course on the learning platform of the Royal College of GPs, and it has been free for all healthcare professionals to access and complete since 2017.

As almost 1,000 healthcare professionals have taken and completed this course with an improvement of approximately 40% in their knowledge, it was agreed that the charity should continue funding the course at a cost of £6,000 for a further three years as it is a very worthwhile educational tool.

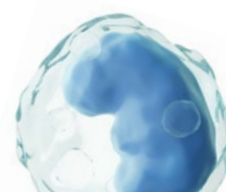
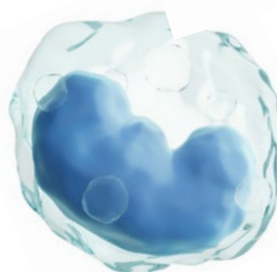
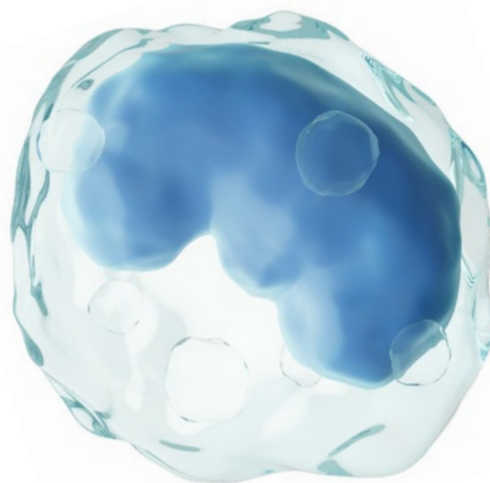
International Congress on Antiphospholipid Antibodies 2022

This international meeting is held every three years and took place in Argentina in 2022. We worked with the organisers and the APS Foundation of America who kindly shared their virtual booth with us and allowed us to share information to the APS community via our channels in the UK.

We were also pleased that Dr Thomas McDonnell, a researcher to whom we have previously awarded two grants, was at the Congress in person to present the results of both these projects: Ion Mobility Mass Spectrometry to find structures in B2GPI in APS patients and Monocytes in APS. Both studies were accepted for presentation at the Congress, one as a poster and the other as a talk.



Dr Thomas McDonnell



How we achieved our objectives:

Offering information and understanding to anyone affected by APS

COVID-19 patient support

As with the last two years, 2022 saw an unprecedented number of patient enquiries made to the charity, and we did our utmost to support anyone who asked for assistance.

As mentioned earlier in this report, the main issues included queries about vaccines, the suitability of antivirals and the reasons why antiphospholipid antibodies are associated with COVID and what this means for patients.

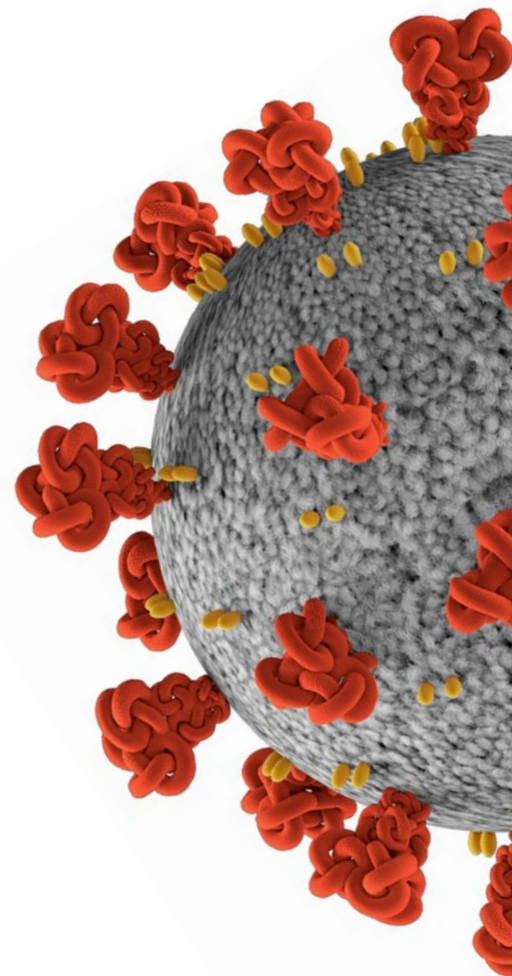
The following queries show a sample of the types of questions we received:

“Please can you confirm if there is any advice on which booster - Moderna or Pfizer is safe for APS patients?”

“When Covid vaccines came out I was told that having APS the only vaccine that was recommended was the Pfizer was the only safe one to have. Has the recommendation changed? Is it safe to have the Moderna vaccine?”

“I have a relative with APS who caught COVID about three months ago and is still not recovered. He is fully vaccinated but went on to develop pneumonia in both lungs and has had three hospital admissions in the past six weeks ... I wondered whether there are any treatment advances in the condition with use of monoclonal antibodies or anything else?”

“I have APS and I have been diagnosed with it for 2 years now, I was just wondering whether if (God forbid) I caught covid, would it affect my blood? Or the APS condition I have? How would it be treated if it did affect it?”



How we achieved our objectives:

Offering information and understanding to anyone affected by APS

APS Awareness Month

APS Support UK works in partnership with other national patient organisations to raise awareness of APS 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.

The campaign was very successful in 2022 and we shared 30 daily awareness facts and 7 Patient Stories (thanks to our website patient volunteers). The post with the highest reach at 20.9K accounts was the APS Awareness Fact #13: 'It's not just a blood clotting disorder!' and we received lots of positive comments, including:

- “ I'm so glad you've shared this... I know I have APS but googling for information is really difficult when there's not much that seems to make sense out there ”
- “ Thanks for sharing. I am reposting this wonderful content in my APS groups on the other social media. Only makes me sad and frustrated that people are taking this valuable information for granted ”
- “ Thank you for posting this. Most of my doctors are unfamiliar with APS and it's often frustrating and challenging to try to resolve or even investigate issues ”

The total reach of the daily APS Awareness Facts and Patient Story graphics in 2022 was far higher than in 2021 with 218,000 accounts being reaching this year compared to 13,100 accounts in 2021, an increase of 1,564%.

Life Insurance for people with APS

We continued to partner with Cura Insurance in 2022 with the aim of helping people with APS obtain life insurance policies; Cura Insurance is a company specialising in pre-existing medical conditions. 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.

Website enhancement: chat plug-in for visitors

In 2022, we introduced a chat plug-in on our website. The chat plug-in feature provides website visitors with a user-friendly method of contacting our organisation directly from the website. This enabled us to offer same-day responses to a significant portion of queries, ensuring that patients received timely and accurate information.

Over the course of the year, we received around 20 queries per month via the chat plug-in which highlights the value of this technology in supporting the APS community effectively.



Dr Ibrahim Tahidi-Esfahani

How we achieved our objectives:

Supporting research into APS

APS Support UK Research Fund

Our APS Research Fund is now in its fourth year. This fund offers small grants of up to £5,000 for research projects and travel awards specifically concentrating on antiphospholipid syndrome.

In 2022 we were, again, in a financial position to offer small grants to researchers, so we promoted the research applications on our website via our social media and direct communication channels early in the year.

As with the last two years, we extended the closing date from 15th April 2022 to 15th June 2022 due to the pressures caused by the pandemic. All applicants were asked to submit additional information on how the COVID-19 pandemic might affect their research proposal and whether they would still be able to conduct the research as outlined in their applications.

We were very fortunate to receive extra funding in 2022 when the Sonia Marsh Trust kindly donated £5,000 specifically for small research projects into APS. This family trust was set up by James Marsh, his two sons, daughter-in-law and grandchildren in memory of James' wife, Sonia, who had APS and died after suffering a stroke.

As with previous years following the pandemic and the subsequently effect on the UK research community, we only received one grant application in 2022. This application was evaluated by our charity's Medical Vice Chairs, Professors David D'Cruz and Anisur Rahman, and the charity awarded £5,000 to:

- Dr Ibrahim Tohidi-Esfahani from University College London to work on the project entitled: 'Complement activation in antiphospholipid syndrome patients with ischaemic stroke or other ischaemic brain injury: a therapeutic target?'

As the Sonia Marsh Trust had kindly donated £5,000 for this project, we put the Trust in touch with Dr Tohidi-Esfahani so they can keep up with the progress of the project directly.

Development and Validation of a EULAR disease activity score in antiphospholipid syndrome

EULAR, the European Alliance of Associations for Rheumatology formerly known as the European League Against Rheumatism, is a European non-governmental organisation which represents the people with arthritis/rheumatism, health professional and scientific societies of rheumatology of all the European nations.

In September 2022, we were contacted by Maria Tektonidou, Professor of Rheumatology at the University of Athens in Greece, as she was chairing a new project for EULAR called "Development and Validation of a EULAR disease activity index for antiphospholipid syndrome". The aim of this project is to create a tool that will help clinicians to detect and rate disease activity and its changes over time and allow investigators to assess the efficacy of treatments in clinical studies. It's the first of its kind for APS.

To assist with the project, the taskforce will be conducting surveys among patients, physicians and other health care professionals. On this occasion, Professor Tektonidou asked us to share a survey called "Item Reduction" on our communication channels with physicians and patients; the aim of this survey was to reduce items identified from a systematic literature review and responses to a previous survey to those considered key features to assess disease activity in APS.

How we achieved our objectives:

Supporting research into APS

European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases: APS and pregnancy patient survey

The European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases (ERN- ReCONNET) aims to improve the management of rare connective tissues diseases (rCTDs), including antiphospholipid syndrome, by:

- Realising the potential of European co-operation among rCTDs stakeholders
- Providing highly specialised care for rCTDs patients and promoting improvements in the cost-effective delivery of diagnosis, management and monitoring of rCTDs patients
- Pooling, advancing and exchanging knowledge and information of rCTDs by providing training and education to stakeholders
- Stimulating and encouraging collaborative patient-centred research in rCTDs
- Promoting the empowerment and involvement of rCTDs patients in the rCTDs community

In 2022, we partnered with ERN-ReCONNET when they asked us to share a survey with our patient group on social media. This survey was aimed at patients and caregivers to find the unmet needs relating to APS pregnancy and family planning. The results of this survey will be used to understand what the main unmet needs are and help to plan new initiatives on pregnancy and family planning in rare diseases, such as education programmes for patients, families and healthcare professionals.

EURORDIS – Rare Diseases Europe APS patient survey

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 1,000 rare disease patient organisations from 74 countries that work together to improve the lives of over 300 million people living with a rare disease globally.

We partnered with EURORDIS this year to share a survey with our patient group with the aim of improving diagnosis time for rare diseases. They asked us to contact people with APS so they could learn about their experiences of receiving a diagnosis; we did this via all our communication channels.



Karim & Hannah

Our Impact in 2022



Our Impact in 2022

Website

In 2022, we had 528,307 page views compared with 511,541 in 2021, a 3.28% increase. Interestingly, we had 42,042 users from the United States compared with 36,445 from the United Kingdom. In terms of demographics, the majority of visits were from female users aged between 25-34. Additionally, over 82% of all website visits were accessed on a mobile device.

528,307 page views

The Home, Symptoms and Pregnancy pages were the three most popular pages viewed in 2022, making up

45% of all website visits

In 2022, we prominently featured volunteer Patient Stories on our website and social media. These narratives serve as a testament to the real-life experiences of people with APS, shedding light on the challenges, triumphs and resilience they embody. By sharing these personal journeys, we aim to create a sense of community and solidarity among APS patients making them feel less isolated and more empowered to manage the complexities of their condition. Our Patient Stories' page had 7,151 views in 2022 compared with 6,609 in 2021;

an increase of **8.2%**

We are reassured that our website continues to be viewed, both nationally and internationally, as a trustworthy, timely and reliable source of APS information.

APS Support UK website linked from the National Health Service website

Thanks to our Digital Marketing trustee, Chris Mansbridge, a link to our website was included on the NHS website main webpage about antiphospholipid syndrome: <https://www.nhs.uk/conditions/antiphospholipid-syndrome/> in October 2022. This has led to an increase in website traffic and helps support more APS patients.

Our Impact in 2022

Social media

Our social media platforms continued to do well throughout 2022, and we posted daily articles offering information and hope to the APS community via Facebook, Twitter and Instagram. These posts receive lots of visitor comments and provide us with a way to communicate directly and regularly with people who are affected by APS; in turn, this allows us to gauge what is important to the community and which topics we need to focus on.

We started an APS Support UK Instagram account towards the latter end of 2021, so we were keen to monitor audience engagement during 2022.

We were pleased to note that, this year, our Instagram account achieved a reach of 13,526, an increase of 245.7% from the previous year. We also received 3,817 profile visits, an increase of 267%.

We were particularly pleased with the feedback, and below are some of the comments:

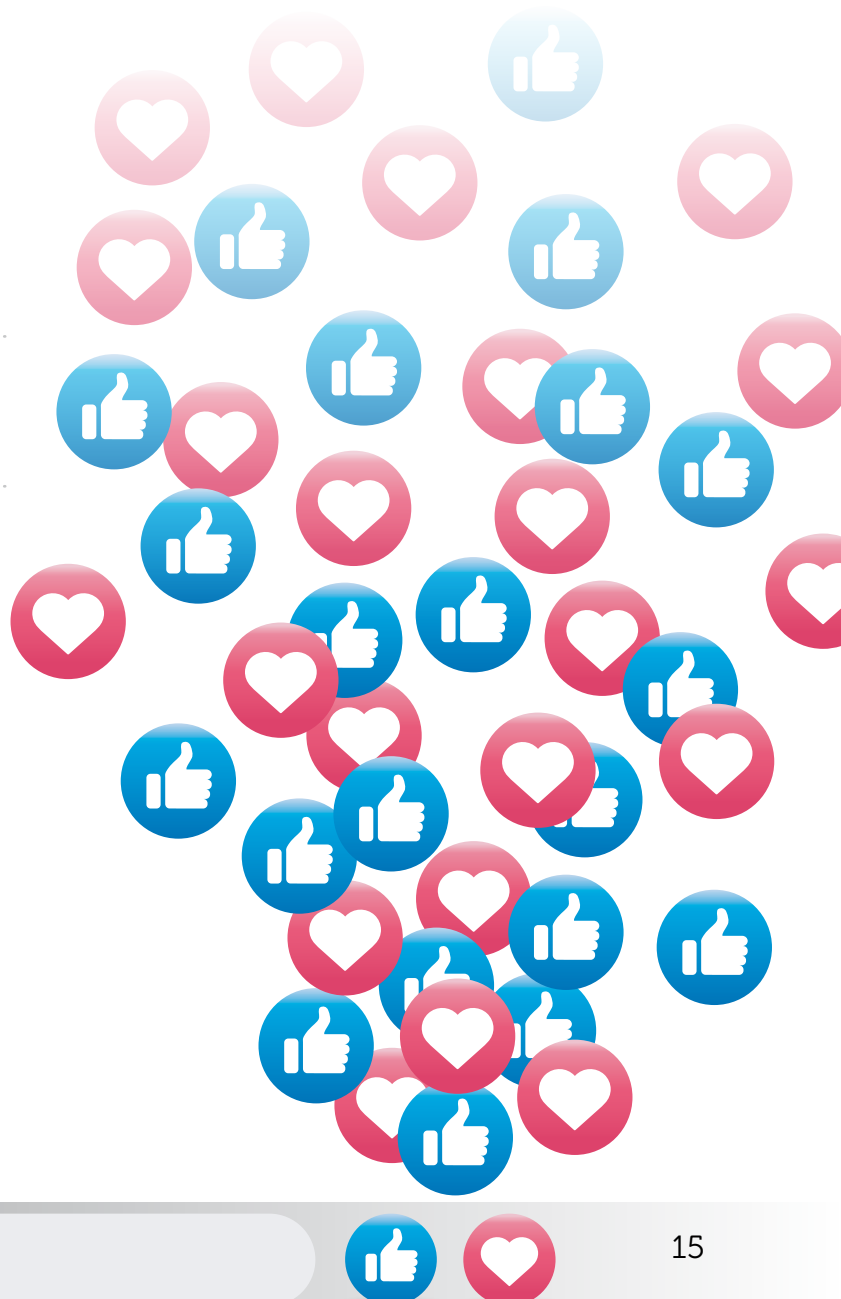
“I’ve had APS for 10 years now, and catastrophic APS in 2020...Everything I’ve read on this site is 100% spot on.”



13,526 reach
an increase of 267%

“Hi there! Thanks for sharing. I am reposting this wonderful content in my APS groups on other social media...Your content has always helped me so much.”

“I’m so glad you’ve shared this... I know I have APS, but googling for information is really difficult when there’s not much that seems to make sense out there.”



Our Impact in 2022

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 online module, help with complex enquiries and can contact their peers, if necessary, on specific APS subjects.

As we have fostered good collaborative connections with other charities, teaching hospitals and leading APS experts, we can call on their professional help when needed. For example, Thrombosis UK and LUPUS UK generously continue to share their information and resources with our charity.

We are also 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. We were delighted when Phil was awarded the Paul Harris Fellowship from the Rotary Club in Solihull in 2022. 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>. In 2022, we appealed for more stories and were amazed by the response so would like to thank Shelby Clifford, Garry Hellings, Kerry Kilsby, Keith Lewis and Sarah Rowe for their stories this year.



Liz Alexander



Suzie Kilsbullen

Our Impact in 2022

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.

Chris Mansbridge successfully applied for Google Grants for Non-profits which means that our charity can spend a \$10,000 a month grant on Google Ads campaigns. This has allowed us to develop a Google Ad Campaign for APS and associated search topics such as 'miscarriage' and 'blood clots'. This means that people searching these terms are directed to our website, so that awareness of APS increases and more people can be offered information and support.

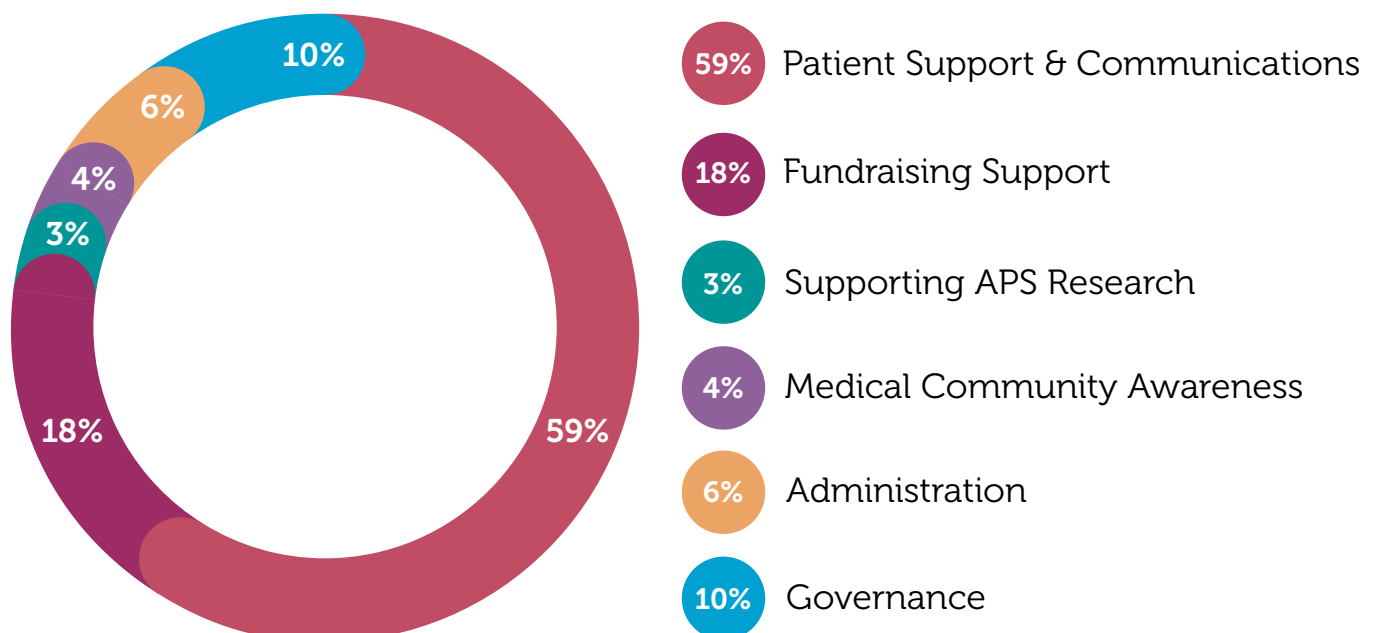
Supporting patients through charitable activities

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

As with the previous two years, COVID-19 enquiries took up a lot of our resources in terms of offering patient support, particularly in the first part of the year. We were also able to disseminate research surveys to the APS patient community which assisted scientists with a number of important projects.

To ensure that the charity's resources are spent wisely, the Management Team record and log the time spent on charitable activities, and the results for 2022 are shown below:

Charity's staff activity breakdown 2022



Our Impact in 2022

APS in the news 2022

Since the pandemic struck, there has been a significant increase in the number of scientific articles published relating to antiphospholipid antibodies (aPL) and antiphospholipid syndrome in recent years. In 2022, there were 693 research articles published relating to APS compared to 542 in 2019: an increase of 28% within three years.

As mentioned earlier in this report, the scientific community is currently very focused on antiphospholipid antibodies/syndrome due to the connection with COVID. We hope this level of research continues to us a greater insight into APS.

In the mainstream media, we supported the singer, Christina Perri, by sharing her posts on all our social media channels. Sadly, Christina has suffered baby loss due to APS and is campaigning to raise awareness of her condition.

There were also a number of APS-related articles in the national, online and local media throughout 2022, including an article by our Ambassador, Phil Godfrey, who had two-page article published in the national Rotary Club magazine: <https://www.rotarygbi.org/magazine/february-march-2022/doing-it-for-christine/>.



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 2022:

- Anticoagulation UK - sadly, this charity closed in June 2022
- APS ACTION
- APS Foundation of America
- APS Foundation of Australia
- Baby Loss Awareness Week 2022
- Different Strokes
- Eat on warfarin
- European Alliance of Associations for Rheumatology
- EURORDIS – Rare Diseases Europe
- German APS Support Group
- International Congress on Antiphospholipid Antibodies 2022 hybrid meeting in Argentina
- LUPUS UK
- Mama Academy
- Mexican APS group on Facebook - we agreed they could share and disseminate our APS infographics
- National Institute for Health and Care Excellence - we reviewed and contributed to the 'Stroke and TIA in over 16s' guidelines
- Philippines APS Support Group
- Prescription Charges Coalition
- Small Charity Coalition – sadly, this organisation closed in March 2022
- 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 2022, we want to express our heartfelt appreciation to our dedicated network of supporters, generous donors, volunteers, collaborators and passionate ambassadors.

Each one of you played a pivotal role in advancing the mission of APS Support UK; whether it was through your financial contributions, sharing your APS journeys, providing expert medical advice or 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 more successful 2023, with you by our side.



Our intrepid ambassador

THANK YOU

Future plans for 2023

New website

We are planning to redevelop our website as the current one is over ten years old and navigation was based on people predominantly using a desktop computer to access it. As we now know that over 82% of our website visitors use mobile devices, it is time for the charity to redesign and simplify the pages and content so that people can find information as easily as possible.

Assessing the potential need for other medical online courses

Following the success of our online APS course partnerships with the Royal College of GPs and the Royal College of Midwives, we intend to monitor the uptake of these courses and identify any unmet needs for possible future online courses by collating our patient enquiries during 2023. The aim is to assess whether there is a need to produce other discipline-specific courses in the future.

Facilitating research collaboration by liaising with our patient group

Throughout 2022, we were involved in a number of research projects where we enabled scientists to connect to our patient group by liaising between them, usually on social media but sometimes via our direct communication channels. We would like to continue in this useful role and work with international organisations, if possible, in 2023.

APS Research Fund awards

We intend to continue offering small grants again in 2023 and will make the application process available on our website at the beginning of the year with a deadline of 15th April 2023. We will advertise the grants through all our communications channels.

Legal and Administrative Information

The Trustees present their final report and the audited financial statements for the year ended 31 December 2022.

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 2022 - 31st December 2022

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
Dr Andrew Pearson (retired due to ill-health 11th January 2022)
Mr James Turner
Dr Michael Shipley (deceased 15th July 2022)
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 in 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.

So far as the trustees are aware, there is no relevant audit information (information needed by the company's auditors in connection with preparing their report) of which the company's auditors are unaware. Each trustee has taken all the steps that he ought to have taken as a trustee in order to make themselves aware of any relevant audit information and to establish that the company's auditors are aware of that information.

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 2022, the charity made a surplus of £13,849 (2021: £61,761). Income totalled £91,541 (2021: £128,035), with expenditure of £77,692 (2021: £66,274).

Total funds at 31 December 2022 are £287,624 (2022: £273,775), of which £93,000 (2021: £93,000) relate to designated funds, with £50,182 (2021: £60,663) relating to restricted funds. £73,000 of designated funds (2021: £73,000) relate to the designated reserve explained in the reserve policy. General funds total £144,442 (2021: £120,112). 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.

The trustees acknowledge their general legal duty to spend income within a reasonable time of receipt and to do so in the charity's best interest, and hence it is not the charity's policy to hold excessive reserves above and beyond those that are prudent. Our reserve policy is in accordance with the provisions of CC19.

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 2022, 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).

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 2022

Including Income and Expenditure Account

INCOMING RESOURCES

	Notes	Unrestricted Funds	Restricted Funds	2022 TOTAL	2021 TOTAL
Donations and legacies		£55,166	£4,830	£59,996	£95,163
Charitable activities		£28,718	£1,280	£29,998	£31,894
Investment income		£1,529	-	£1,529	£978
Other income		£18	-	£18	-
TOTAL INCOME	3	£85,431	£6,110	£91,541	£128,035

EXPENDITURE

	Notes	Unrestricted Funds	Restricted Funds	2022 TOTAL	2021 TOTAL
Raising funds		£2,582	-	£2,582	£1,024
Charitable activities		£58,519	£16,591	£75,110	£65,250
TOTAL EXPENDITURE	4	£61,101	£16,591	£77,692	£66,274

NET INCOME / (EXPENDITURE) FOR THE PERIOD

	Notes	Unrestricted Funds	Restricted Funds	2022 TOTAL	2021 TOTAL
TOTAL NET INCOME		£24,330	(£10,481)	£13,849	£61,761

FUNDS

	Notes	Unrestricted Funds	Restricted Funds	2022 TOTAL	2021 TOTAL
Funds at 1 January 2022		£213,112	£60,663	£273,775	£212,014
FUNDS AT 31 December 2022	6	£237,442	£50,182	£287,624	£273,775

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 activities year ended 31 December 2021

Including Income and Expenditure Account

INCOME

	Notes	Unrestricted Funds	Restricted Funds	2021 Total
Donations and legacies		£63,433	£31,730	£95,163
Charitable activities		£31,894	-	£31,894
Investment income		£978	-	£978
TOTAL INCOME	3	£96,305	£31,730	£128,035

EXPENDITURE

	Notes	Unrestricted Funds	Restricted Funds	2021 Total
Raising funds		£1,024	-	£1,024
Charitable activities		£57,310	£7,940	£65,250
TOTAL EXPENDITURE	4	£58,334	£7,940	£66,274

NET EXPENDITURE FOR THE PERIOD

	Notes	Unrestricted Funds	Restricted Funds	2021 Total
NET INCOME FOR THE PERIOD		£37,971	£23,790	£61,761

FUNDS

	Notes	Unrestricted Funds	Restricted Funds	2021 Total
Funds at 1 January 2021		£175,141	£36,873	£212,014
FUNDS AT 31 December 2021	6	£213,112	£60,663	£273,775

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 2022

CURRENT ASSETS

	Notes	2022		2021	
Gift aid recoverable		£6,750		£18,113	
Cash at bank and in hand	9	£282,171		£256,869	
		£288,921		£274,982	

CREDITORS

	Notes	2022		2021	
Amounts falling due within one year Accruals		(£1,297)		(£1,207)	
NET ASSETS	8		£287,624		£273,775

FUNDS

	Notes	2022		2021	
Restricted funds	6		£50,182		£60,663
Unrestricted funds					
General funds	6		£144,442		£120,112
Designated funds	6		£93,000		£93,000
TOTAL FUNDS			£287,624		£273,775

For the financial period ended 31 December 2022, 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 27 September 2023
and signed on its behalf by

J Turner
Trustee

Notes to the accounts for the year ended 31 December 2022

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 2023), 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 gift to which they relate.

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 2022

3. INCOMING RESOURCES

Donations & Legacies	Unrestricted Funds	Restricted Funds	2022 TOTAL	2021 TOTAL
Donations	£51,675	£4,830	£56,505	£75,063
Legacies	£1,000	-	£1,000	-
Gift aid recoverable	£2,491	-	£2,491	£20,100
TOTAL	£55,166	£4,830	£59,996	£95,163

Charitable activities	Unrestricted Funds	Restricted Funds	2022 TOTAL	2021 TOTAL
Fundraising income	£18,701	£1,280	£19,981	£30,470
Membership renewals	£10,017	-	£10,017	£1,424
TOTAL	£28,718	£1,280	£29,998	£31,894

Investment Income	Unrestricted Funds	Restricted Funds	2022 TOTAL	2021 TOTAL
Bank Interest	£1,529	-	£1,529	£978
TOTAL	£1,529	-	£1,529	£978

Other Income	Unrestricted Funds	Restricted Funds	2022 TOTAL	2021 TOTAL
Sundry Income	£18	-	£18	-
TOTAL	£18	-	£18	-

	Unrestricted Funds	Restricted Funds	2022 TOTAL	2021 TOTAL
TOTAL INCOME	£85,431	£6,110	£91,541	£128,035

Notes to the accounts for the year ended 31 December 2022

4. EXPENDITURE

Raising funds	Unrestricted Funds	Restricted Funds	2022 TOTAL	2021 TOTAL
Fundraising costs	£2,582	-	£2,582	£1,024
TOTAL	£2,582	-	£2,582	£1,024

Charitable activities	Unrestricted Funds	Restricted Funds	2022 TOTAL	2021 TOTAL
Staff costs	£46,927	-	£46,927	£49,535
Insurance costs	£680	-	£680	£679
Office costs	£1,956	-	£1,956	£674
Raising awareness	£2,894	£ 10,560	£13,454	£5,247
Rent	£4,104	-	£4,104	£4,104
Legal and professional fees	£571	-	£571	£372
Accountancy	£1,387	-	£1,387	£1,304
Grants paid	-	£6,000	£6,000	£3,335
Bank charges	-	£ 31	£31	-
TOTAL	£58,519	£16,591	£75,110	£65,250

	Unrestricted Funds	Restricted Funds	2022 TOTAL	2021 TOTAL
TOTAL EXPENDITURE	£61,101	£16,591	£77,692	£66,274

The independent examination fee included in accountancy amounted to £1,387 (2021: £1,304).

Grants of £nil (2021: £nil) were paid as part of the Louise Gergel Fellowship Project.

Grants of £6,000 were paid to the Royal College of General Practitioners.

Grants of £3,335 were paid to the University of Kent in the prior year.

Notes to the financial statements for the year ended 31st December 2022

5. EMPLOYED STAFF COSTS AND NUMBERS

	2022 TOTAL	2021 TOTAL
Salaries and wages	£44,985	£47,482
Social security costs	£590	£631
Pension	£1,352	£1,422
TOTAL	£46,927	£49,535

No employee earned more than £60,000 during this or the prior period. The total number of employees during the period was 2 (2021: 2).

Key management were paid remuneration totalling £42,850 (2021: £41,873).

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

Trustees' indemnity insurance of £228 (2021: £228) for the Board of Trustees was paid during the year.

Notes to the accounts for the year ended 31 December 2022

6. MOVEMENT IN FUNDS

Restricted funds	At 1 January 2022	Income	Expenditure	Transfers	At 31 December 2022
Louise Gergel Fellowship	£19,120	£280	(£31)	-	£19,369
Research and Projects Fund	£23,648	£1,830	(£6,000)	-	£19,478
APS Research Fund	£5,000	£4,000	-	-	£9,000
Digital Media Assistant	£12,895	-	(£10,560)	-	£2,335
TOTAL	£60,663	£6,110	(£16,591)	-	£50,182

Designated funds	At 1 January 2022	Income	Expenditure	Transfers	At 31 December 2022
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 2022	Income	Expenditure	Transfers	At 31 December 2022
General funds	£120,112	£85,431	(£61,101)	-	£144,442
TOTAL	£273,775	£91,541	(£77,692)	-	£287,624

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 initiatives 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 £5,000 to APS-specific research projects on a yearly basis.

Digital Media Assistant

This fund represents monies received to engage a digital media assistant to oversee the social media presence and search engine optimisation of the charity.

Notes to the accounts for the year ended 31 December 2021

6. MOVEMENT IN FUNDS - PRIOR YEAR FUNDS MOVEMENTS

Restricted funds	At 1 January 2021	Income	Expenditure	Transfers	At 31 December 2021
Louise Gergel Fellowship	£17,940	£1,180	-	-	£19,120
Research and Projects Fund	£18,933	£8,050	(£3,335)	-	£23,648
APS Research Fund	-	£5,000	-	-	£5,000
Digital Media Assistant	-	£17,500	(£4,605)	-	£12,895
TOTAL	£36,873	£31,730	(£7,940)	-	£60,663

Designated funds	At 1 January 2021	Income	Expenditure	Transfers	At 31 December 2021
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 2021	Income	Expenditure	Transfers	At 31 December 2021
General funds	£82,141	£93,305	(£58,334)	-	£120,112
TOTAL	£212,014	£128,035	(£66,274)	-	£273,775

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.

Notes to the accounts for the year ended 31 December 2022

7. RELATED PARTY TRANSACTIONS

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

8. ANALYSIS OF NET ASSETS BETWEEN FUNDS

2022	Restricted funds	Designated funds	Unrestricted funds	2022 Total funds
Current assets	£50,182	£93,000	£145,739	£288,921
Current liabilities	-	-	(£1,297)	(£1,297)
NET ASSETS	£50,182	£93,000	£144,442	£287,624

2021	Restricted funds	Designated funds	Unrestricted funds	2021 Total funds
Current assets	£60,663	£93,000	£121,319	£274,982
Current liabilities	-	-	(£1,207)	(£1,207)
NET ASSETS	£60,663	£93,000	£120,112	£273,775

9. CASH AT BANK AND IN HAND

Bank balances are held as follows:

	2022	2021
NatWest current account	£56,929	£57,417
NatWest deposit account	£32,628	£32,557
Shawbrook bank	£30,561	£30,419
Cambridge and Counties	£82,046	£56,028
Hampshire Bank	£60,298	£60,000
Louise Gergel account	£19,369	£19,120
PayPal	£340	£1,328
TOTAL	£282,171	£256,869

Accounts



APS Support UK

For people with antiphospholipid syndrome



Paula takes to the skies!



Rosie does TrekFest



The Sonia Marsh Trust



Hannah & Karim Newport 10k

Overview

Antiphospholipid syndrome (APS) is a 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.



Tom Cottey's Bike Ride



In Memory of Sue

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; we always do our utmost to help those affected by antiphospholipid syndrome (APS).

Early diagnosis **saves lives**

Our Objectives

APS is a life-threatening autoimmune disease that causes the blood to clot too quickly. The condition can cause potentially 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
- 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 section 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.



Phil Godfrey

COVID-19 Impact in 2021

Throughout 2021, our charity continued to be severely impacted by the global COVID-19 outbreak. In the previous year, our resources had been stretched very thinly due to a surge of patient enquiries, and these did not abate during 2021.

One of the reasons for this was published research indicating that people with rare autoimmune conditions were at more risk of dying from COVID: <https://www.nottingham.ac.uk/news/rare-autoimmune-diseases-covid-19-pandemic> and that dangerous new coronavirus strains may incubate in APS patients: <https://www.latimes.com/science/story/2021-01-30/long-term-covid-19-patients-are-incubating-dangerous-new-coronavirus-strains>. Not surprisingly, such reports caused concern amongst APS patients.

This was compounded by the UK government changing the information regarding the suitability and safety of vaccines for people with APS. Until 7th April 2021, the government advice from the UK's Medicines and Healthcare products Regulatory Agency (MHRA) and the Joint Committee on Vaccination and Immunisation (JCVI) has been that each of the available COVID vaccines can be used in any patient group.

There was no evidence to suggest that patients with APS were at increased risk of complications from any of the available COVID vaccines. However, on 7th April 2021, the government released new guidance based on the analysis of a small number of people who had suffered very rare adverse events of clots and low platelets in patients who received the first dose of the Astra Zeneca vaccine.

This [updated guidance from the MHRA](#) states that as "a precautionary measure, administration of the COVID-19 Vaccine AstraZeneca in patients with a history of cerebral venous sinus thrombosis or antiphospholipid syndrome should only be considered when the benefit outweighs any potential risks".

Unfortunately, this rather ambiguous guidance led to an alarming situation where APS patients were given conflicting advice by healthcare practitioners and vaccination centres; inevitably, this led to some people missing their important second vaccination jabs.

APS Support UK persistently pressed for clear, updated guidance from the authorities. On 8th June 2021, the JCVI advised that those who have received their first dose of AstraZeneca vaccine without suffering the rare side-effect of a major blood clot occurring at the same time as having low levels of platelets should continue to be offered the second dose to complete the course.

The government also provided a specific section about APS and the vaccination on the GOV.UK website for people with APS titled: '[Can people with antiphospholipid syndrome have the vaccination?](#)'

Despite this time-consuming issue and the resulting massive increase in workload, APS Support UK still managed to meet all our main objectives.

Charity objectives achieved in 2021

Raising awareness of APS in the medical community

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

One of our volunteer ambassadors, Yvonne Wren, is an Expert Patient, and she gave a talk entitled 'Living with APS – a patient's perspective' to the post-graduate students at the Faculty of Biology, Medicine and Health at Manchester University in February 2021. Unlike the previous year, Yvonne could not visit in person due to the lockdown, so it was conducted via Zoom.

Campaign to change recurrent miscarriage guidelines

The charity Tommy's, published in the Lancet that the miscarriage service in the UK is "not fit for purpose and needs overhauling". We contacted them, and they agreed that we could join their campaign and added us to their collective letter to the government: <https://www.tommys.org/sites/default/files/2021-04/Letter%20to%20Health%20Secretary%2030.04.pdf>. There will be an MP lobbying campaign in the future.

APS article in the Journal of British Midwifery

The British Journal of Midwifery published an article about APS and Pregnancy written by Professor Anisur Rahman, including one of our patient's stories in June 2021 to coincide with APS Awareness Month: <https://aps-support.org.uk/storage/files/shares/pdfs/BMJ%202021%20Charity%20spotlight.pdf>.

Royal College of Midwives' APS course

From listening to our patients, it is apparent there is a need to make more information about APS available to midwives. Therefore, we held a scoping meeting in 2021 with the Royal College of Midwives to determine whether they would be interested in proceeding with this and what costs, if any, would be involved. The meeting went well, and the RCM agreed to set up an online APS midwives' course on their RCM i-Learn platform.

The RCM was happy to design and host the APS module without any fees, but the charity would be required to write the content. One of our Medical Vice Chairs, Professor Anisur Rahman, managed to recruit Bethan Goulden, an Obstetric Medicine Research Fellow working at UCL, who kindly wrote the APS online module. As part of the module includes patients' perspectives, we did an appeal on Facebook to discover what these issues were and then honed them down to create the list of key perspectives. The module has now been written, reviewed by all stakeholders, and we are now waiting to hear from the RCM when it will be launched on their i-Learn platform.



Royal College
of Midwives
i-learn

How we achieved our objectives:

Offering information and understanding to anyone affected by APS

COVID-19 patient support

As with last year, 2021 saw an unprecedented number of patient enquiries made to the charity, and we did our utmost to support anyone who asked for assistance.

As mentioned earlier in this report, the main issues included the changing of government guidelines for the safety of the Astra-Zeneca vaccine for people with APS, press reporting about links between COVID and antiphospholipid antibodies, and shielding issues.

The following queries show a sample of the types of questions we were being asked:

“ I have had my first dose of the Oxford AZ vaccine, but following the news today, I am worried about having the second dose. Are there any updated guidelines for people with APS/SLE having a second Oxford AZ vaccine? ”

“ Being a person with APS, I watched the briefing about the Astra Zeneca vaccine this afternoon. Naturally, I am concerned but realise at the age of 65, only just, and on Warfarin for life, having had the AZ vaccine first dose, what should I do? ”

“ Do you have any up-to-date guidance on which of the Coronavirus vaccines are safe for those with APS, please? I’m just asking in relation to the concerns raised in the media around the links between the Astra Zeneca vaccine and blood clots. ”

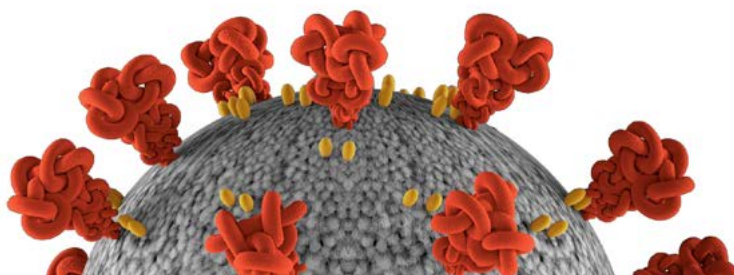
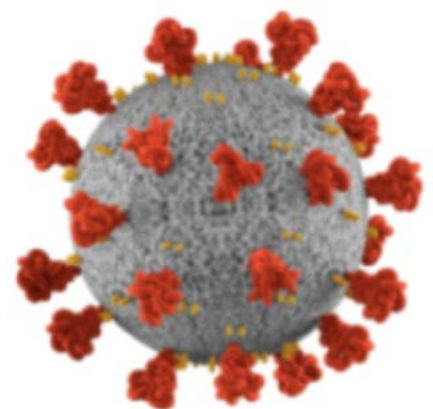
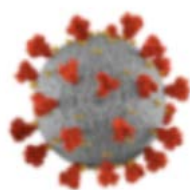
As with the previous year, there was a lot of confusion in 2021 as to whether APS patients needed to shield, which was exacerbated by the pausing and re-starting of shielding guidelines.

This prompted many queries along the lines of the following:

“ I want to know more about APS and fitness to return to the workplace in the current pandemic, so please can you advise whether we are supposed to be shielding or can go back to the workplace? ”

Along with many other rare diseases, APS was never explicitly mentioned in the guidelines, so it was often difficult to know how exactly to advise patients about shielding in a meaningful way. Some patients were identified as being at high risk of complications from COVID-19 and received a letter from their GP, hospital or the NHS national service.

After contacting the relevant authorities, we discovered that APS is not listed as a clinically extremely vulnerable medical condition, so we were able to share this with the APS community.



How we achieved our objectives:

Offering information and understanding to anyone affected by APS

University of Oxford autoimmune conditions workplace poster

We were contacted by the University of Oxford and invited to help create a workplace poster that aimed to raise awareness of the impact that infection can have on people with autoimmune diseases.

Working with other charities, such as the MS Society and LUPUS UK, we produced an information sheet for a campaign endorsed by the National Association of Disabled Staff Networks (NADSN), which is for staff working in higher education and the materials are available online: <https://www.nadsn-uk.org/immune-system-disorders-in-the-workplace/>.

APS and Stroke video

The charity, Different Strokes approached us following contact via our respective Twitter accounts and invited us to create a video with them explaining how APS can cause stroke in younger people. Our Medical Vice Chair, Professor Anisur Rahman, made a collaborative 20-minute presentation which is now available on our YouTube channel: <https://www.youtube.com/watch?v=uIWBvSWcYrA>.

Life Insurance for people with APS

It is very difficult for people with APS to obtain life insurance policies, so we partnered with Cura Insurance, a company specialising in pre-existing medical conditions. Although there is still no guarantee that people will be offered life insurance policies, we feel this is a step in the right direction. Thanks to our trustee, Chris Mansbridge, we created a free google ad campaign to promote APS and Life Insurance and now have a webpage to guide patients: <https://aps-support.org.uk/self-help/living-with-aps/aps-and-life-insurance>.

Immune system disorders: a guide

Infections can be caused by viruses, bacteria and fungi. They can be spread between people by a variety of means and do not cause a big problem if you have a working immune system. However, there are many conditions that affect the immune system in people of working age, which could make it harder to fight infection. These include but are not limited to: Diabetes, Lupus, Rheumatoid arthritis, Sjögren's Syndrome, Psoriasis, Uveitis, HIV/AIDS (caused by a virus), Multiple Sclerosis, Multiple Chemical Sensitivities, Crohn's Disease, Ulcerative Colitis, Antiphospholipid Syndrome, Myalgic Encephalopathy, Axial Spondyloarthritis, and cancer.

How many people have immune related problems?

When combined, approximately 1 in 5 working age people will have an immune related problem to differing degrees. This means that in a department of 100 people, 19 of the people around you may have an immune system problem. As most of these conditions are invisible, and cannot be detected by looking at someone, it is very likely that at least one of your friends/colleagues has a problem and you don't know about it. Many of these conditions are rare and present in a way that is not easy to identify and time to diagnosis can often take years. Up to 11 years has been reported in some cases. This makes it even more likely that someone around you has an immune system problem. Infections can be triggers of some of these conditions. Following COVID-19 there has been an increase in people diagnosed with ME and chronic fatigue syndrome, increasing the number of people even further.

How do these conditions affect the immune system and risk of infection?

There are 4 possible impacts which can occur simultaneously in an individual:

- 1) The condition reduces the ability of the immune system to function so it cannot fight infection. This is known as immunocompromised.
- 2) The immune system response is permanently increased so the individual has a frequent or constant fever.
- 3) The immune system is dysfunctional and attacks the body's own cells. This is known as autoimmunity.
- 4) The need for treatment that suppresses the immune response to dampen the immune response or inflammation, increasing the risk of severe infection. This is known as immunosuppression.

All of these result in an increased risk of infection, slow recovery, and/or possible problems with live vaccines. Infections can also cause flare up of the underlying disease or disruption in medication regime, making an infection especially devastating with long-term complications. Each infection also results in a period of self-isolation to recover. People therefore end in multiple periods of isolation which are emotionally and physically challenging as we have all experienced with COVID-19.

What else happens with immune system problems?

These depend on the underlying disease. Additional symptoms can include fatigue, chronic pain, headaches, sleep problems, difficulties with the environment such as light and scents, and many others. These symptoms can be aggravated by active infections.

What can you do to help?

Help to create a healthy working environment by protecting your co-workers. Think twice about the impact of your actions on others. If you are ill, please stay home so you do not spread the infection to others. If you have a cough or are sneezing, please consider working from home if possible. If not, keep a physical distance from others and wear a mask to reduce the spread of infection. Make an extra effort to keep asking friends and colleagues who have immune system disorders what they are comfortable with in terms of contact during these times to reduce risk and alienation. The use of sanitiser and hand washing frequently will also help to reduce the spread of infection. This will help keep environments such as home, the office, the bus, and social spaces as inclusive and welcoming to all as possible. If you have a friend, family member or colleague who has an immune system disorder and they are unwell, remember how awful isolation is and arrange to check in on them via phone or virtually as done through the pandemic. Offer to help with cooking or shopping. Be kind and courteous but do not make the individual feel as if they are a burden. Finally, do not tell someone that they look well, as this indicates you think they are clearly fine. In invisible disabilities, the outer appearance does not reflect the difficulties inside.

Thank you to all the organisations for their support in developing this information campaign. Please do click on the logos to the right to learn more.



Struggling to get life insurance? Try Cura Insurance!

We know it can be very difficult to obtain a life insurance policy if you have a diagnosis of antiphospholipid syndrome. This is why we have partnered with Cura Insurance who specialise in securing insurance policies for people with medical conditions, such as APS.

If you are interested in talking to Cura about a life insurance quote, please visit our website at cut.ly/VUalaDS or scan the QR code above. Alternatively you can contact Cura directly and give them our referral code: APSUK



How we achieved our objectives:

Supporting research into APS

APS Support UK Research Fund

Our APS Research Fund is now in its third year. This fund offers small grants of up to £5,000 for research projects and travel awards specifically concentrating on antiphospholipid syndrome.

In 2021 we were, again, in a financial position to offer small grants to researchers, so we promoted the research applications on our website via our social media and direct communication channels early in the year.

As with the previous year, we extended the closing date from 15th April 2021 to 15th June 2021 due to the pressures caused by the pandemic. All applicants were asked to submit additional information on how the COVID-19 pandemic might affect their research proposal and whether they would still be able to conduct the research as outlined in their applications.

Unlike previous years, we only received one grant application, probably due to the effect of COVID on the research community. This application was evaluated by our charity's Medical Vice Chairs, Professors David D'Cruz and Anisur Rahman, and the charity awarded £3335 to:

- Dr Karen Hambly from the University of Kent, School of Sport and Exercise Sciences to work on the project: 'Associations of sitting accumulation patterns with self-reported fatigue in adult women with primary antiphospholipid syndrome'.

The charity also agreed to help recruit patients for this study once full ethics approval had been granted. We did this by promoting the study and circulating Dr Hambly's study via social media; the quota of 50 patients was achieved in one day!



Professor Ian Giles



Dr Karen Hambly

How we achieved our objectives:

Supporting research into APS

APS Research Fund 2021 Peer Review Panel

To assist with the research funding grant-making selection process, the charity established a full Peer Review Panel in 2021 to assess the potential impact of the research on the understanding of disease mechanisms, to help increase survival rates and reduce the effects that antiphospholipid syndrome can have on the quality of life. The panel now consists of the following medical APS experts and patient representatives:

- Professor Hannah Cohen (Chair) – consultant haematologist at University College Hospital London and professor of haematology at University College London
- Professor Beverley Hunt OBE - national and international expert in thrombosis and acquired bleeding disorders based at Guys and St Thomas' Hospital in London

- Professor Ian Giles, Professor and Honorary Consultant Rheumatologist at University College London Hospital

- Lisa Thom – APS patient and representative

We'd like to thank all our volunteer Peer Review Panel for generously giving their expertise and time: <https://aps-support.org.uk/about-aps-support/research/research-grants/peer-review-panel>.



Professor Hannah Cohen



Professor Beverley Hunt OBE

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 lungs.

In pregnancy, APS is the most important treatable cause of recurrent miscarriage, and it 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

Our Impact in 2021



Our Impact in 2021

Website

In 2021 we had 215,214 website visits from 220 countries, which is a 272% increase from last year. 24% of these came from the UK, while 18% came from the United States. In terms of demographics, the majority of visits were from female users aged between 25-34. Additionally, over 79% of all website visits were accessed on a mobile device.

The Homepage, Symptoms page and COVID-19 Information, were the three most popular pages viewed in 2021, making up

215,214 website visits **51%** of all website visits

Our website traffic has increased enormously in the last two years; last year, the 207% increase in visitors was undoubtedly driven by the updates and information we provided about COVID-19 and APS. In 2021, we saw another massive increase of 272%; again, COVID and vaccine searches may be driving traffic to our website, but our increased Search Engine Optimisation and Google Ads campaigns will have been a contributing factor.

One of our Medical Vice Chairs, Professor Anisur Rahman, also asked the charity Versus Arthritis to include a link to our website which they kindly did on their APS content page: <https://www.versusarthritis.org/about-arthritis/conditions/antiphospholipid-syndrome/>.

We know that our website was viewed, both nationally and internationally, as a trustworthy, timely and reliable source of APS information throughout the pandemic. The charity received many messages of thanks, including:

“ I was just recently diagnosed with APS and so far, everybody has directed me to your website even though I don't live in the UK. I'm actually living in Australia and your website is the best source of information. ”

“ The site has been an invaluable resource, and your doctor/specialist directory is ingenious! ”

“ I just wanted to thank you for the information supplied on your website regarding AZ vaccines. ”

“ Thanks for the information. More power to your organisation! ”

Our Impact in 2021

Social Media

Throughout 2021, we had 809 new Facebook Likes: an increase of 384.4%, and we reached 8000 Likes by June 2021, which was fuelled by our APS Awareness Month graphic traffic campaign.

We also received positive comments throughout the year, including:

“Thank you so much for this (COVID update) and your continued resolve to find the best information for us”

“I’m so glad to see these two wonderful charities who have both helped me immensely working together, thank you all for your brilliant work APS Support UK - for people with antiphospholipid syndrome and Different Strokes Charity.”

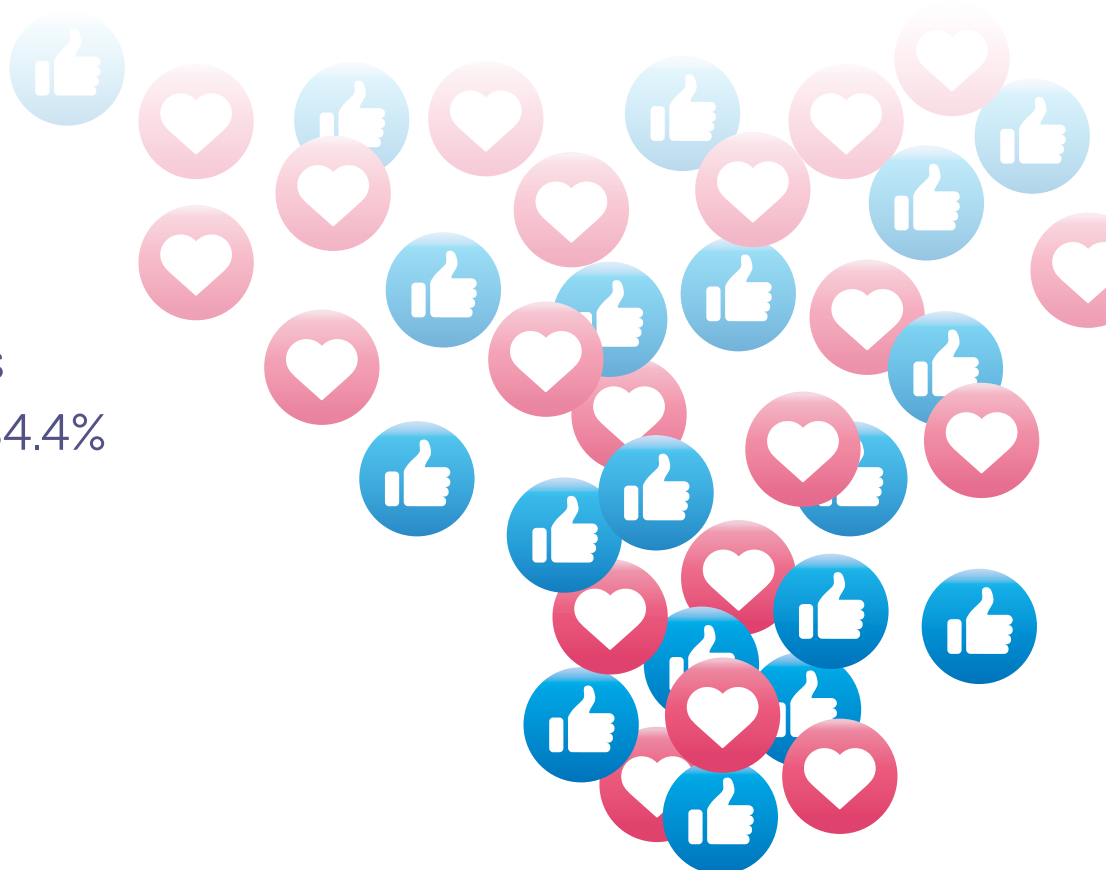
“Thank you...everyone at APS Support UK - for people with antiphospholipid syndrome for all the work you have done and continue to do for us all with APS!”

“I wanted to let you know how impressed I am with the volume of information & research that’s being published on social media by the charity. Amazing content.”

After listening to the APS community, we investigated the benefits of starting an APS Support UK Instagram account. As charities are often rich with compelling stories and imagery, we decided this would be an excellent way to raise awareness of APS and engage with a new audience. We began posting content on our Instagram account at the beginning of August 2021 and our entire reach to the end of the year was 3,934, with 1,204 profile visits. Naturally, these are early days, and we will monitor audience engagement throughout 2022.



809 new likes
an increase of 384.4%



Our Impact in 2021

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 online module, help with complex enquiries and can contact their peers, if necessary, on specific APS subjects.

In 2021, we developed our APS Research Fund Peer Review Panel thanks to Professors Hannah Cohen, Ian Giles, Beverley Hunt, and our patient representative, Lisa Thom.

As we have good collaborative connections with other charities, teaching hospitals and leading APS experts, we can call on their professional help when needed. For example, Thrombosis UK and LUPUS UK generously shared their COVID-19 information for our patient group.

We are also 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 is a major fundraiser for our charity, and we are very grateful for his continued support and incredible efforts on behalf of APS patients.

Another one of our volunteer ambassadors, Yvonne Wren, is an Expert Patient, and she regularly presents her talk 'Living with APS – a patient's perspective' to post-graduate students wherever possible.

We are also very grateful to all the wonderful volunteers who agreed to share their APS experiences on the Patients Stories section of our website: <https://aps-support.org.uk/self-help/patient-stories>. In 2021, we appealed for more stories and were amazed by the response.



Karen's Bibathon



Meltz by Megan!

Our Impact in 2021

Search Engine Optimisation and Google Ads campaign

Our Digital Media Marketing trustee, Christopher Mansbridge, has continued to make significant improvements to the charity's website, so much so that APS Support UK is now usually ranked #1 in Google rankings.

Chris Mansbridge successfully applied for Google Grants for Non-profits which meant that the charity could spend a \$10,000 a month grant on Google Ads campaigns. This allowed us to develop a Google Ad Campaign for 'APS and life insurance' plus 'APS and blood clots'. This means that people searching these terms are directed to our website, increasing awareness of APS and supporting people.

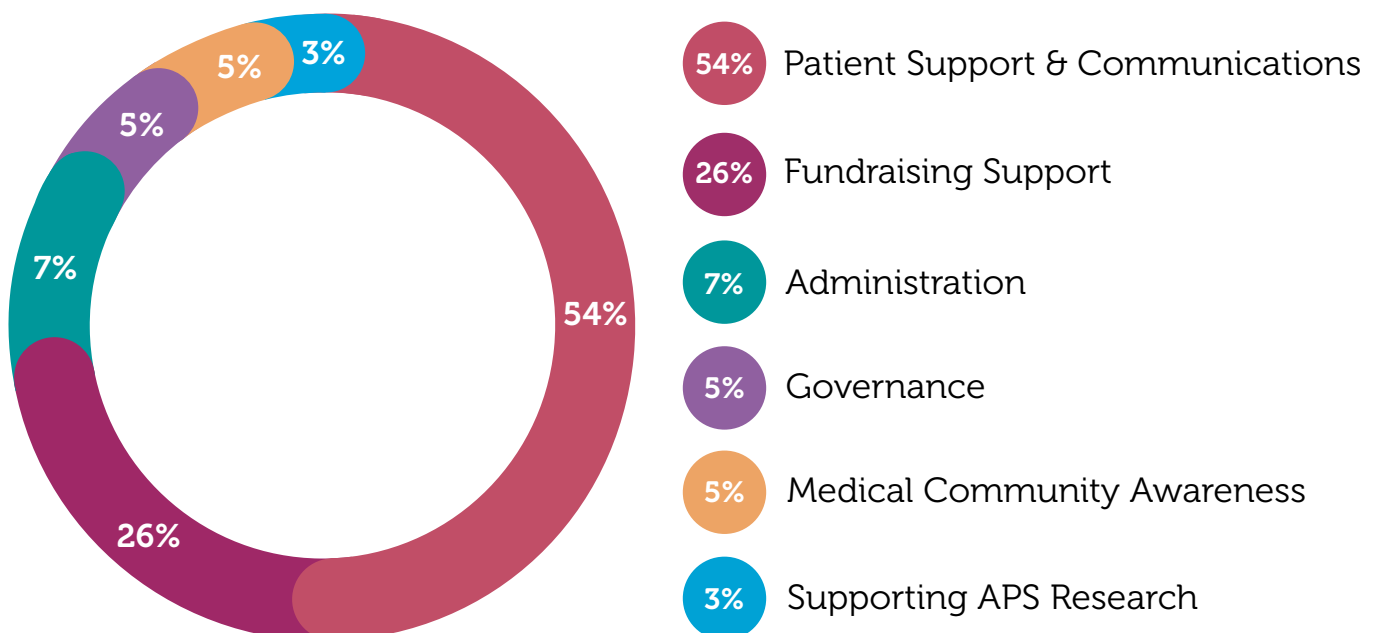
Supporting patients through charitable activities

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

As in the previous year, COVID-19 enquiries took up a lot of our resources in terms of offering patient support. However, we did manage to be more proactive in 2021 and sent out more newsletters and e-shots than in 2020, particularly alerting the APS community to any changes regarding vaccine guidelines.

To ensure that the charity's resources are spent wisely, we record and log the time spent on charitable activities, and the results for 2021 are shown below:

Charity's staff activity breakdown 2021



Our Impact in 2021

APS in the news 2021

As in the previous year, 2021 saw a considerable increase in the number of scientific articles published relating to antiphospholipid antibodies (aPL) and antiphospholipid syndrome.

One publication that did cause quite a lot of consternation was the study from Nottingham University that found that people with rare rheumatic autoimmune diseases were more likely to die from COVID: <https://www.nottingham.ac.uk/news/rare-autoimmune-diseases-and-covid-19>.

Throughout the year, there were a number of APS-related articles in the national, online and local media, including an article in the Huff Post UK about the second AZ vaccine and APS: https://www.huffingtonpost.co.uk/entry/second-dose-of-the-astrazeneca-vaccine_uk_607971b8e4b0bc5a3a55a899 and one APS patient's story went global after it appeared on yahoo: <https://uk.news.yahoo.com/woman-longs-mum-warned-pregnancy-060029803.html>.

Collaboration

As we are such 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 2021:

- [Anticoagulation UK](#) sadly, this charity closed in June 2022
- [APS ACTION](#)
- [APS Foundation of America](#)
- [APS Foundation of Australia](#)
- [Baby Loss Awareness Week 2021](#)
- [The Brain Charity](#)
- [Different Strokes](#)
- [Eat on warfarin](#)
- [German APS Support Group](#)
- [LUPUS UK](#)
- [Mama Academy](#)
- [National Association of Disabled Staff Networks](#)
- [Philippines APS Support Group](#)
- [Prescription Charges Coalition](#)
- [Spanish APS Association](#)
- [Thrombosis UK](#)
- [Tommy's Baby Charity](#)
- [World Thrombosis Day](#)



Thanks for all your Help and Support

We would like to say a heartfelt thank you to everyone who supported us throughout the very difficult year that was 2021. This includes all the APS patients who helped us provide up to date information by sharing their COVID-19 experiences, especially those working on the frontline in ICU and COVID wards.

We would also like to thank the NHS, GPs, hospitals and national vaccine centres who sought to make sense of an emerging crisis and give meaningful advice to APS patients. In addition, we appreciate the direct assistance given by the Medicines and Healthcare products Regulatory Agency (MHRA) in December 2021 regarding the suitability of the Pfizer and AstraZeneca COVID vaccines for people with APS.

Fortunately, we already had established good collaborative connections with other related charities; these links became invaluable when our resources became overstretched due to the pandemic, and we were able to share their associated information and COVID guidelines. In particular, we would like to thank Professor Beverley Hunt OBE and Thrombosis UK for sharing their anticoagulants vaccine advice, and Paul Howard and Lupus UK for patient shielding guidance.

Thanks to our two Medical Vice-Chairs, Professor David D'Cruz and Anisur Rahman, who are both world-leading APS experts, we were able to keep the new COVID information page up to date on our website. These ongoing statements allowed us to answer a lot of generic patient enquiries which meant we could spend more time on more complicated queries.

We are also extremely grateful to our charity ambassadors who give personal talks around the country to help raise awareness of APS. In particular, the support of our ambassador, Phil Godfrey, this year was outstanding as the pandemic meant that our ability to raise funds was severely restricted. Fortunately, Phil continued to embrace Zoom technology, so was able to raise funds by talking about APS to generous UK Rotary Clubs and zoomed 300+ in 2021. Phil also remains a personal major donor to APS Support UK.



Future plans for 2022

Online Midwives course

We understand from the Royal College of Midwives that the APS module on their i-Learn platform will be the first to be developed on a new prototype that is more user-friendly for busy midwives. We expect to be working with the RCM to help develop this so we can launch the course in 2022.

APS Research Fund awards

We intend to continue offering small grants again in 2022, and we will be making the application process available on our website at the beginning of the year with a deadline of 15th April 2022.

Arthur Ogden's legacy expenditure

The charity is exploring the best way to use the £60,000 legacy we received as we are determined to spend it wisely but also meet the needs of patients. Therefore, the trustees intend to survey the APS community to ask their opinions on how best to utilise this funding.

Royal College of GPs online course

The trustees will assess whether the charity should continue to fund the online course for GPs. It is currently free for all healthcare professionals to access and complete, so we look at the uptake of the course and make a decision regarding its future accessibility.



Dr Karen Hamblly



Online Midwives Course

Legal and Administrative Information

The Trustees present their final report and the audited financial statements for the year ended 31 December 2021.

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.

Reference and administrative details

The organisation is a charitable company limited by guarantee, incorporated on 1 June 2010 and registered as a charity on 17 September 2010.

The company was established under a Memorandum of Association, which established the objects and powers of the charitable company and is governed under its articles of association.

Charity Registration Number:	1138116
Company Registration Number:	07268671
Date of Incorporation:	2010
Financial Year:	1st January 2021 - 31st December 2021
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 Dr Andrew Pearson Mr James Turner Dr Michael Shipley 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.

Risk Assessment

The trustees actively review the major risks which the charity faces on a regular basis and believe that maintaining the free reserves stated, combined with the annual review of the controls over key financial systems carried out on an annual basis, will provide sufficient resources in the event of adverse conditions.

The trustees have also examined the other operational and business risks that they face and consider the systems in place for the day-to-day operation of APS Support UK to be appropriate to our current size. Still, they are aware that as the charity grows, we will need to develop and implement procedures and reporting regimes to mitigate the risks associated with running a charitable company.

Update on Coronavirus 2021

In March 2021, the unprecedented coronavirus outbreak affected our future plans and restricted our ability to raise funds. We took steps to mitigate the impact to the charity and the trustees take the view that we hold sufficient bank reserves to carry us through, even if the pandemic continues for several more months and beyond. We are not considering any further cost cutting measures at the time of writing (September 2021), but we will be keeping the situation under close review.

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 in 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.

So far as the trustees are aware, there is no relevant audit information (information needed by the company's auditors in connection with preparing their report) of which the company's auditors are unaware. Each trustee has taken all the steps that he ought to have taken as a trustee in order to make themselves aware of any relevant audit information and to establish that the company's auditors are aware of that information.

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 2021, the charity made a surplus of £61,761 (2020: £35,570). Income totalled £128,035 (2020: £127,590) with expenditure of £66,274 (2020: £92,020).

Total funds at 31 December 2021 are £273,775 (2021: £212,014) of which £93,000 (2021: £93,000) relate to designated funds, with £60,663 (2020: £36,873) relating to restricted funds. £73,000 of designated funds relate to the designated reserve explained in the reserve policy. General funds total £120,112 (2020: £82,141). 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.

The trustees acknowledge their general legal duty to spend income within a reasonable time of receipt and to do so in the charity's best interest, and hence it is not the charity's policy to hold excessive reserves above and beyond those that are prudent. Our reserve policy is in accordance with the provisions of CC19.

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 2021, 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

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).

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 2021

INCOMING RESOURCES

	Notes	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
Donations and legacies		£63,433	£31,730	£95,163	£98,840
Charitable activities		£31,894	-	£31,894	£27,930
Investment income		£978	-	£978	£803
Other income		-	-	-	£17
TOTAL INCOME	3	£96,305	£31,730	£128,035	£127,590

EXPENDITURE

	Notes	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
Raising funds		£1,024	-	£1,024	£1,494
Charitable activities		£57,310	£7,940	£65,250	£90,526
TOTAL EXPENDITURE	4	£58,334	£7,940	£66,274	£92,020

NET INCOME / (EXPENDITURE) FOR THE PERIOD

	Notes	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
TOTAL NET INCOME		£37,971	23,790	£61,761	£35,570

FUNDS

	Notes	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
Funds at 1 January 2021		£175,141	£36,873	£212,014	£176,444
FUNDS AT 31 December 2021	6	£213,112	£60,663	£273,775	£212,014

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 activities year ended 31 December 2020

Including Income and Expenditure Account

INCOME

	Notes	Unrestricted Funds	Restricted Funds	2020 Total
Donations and legacies		£93,415	£5,425	£98,840
Charitable activities		£25,272	£2,658	£27,930
Investment income		£803	-	£803
Other income		£17	-	£17
TOTAL INCOME	3	£119,507	£8,083	£127,590

EXPENDITURE

	Notes	Unrestricted Funds	Restricted Funds	2020 Total
Raising funds		£1,494	-	£1,494
Charitable activities		£61,778	£28,748	£90,526
TOTAL EXPENDITURE	4	£63,272	£28,748	£92,020

NET EXPENDITURE FOR THE PERIOD

	Notes	Unrestricted Funds	Restricted Funds	2020 Total
NET EXPENDITURE FOR THE PERIOD		£56,235	(£20,665)	£35,570

FUNDS

	Notes	Unrestricted Funds	Restricted Funds	2020 Total
Funds at 1 January 2020		£118,906	£57,538	£176,444
FUNDS AT 31 December 2020	6	£175,141	£36,873	£212,014

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 2021

CURRENT ASSETS

	Notes	2021		2020	
Gift aid recoverable		£18,113		£852	
Prepayments and accrued income		-		£60,000	
Cash at bank and in hand		£256,869		£154,331	
		£274,982		£215,183	

CREDITORS

	Notes	2021		2020	
Amounts falling due within one year Accruals		(£1,207)		(£3,169)	
NET ASSETS	7		£273,775		£212,014

FUNDS

	Notes	2021		2020	
Restricted funds	6		£60,663		£36,873
Unrestricted funds					
General funds	6		£120,112		£82,141
Designated funds	6		£93,000		£93,000
TOTAL FUNDS			£273,775		£212,014

For the financial period ended 31 December 2021, 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 period and of its income and expenditure for the financial period, 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 31 October 2022
and signed on its behalf by

J Turner
Trustee

Notes to the accounts for the year ended 31 December 2021

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 SOFA when the charity has unconditional entitlement to the resources.

Income from tax reclaims are included in the SOFA at the same time as the gift to which they relate.

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 2021

3. INCOMING RESOURCES

Donations & Legacies	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
Donations	£47,087	£27,976	£75,063	£32,671
Legacies	-	-	-	£60,000
Gift aid recoverable	£16,346	£3,754	£20,100	£6,169
TOTAL	£63,433	£31,730	£95,163	£98,840

Charitable activities	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
Fundraising income	£30,470	-	£30,470	£18,731
Membership renewals	£1,424	-	£1,424	£8,706
Merchandise sales	-	-	-	£493
TOTAL	£31,894	-	£31,894	£27,930

Investment Income	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
Bank Interest	£978	-	£978	£803
TOTAL	£978	-	£978	£803

Other Income	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
Sundry Income	-	-	-	£17
TOTAL	-	-	-	£17

	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
TOTAL INCOME	£96,305	£31,730	£128,035	£127,590

Notes to the accounts for the year ended 31 December 2021

4. EXPENDITURE

Raising funds	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
Fundraising costs	£1,024	-	£1,024	£1,321
Merchandise purchases	-	-	-	£173
TOTAL	£1,024	-	£1,024	£1,494

Charitable activities	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
Staff costs	£49,535	-	£49,535	£53,827
Insurance costs	£679	-	£679	£693
Office costs	£674	-	£674	£1,510
Publicity and advertising	£642	£4,605	£5,247	£1,068
Rent	£4,104	-	£4,104	£3,078
Legal and professional fees	£372	-	£372	£363
Accountancy	£1,304	-	£1,304	£1,123
Grants paid	-	£3,335	£3,335	£28,748
Sundry expenses	-	-	-	£116
TOTAL	£57,310	£7,940	£65,250	£90,526

	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
TOTAL EXPENDITURE	£58,334	£7,940	£66,274	£92,020

The independent examination fee included in accountancy amounted to £1,304 (2020: £1,123).

Grants of £nil (2020: £5,000) were paid as part of the Louise Gergel Fellowship Project.

Grants of £3,335 were paid to the University of Kent.

Notes to the financial statements for the year ended 31st December 2021

5. EMPLOYED STAFF COSTS AND NUMBERS

	2021 TOTAL	2020 TOTAL
Salaries and wages	£47,482	£51,149
Social security costs	£631	£1,143
Pension	£1,422	£1,535
TOTAL	£49,535	£53,827

No employee earned more than £60,000 during this or the prior period. The total number of employees during the period was 2 (2020: 2).

Key management were paid remuneration totalling £41,873 (2020: £40,586).

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

Trustees' indemnity insurance of £228 (2020: £228) for the Board of Trustees was paid during the year.

Notes to the accounts for the year ended 31 December 2021

6. MOVEMENT IN FUNDS

Restricted funds	At 1 January 2021	Income	Expenditure	Transfers	At 31 December 2021
Louise Gergel Fellowship	£17,940	£1,180	-	-	£19,120
Research and Projects Fund	£18,933	£8,050	(£3,335)	-	£23,648
APS Research Fund	-	£5,000	-	-	£5,000
Digital Media Assistant	-	£17,500	(£4,605)	-	£12,895
TOTAL	£36,873	£31,730	(£7,940)	-	£60,663

Designated funds	At 1 January 2021	Income	Expenditure	Transfers	At 31 December 2021
Research and Projects fund	£20,000	-	-	-	£20,000
Designated reserve fund	£73,000	-	-	-	£73,000
TOTAL	£93,000	-	-	-	£93,000

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 initiatives 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 £5,000 to APS-specific research projects on a yearly basis.

Digital Media Assistant

This fund represents monies received to engage a digital media assistant to oversee the social media presence and search engine optimisation of the charity.

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 initiatives such as conferences etc.

Notes to the accounts for the year ended 31 December 2021

7. ANALYSIS OF NET ASSETS BETWEEN FUNDS

2021	Restricted funds	Designated funds	Unrestricted funds	2021 Total funds
Current assets	£60,663	£93,000	£121,319	£274,982
Current liabilities	-	-	(1,207)	(£1,207)
NET ASSETS	£60,663	£93,000	£120,112	£273,775

2020	Restricted funds	Designated funds	Unrestricted funds	2020 Total funds
Current assets	£36,873	£93,000	£85,310	£215,183
Current liabilities	-	-	(£3,169)	(£3,169)
NET ASSETS	£36,873	£93,000	£82,141	£212,014

8. RELATED PARTY TRANSACTIONS

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

9. LEGACY

A legacy of £60,000 was bequeathed on 2nd July 2020 from the estate of Arthur Ogden, who passed away in April 2020. Phil Godfrey who has been a most generous supporter and ambassador of our charity for many years, kindly varied Arthur's will (as an Executor, with approval of the other two Executors) for this money to come from Phil's part of Mr Ogden's Estate.

This was carried out with the full agreement of Mr Ogden, prior to his death.

This generous legacy was received into the charity accounts on 15th April 2021.

The legacy is accrued in the accounts for the year ended 31st December 2020 as we were aware that the legacy was in probate during 2020.

Accounts



APS Support UK

For people with antiphospholipid syndrome



Ana's 300,000 Steps!



Phil embraced Zoom



Danny's Static 500km

Overview

Antiphospholipid syndrome (APS) is a 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.



Ana's 300,000 Steps!



In Memory of Sarah

Introduction and Message from the Chair

2020 was the most challenging year that APS Support UK has ever faced due to the unprecedented global COVID-19 pandemic. Not only was the charity's ability to raise funds severely restricted but demand for our services and information increased enormously.

This increased demand was predominantly from people affected by antiphospholipid syndrome but also included doctors, nurses, hospital and even vaccination centres. Overall, our website traffic grew 207% and we received an 80% increase of patient enquiries. There was also a 27% increase in medical journals featuring aPL.

We were pleased that we were just about able to keep pace with this demand and our team did their utmost to answer every single patient enquiry. Our website was described by one patient as a "beacon of hope" in this difficult year and it was encouraging to see that the GP online course we host with the Royal College of GPs had a sharp increase in uptake of 43% in 2020.

Despite, our resources being rather over-stretched, we still managed to meet all our charity's objectives including one of our main aims by offering small research grants for APS studies; given the extenuating circumstances, we decided to extend the deadline for grant applicants to June 2020. We were delighted to award four grants totalling £19,749 to applicants from Imperial College London, University College London and the University of Birmingham. The latter project is a pilot scheme that will generate data for use in a collaborative study involving the charity, Tommy's.

The charity board of trustees expanded further in 2020 when Chris Mansbridge was invited to join us as our Digital Media Marketing Trustee. Chris is a highly professional Digital Media Content expert and we have no doubt that his skillset and expertise

will bring a lot to our board table; he has already worked wonders with our website and search engine optimisation.

We may be a small charity but, in 2020, we really did punch above our weight! We hope that 2021 will be calmer, not only for our charity but for the world!

All the trustees would like to thank our Chief Executive, Kate Hindle and her team for the professional and determined way in which they have responded to the challenges of the last year. I am constantly amazed by what they are able to achieve.

I am also grateful to all the trustees and our medical advisers for the skill, expertise and commitment they bring. They give generously of their time and offer guidance and support that is greatly valued.

Working together and with the support of our members puts us in a good position for the next phase of the charity's work.



A handwritten signature in blue ink, reading 'Estelle'.

Baroness Estelle Morris
Chair of APS Support UK

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; we always do our utmost to help those affected by antiphospholipid syndrome (APS).

Early diagnosis **saves lives**

Our Objectives

APS is a life-threatening autoimmune disease that causes the blood to clot too quickly. The condition can cause potentially 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
- 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 section below. The directors confirm that they have paid due regard to the Charity Commission guidance on public benefit before deciding which activities the charity should undertake.



Phil Godfrey

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 lungs.

In pregnancy, APS is the most important treatable cause of recurrent miscarriage, and it 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

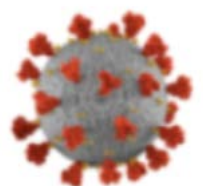
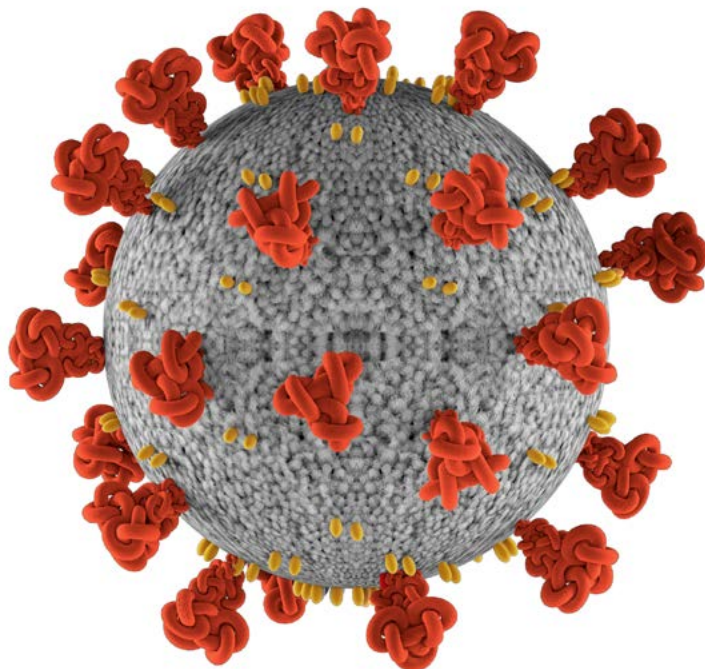
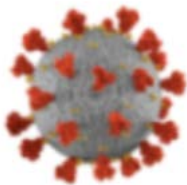
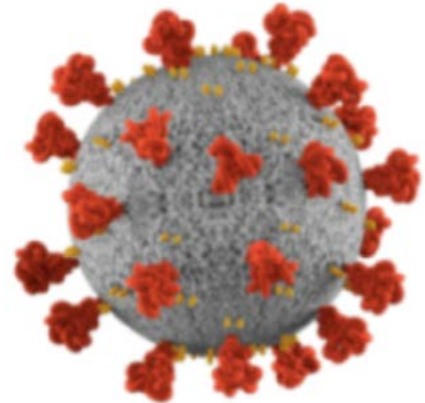
COVID-19 Impact in 2020

In March 2020, the unprecedented global COVID-19 outbreak affected our future plans, restricted our ability to raise funds and was the busiest year the charity has ever known since it began.

With staff working from home throughout the year and national lockdowns in place, we were unable to hold the national Patients' Day we had planned for June 2020 in Birmingham.

However, because of the pandemic, the charity's resources were stretched very thinly throughout the year due to increased website traffic of 207%, 80% more patient enquiries, an 11% increase of Facebook followers and a 27% increase in medical journal articles featuring antiphospholipid antibodies.

Despite this huge increase in workload, APS Support UK still managed to meet all our main objectives.



Charity objectives achieved in 2020

Raising awareness of APS in the medical community

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

One of our volunteer ambassadors, Yvonne Wren, is an Expert Patient and she gave a talk entitled 'Living with APS – a patient's perspective' to the post-graduate students at the Faculty of Biology, Medicine and Health at Manchester University in January 2020. The talk was very well received, with positive feedback and an offer to speak at future events.

Aberdeen Royal Infirmary Early Pregnancy Unit

We received a request from a Gynaecology Specialist Nurse working within the Recurrent Pregnancy Loss Service for Grampian NHS. The unit now screens for antiphospholipid antibodies as part of their investigations, but they did not have any information for their patients who were diagnosed with APS. We, therefore, sent leaflets and links to our website and Fact Sheets for the unit to share with their patients.

Royal College of GPs online APS course

APS Support UK decided to continue funding the Royal College of GPs (RCGP) eLearning course on antiphospholipid syndrome for a further three years in 2018 due to the successful uptake of the module. The course was updated to include the latest APS information and guidelines in 2020 by our Medical Advisors who liaised with the RCGP to make the necessary changes.

This online course can be accessed freely by all GPs, healthcare professionals, medical trainees and students throughout the UK. We saw a sharp increase in uptake of the course during 2020; this may have been due to the perceived link between antiphospholipid antibodies and COVID-19 that was first publicised in April 2020 in the [New England Journal of Medicine](#) which raised awareness of APS in the medical community.

In 2020, the number of doctors completing the course rose by 43% over the year with 662 as the final figure. It is also very encouraging that pre-course knowledge assessment increased from 48% to 84% on course completion.



Royal College of
General Practitioners

How we achieved our objectives:

Offering information and understanding to anyone affected by APS

COVID-19 patient enquiries

2020 saw an unprecedented number of patient enquiries made to the charity, with an increase of almost 80% over the year. We did our utmost to support anyone who asked for assistance and were humbled by a lot of the emails we received from people with APS, particularly those who worked on the frontline in ICU and on COVID-19 wards at the height of the pandemic.

At the beginning of the first wave and lockdown, enquiries tended to be quite general medical questions such as:

“Are people with APS at greater risk of catching or dying from COVID-19?”

“Does taking anticoagulants make you more vulnerable to COVID-19?”

Once the first lockdown was lifted, the questions became rather more complex especially from those people working on the frontline; for example:

“Should ICU nurses with APS be working in COVID-19 wards?”

“Should anyone with APS be a keyworker?”

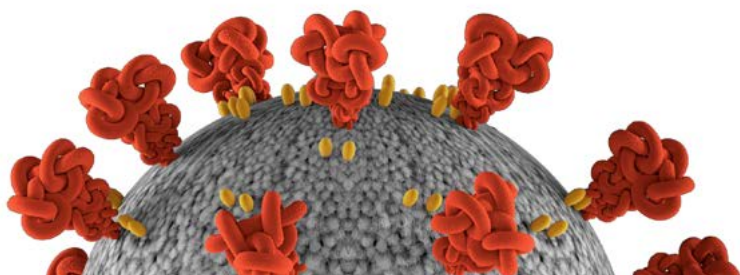
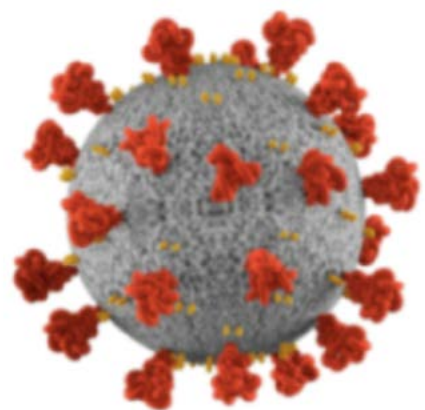
“Is hydroxychloroquine an immunosuppressant?”

Throughout the pandemic in 2020 there was a lot of confusion as to whether APS patients needed to shield, and this uncertainty, understandably, generated a lot of enquiries from worried patients. The queries varied over time to match the ever-changing government and NHS guidance in this unique and emerging medical situation.

When the first national lockdown began on 23rd March 2020, the UK government originally recommended that anyone who qualified for a ‘flu vaccination on medical grounds, was over the age of 70 and/or had certain medical conditions would be in the high-risk group. This prompted many queries along the lines of:

“Why isn’t APS included in the medical conditions on the government’s high-risk group?”

“Should APS patients self-isolate?”



How we achieved our objectives:

Offering information and understanding to anyone affected by APS

Along with many other rare diseases, APS was never mentioned specifically in the guidelines, so it was often difficult to know how exactly to advise patients about shielding in a meaningful way. Some patients were identified as being at high risk of complications from COVID-19 and received a letter from their GP, hospital or the NHS national service. The problem was that it was unclear for several weeks why this was and we received many enquiries asking:

“ Why haven't some patients received a letter from the NHS stating they are in the extremely vulnerable category? ”

After some investigating, we were informed that some patients were identified by an algorithm depending on the severity of their condition and clotting events. Eventually, shielding was paused in August 2020 and, as the lockdown lifted, we began receiving queries such as:

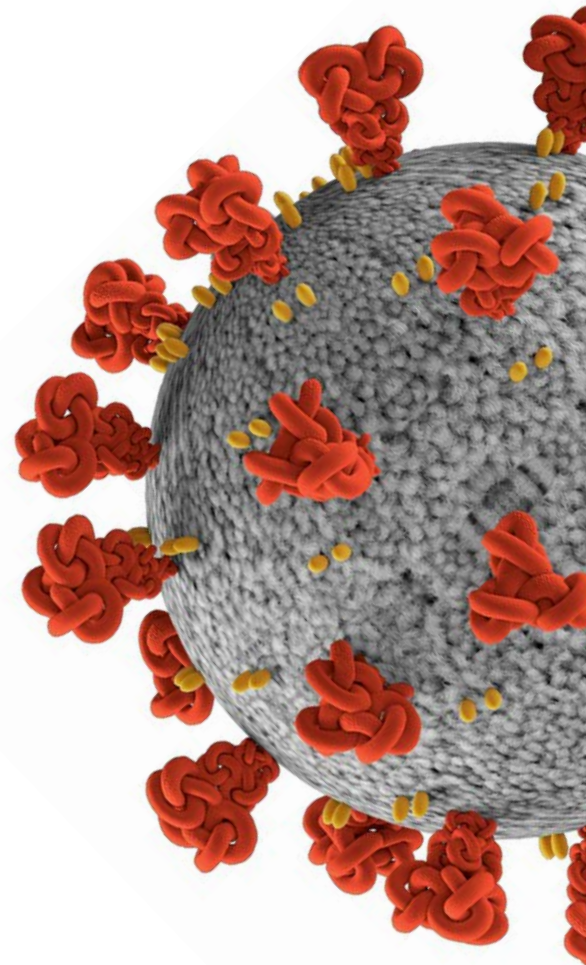
“ Is APS considered to be a vulnerable condition and can I go back to work? ”

After contacting the relevant authorities, we discovered that APS is not listed as a clinically extremely vulnerable medical condition, so we were able to share this with the APS community.

COVID-19 website and social media updates

Due to the enormous volume of enquiries, we created a [new page about COVID-19 and APS](#) on our website. Our Medical Advisors helped formulate these ongoing statements, so we were able to answer a lot of patients' enquiries generically. This allowed us more time to spend on the more complicated queries.

Our website updates were invaluable to a lot of APS patients as the global pandemic was a rapidly evolving situation and we did our best to keep our APS and COVID information up-to-date with changing guidelines and advice from the government and NHS.



How we achieved our objectives:

Offering information and understanding to anyone affected by APS

The UK Medicines and Healthcare products Regulatory Agency (MHRA)

In December 2020, two COVID-19 vaccines were approved for use in the UK by the Medicines and Healthcare products Regulatory Agency (MHRA).

We received a deluge of enquiries about the suitability of these new COVID-19 vaccines for people with APS. We, therefore, contacted the MHRA directly in December 2020 to ask whether both the Pfizer/BioNTech and Oxford/AstraZeneca COVID-19 vaccines were considered to be suitable for anyone with antiphospholipid syndrome. The MHRA promptly replied and informed us that, although there is no published safety data specifically for APS patients, "all three authorised vaccines may be administered to these patients".

Dr June Raine, chief executive of the MHRA, appeared on the Andrew Marr Show on 6th December 2020 and highlighted that there is a "special piece of advice for anyone on a blood thinner or an anticoagulant, but that simply means you can have the vaccine if the benefits outweigh the risks".

As the majority of patients with APS do take anticoagulants, we reached out to the charity, Thrombosis UK, who generously allowed us to share their guidelines with our patient group.



Dr Deepa Jayakody

Welsh language APS poster

Due to requests from patients in Wales, we translated our APS poster into the Welsh language thanks to the translation skills of two volunteers. This poster is now free to download from our website.

YDYCH CHI'N YMWBODOL O APS?

Mae Syndrom Gwrth-ffosfolipid (APS) yn gyflwr awto-immiwn sy'n peryglu bywyd a all achosi strôc, trawiad ar y galon, DVTs a chlotiau gwaed yn yr ysgyfaint.

Mewn beichiogrwydd, APS yw'r achos pwysicaf y gellir ei drin o golli plentyn yn fyrych yn ystod beichiogrwydd ac mae hefyd yn gysylltiedig gyda marw-enedigaeth, cyneclampsia a babanod cynamserol.



APS Support UK
For people with antiphospholipid syndrome

aps-support.org.uk
0300 323 9943

Elusen gofrestredig 1138116. Hawffaint 2018

How we achieved our objectives:

Supporting research into APS

APS Support UK Research Fund

Our APS Research Fund is now in its second year. This fund offers small grants of up to £5,000 for research projects and travel awards specifically concentrating on antiphospholipid syndrome.

In 2020 we were, again, in a financial position to offer small grants so promoted the research applications on our website via our communication channels early in the year; these were also publicised by Thrombosis UK and Anticoagulation UK.

The original closing date was 15th April 2020 but, due to COVID-19 and the incredible strain it put on the medical community, we extended this until 15th June 2020. All applicants were asked to submit additional information on how the COVID-19 pandemic might affect their research proposal, and whether they would still be able to conduct the research as outlined in their applications.

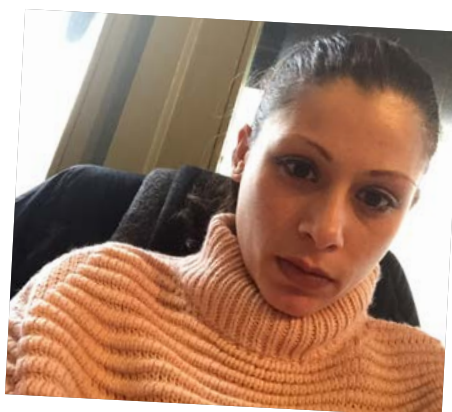
After being evaluated by our charity's Medical Vice Chairs, Professors David D'Cruz and Anisur Rahman, the charity awarded a total of £19,749 to the following four grant applicants (this is an increase of approximately £8,000 compared to grants awarded in 2019):

- Dr Deepa Jayakody Arachchillage from Imperial College London for the project: 'Fibrinolysis in thrombotic APS'.



Dr Jennifer Tamblyn

- Dr Jennifer Tamblyn from the Institute of Metabolism and Systems Research at the University of Birmingham for work on the project: 'ApS Stratification STudy - ASSIST'. This study will generate the pilot data to support a large multi-centre prospective APS risk stratification study using the Tommy's National RPL Network. The Louise Gergel Fellowship, our memorial fundraising sub-committee, also awarded the Louise Gergel Prize of £5000 to help further Dr Tamblyn's important research into APS and pregnancy.
- Dr Thomas McDonnell from University College London for work on the project: 'The Role of Monocytes in APS: Does Phenotyping Hold the Key?'
- Dr Maria Efthymiou from the Haemostasis Research Unit at University College London for work on the project: 'Development of a shear stress-based model assay termed 'in vitro thrombosis model' integrating platelets, the coagulation system, and the endothelium for the assessment of thrombus formation in APS'.



Dr Maria Efthymiou

How we achieved our objectives:

Supporting research into APS

UCB partnership with Patient Advisory Board

UCB is a multinational biopharmaceutical company who reached out to us early in 2020 as they wanted to form a partnership with APS Support UK to learn more about patients' needs. Their objective was to hold a Patient Advisory Board with five patients living with antiphospholipid syndrome, and a representative from APS Support UK, to understand the patient experience of living with APS and gain the patient perspective on the design of a clinical study.

We agreed to recruit the five volunteers by identifying APS patients who had very different experiences of APS, such people who had suffered catastrophic APS, stillbirth, stroke and DVTs.

The online patient workshops were held in June 2020 with 13 attendees: the five patient volunteers, the Charity Manager from APS Support UK and seven members of staff from UCB. The meeting was a great success with senior members of UCB stating that it was "truly special", "of extraordinary value" and the interactions with patients would help immensely when "thinking and planning any development with APS".

The five volunteer patients were reimbursed by UCB for their time and expenses and APS Support UK received £1,250 for organising the Patient Advisory Board and participating in the online workshops.

Due to the success of the workshops, UCB requested that our charity develops a Patient Council so we can build a long-term partnership with the company. The trustees agreed to be involved with further activities, but would need to consider future requests depending on the charity's resources.

Fatigue and physical activity in APS patients

Back in 2015, APS Support UK awarded £1000 funding to researchers at Kings College London for a project that was investigating the symptom of fatigue in APS patients. Our charity assisted with this study by liaising with our patient group and distributing a questionnaire in 2017. In 2020, the research paper was finally published in the journal *Lupus*: '[Fatigue in adults with primary antiphospholipid syndrome: findings from a mixed-methods study](#)'.

Following the publication of the paper, the researchers decided to develop this project further and applied to the National Institute of Health Research for a grant to design a self-management programme that will help people with APS to better understand and manage their symptoms.

During 2020, we supplied a letter of support with their grant application agreeing to recruit patients for a workshop and distributed an online survey directly to our patient group explaining that Dr Lindsay Bearne was hoping to develop a programme to support people with APS manage their day-to-day symptoms, such as fatigue, low mood and sleep difficulties, as their earlier research indicated this had a big impact on people's lives.

We also invited patients to join the potential APS Symptom Management Application steering committee and agreed for the Charity Manager to sit on this board too. The grant application was submitted in 2020 and the researchers should learn the outcome in 2021.

Our Impact in 2020



Our Impact in 2020

Website

In 2020 we had 57,834 website visits from 192 countries, which is a 207% increase from last year. 47% of these came from the UK, while 22% came from the United States. In terms of demographics, the majority of visits were from female users aged between 25-34. Additionally, over 68% of all website visits were accessed on a mobile device.

57,834 website visits

The Homepage, Symptoms page and COVID-19 Information, were the three most popular pages viewed in 2020, making up

42% of all website visits

Providing up-to-date and reliable information about COVID-19 and APS on our website

The huge 207% increase in visitors to our website was, undoubtedly, driven by the updates and information that we provided about COVID-19 and APS. We know that our website was viewed both nationally, and internationally, as a trustworthy, timely and reliable source of APS information throughout the pandemic. The charity received many messages of thanks including:

“ My donation was a thank you for all the work your charity has done in helping provide my family with up-to-date help and advice especially during the pandemic. Both my daughters have APS. It has been a difficult time for everyone when hospital clinics and face to face appointments with GPs and Consultants have had to be cancelled so thank you again. ”

“ Thanks again for getting back to me as APS support is the only source of information that I trust at the moment. ”

“ I am disappointed I will not be fully vaccinated, but felt I was not getting the best information on AZ vaccine relative to APS until I found your website. Once again thank you for the information you have supplied. I also no longer feel I am alone as other APS patients have experienced similar issues to me. ”

“ Thank you for all your wonderful work, your updates are very reassuring. ”

Our Impact in 2020

Social media

Throughout 2020, our Facebook Likes grew from 6,566 to 7,219, an increase of 10%, and our Facebook Followers increased from 6,475 to 7,189, a rise of 11%. As with the sharp increase of traffic to our website, we believe the significant rise in Facebook Likes and Followers was due to the information we provided about COVID-19 on our social media channels during the global pandemic. We also received favourable reviews throughout the year including:

“Have had no support/information from GP so this group is really informative. Good to know symptoms experienced are “normal”.”

“I really thought I had dementia until I understood things like brain fog come with the condition. Thank you for the research, facts, updates and community.”

“There is a lot of useful and interesting information provided.”

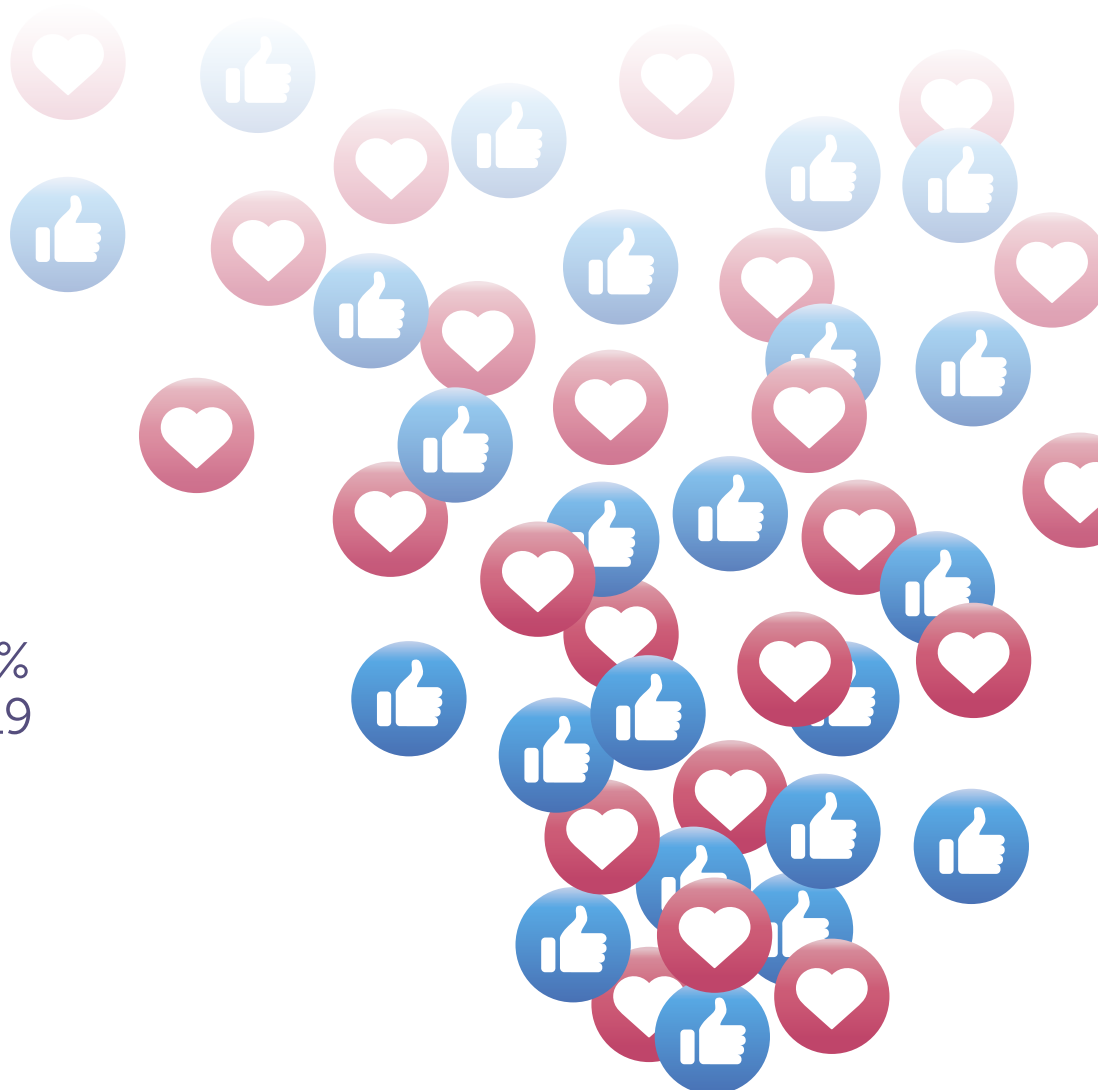
“Not just informative, but with humour and compassion.”

“Nice to know there is support out there. I started warfarin in July. The help groups are better because most GPs know nothing about APS.”



7,219 likes

an increase of 10%
from 6,566 in 2019
to 7,219 in 2020



Our Impact in 2020

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 online module, help with complex enquiries and can contact their peers, if necessary, on specific APS subjects.

In 2020, Christopher Mansbridge joined the board of trustees. We advertised on Reach Volunteering for a Digital Media Marketing trustee, and we were delighted when Chris applied and accepted the role on our board. Chris is a very experienced and qualified Digital Media Content professional, we feel fortunate to have him on our team.

As we have good collaborative connections with other charities, teaching hospitals and leading APS experts, we are able to call on their professional help when needs be. For example, Thrombosis UK and LUPUS UK generously shared their COVID-19 information for our patient group.

We manage to keep our professional expenses down thanks to the pro bono services of an expert proof-reader, two Welsh translators, two graphic designers and an audio visual professional. These qualified people all have links to APS and save the charity thousands of pounds every year.

We are also extremely grateful to our charity ambassadors who give personal talks around the country to help raise awareness of APS, particularly Phil Godfrey who embraced Zoom technology during lockdown so he could continue speaking to Rotary Clubs across the UK. In 2020, Phil spoke to 139 clubs and, by the end of the year, the total number he has been to visit (in person or virtually) is 256. Phil is a major fundraiser for our charity and his talks not only raise funds but awareness of APS with many Rotary Clubs helping share information about APS on their communication channels including Leicester, Edgware and West Fife, Eyemouth & District.

Another one of our volunteer ambassadors, Yvonne Wren, is an Expert Patient and she regularly presents her talk 'Living with APS – a patient's perspective' to the post-graduate students wherever possible.

This year, as we developed a partnership with the pharmaceutical company, UCB, we also recruited five volunteer APS patients to take part in the online workshop. These volunteer patients also kindly agreed to establish a Patient Advisory Board for any future projects with UCB.



Pauline Bain



Pauline's Smart Medal!

Our Impact in 2020

Search Engine Optimisation

In January 2020, we were fortunate to recruit Christopher Mansbridge via Reach Volunteering. Chris is a highly professional Digital Media Content expert, and he has kindly accepted the role of APS Support UK's Digital Media Marketing trustee.

Throughout 2020, Chris worked on improving search engine optimisation by altering the charity's website, analysing common search terms and key pages. This skilled project has improved our Google ranking enormously; so much so that if the search term "APS" is entered, then APS Support UK now appears in the top #3 listings and often appears as #1, even ahead of the NHS!

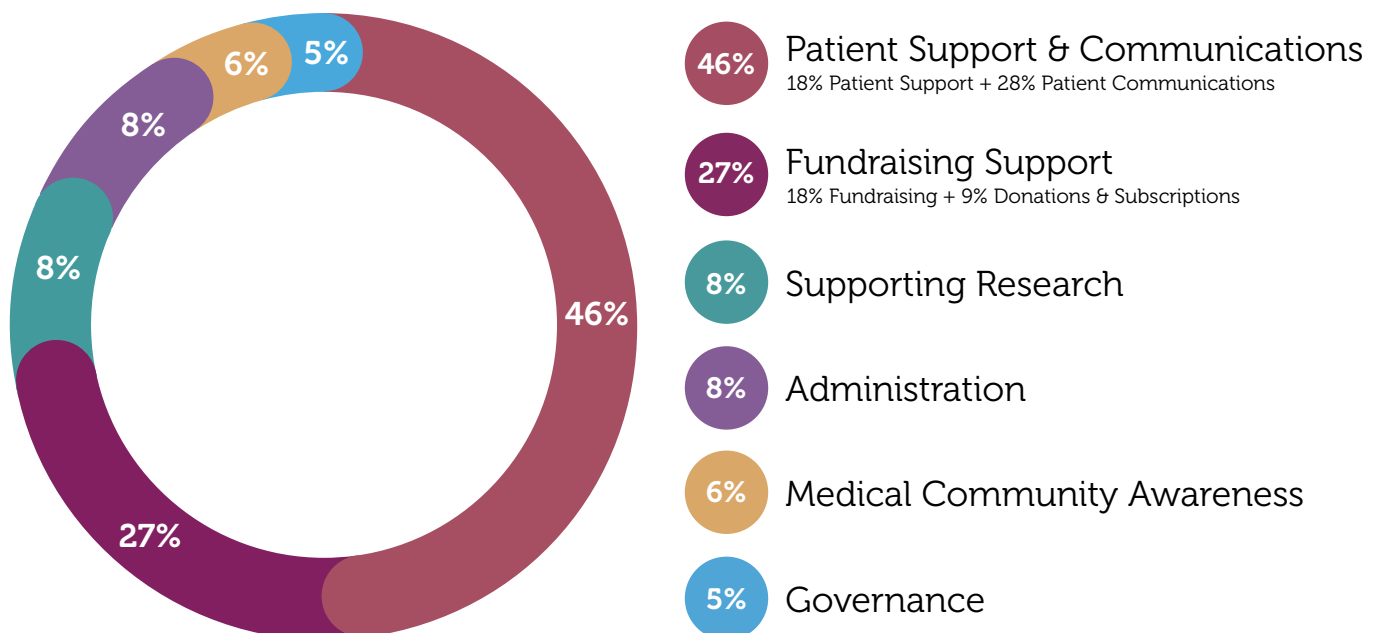
Supporting patients through charitable activities

We do not provide specific medical advice as we would be negligent to do so, but signpost and guide patients so they feel less isolated and confused. We aim to make them feel part of the APS community by giving reliable information, understanding and support.

As mentioned throughout this report, COVID-19 enquiries took most of our resources in terms of offering patient support. In previous years, we have sent out regular newsletters and e-shots, but we had to prioritise these in 2020 to ensure patients received the most important information.

To ensure that the charity's resources are spent wisely, we record and log the time spent on charitable activities and the results for 2020 are shown below:

Charity's staff activity breakdown 2020



Our Impact in 2020

APS in the news 2020

2020 saw an increase of 27% in the number of scientific articles published relating to antiphospholipid antibodies (aPL) and antiphospholipid syndrome from the previous year. This was undoubtedly accelerated by an article published in April 2020 in the New England Journal of Medicine which discussed the finding of antiphospholipid antibodies in patients with COVID-19. Throughout the year, a total of 839 research papers were published on PubMed, with one article even appearing in Time Magazine. We can say with certainty that 2020 saw increased awareness of APS in the medical community.

Sadly, the television presenter and journalist, Lynn Faulds-Wood, died in April 2020. Lynn had been previously diagnosed with APS and had campaigned to raise awareness of the condition for a number of years. Naturally, there were lots of media articles reporting this sad news and her husband, John Stapleton and son, Nick, also appeared on Good Morning Britain in May 2020 as they wished to honour Lynn and raise awareness of APS.

The Metro began a new series in September 2020 called 'What it feels like ...' and the first article published was: 'What it feels like ... to have two strokes'. This was written by BBC Radio 4 Student Journalist of the Year finalist, Amber Sunner, who had two childhood strokes caused by APS.

Throughout the year, there were a number of APS-related articles in the national media, including the Big Issue and Daily Mail, plus various features in local newspapers such as the Mansfield, Ashfield and Warsop Journal, the Newark Advertiser and the Henley Bridge Gazette.



Collaboration

As we are such 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 2020:

- [Animal Aid](#)
- [Anticoagulation UK](#)
- [APS ACTION](#)
- [APS Foundation of America](#)
- [APS Foundation of Australia](#)
- [Baby Loss Awareness Week 2020](#)
- [The Brain Charity](#)
- [Different Strokes](#)
- [Eat on warfarin](#)
- [German APS Support Group](#)
- [LUPUS UK](#)
- [Mama Academy](#)
- [National Association of Disabled Staff Networks](#)
- [Philippines APS Support Group](#)
- [Prescription Charges Coalition](#)
- [Spanish APS Association](#)
- [Thrombosis UK](#)
- [Tommy's Baby Charity](#)
- [World Thrombosis Day](#)



Thanks for all your Help and Support

We would like to say a heartfelt thank you to everyone who supported us throughout the very difficult year that was 2020. This includes all the APS patients who helped us provide up to date information by sharing their COVID-19 experiences, especially those working on the frontline in ICU and COVID wards.

We would also like to thank the NHS, GPs, hospitals and national vaccine centres who sought to make sense of an emerging crisis and give meaningful advice to APS patients. In addition, we appreciate the direct assistance given by the Medicines and Healthcare products Regulatory Agency (MHRA) in December 2020 regarding the suitability of the Pfizer and AstraZeneca COVID vaccines for people with APS.

Fortunately, we already had established good collaborative connections with other related charities; these links became invaluable when our resources became overstretched due to the pandemic, and we were able to share their associated information and COVID guidelines. In particular, we would like to thank Professor Beverley Hunt OBE and Thrombosis UK for sharing their anticoagulants vaccine advice, and Paul Howard and Lupus UK for patient shielding guidance.

Thanks to our two Medical Vice-Chairs, Professor David D'Cruz and Anisur Rahman, who are both world-leading APS experts, we were able to keep the new COVID information page up to date on our website. These ongoing statements allowed us to answer a lot of generic patient enquiries which meant we could spend more time on more complicated queries.

Throughout 2020, we managed to keep our professional expenses down thanks to the pro bono services of an expert proof-reader, two graphic designers, an audio-visual professional plus two Welsh translators. These qualified people all have links to APS and save the charity thousands of pounds every year.

This year also saw our first partnership with the multinational biopharmaceutical company, UCB, who reached out to us as they wanted to know more about the needs of patients with APS. This would not have been possible without the five patient volunteers who kindly gave up their time and shared experiences at the patient workshop in June 2020.

We are also extremely grateful to our charity ambassadors who give personal talks around the country to help raise awareness of APS. In particular, the support of our ambassador, Phil Godfrey, this year was outstanding as the pandemic meant that our ability to raise funds was severely restricted. Fortunately, Phil embraced Zoom technology very early on in the first lockdown, so was able to continue to raise funds by talking about APS to generous UK Rotary Clubs and zoomed 139 in 2020. Phil also remains a personal major donor to APS Support UK.

Finally, thanks to recruitment via Reach Volunteering, Chris Mansbridge joined the APS Support UK board of trustees as our Digital Media Marketing Trustee. Chris is a highly professional Digital Media Content expert and has already improved our charity's web presence and raised awareness of APS.



Future plans for 2021

Online Midwives course

From listening to our patients, we feel there is a need to explore the possibility of developing an online course about APS for midwives. In 2021, we plan to contact the Royal College of Midwives to find out whether they would be interested in proceeding with this and what costs, if any, will be involved.

APS Research Fund awards

We launched the APS Research Fund at the end of 2018 and, in 2019, awarded five grants totalling approximately £12,000 and, in 2020, we granted four awards totalling approximately £20,000.

We intend to continue offering small grants again in 2021, and we will be making the application process available on our website at the beginning of the year with a deadline of 15th April 2021. We are looking forward to receiving grant applications and awarding funding once again to worthy APS projects.

APS Research Fund peer review panel

To assist with the research funding grant-making selection process, the charity will establish a Peer Review Panel to assess the potential impact of the research on the understanding of disease mechanisms, to help increase survival rates and reduce the effects that antiphospholipid syndrome can have on the quality of life.

The panel will review the importance, relevance, originality and impact of the grant applications, together with their scientific rigour. Medical professionals will be invited to join the Peer Review Panel in 2021.

Google Ads campaigns

Chris Mansbridge has successfully applied for a Google Grants for Non-profits which now means the charity has \$10,000 a month grant to spend on Google Ads campaigns. This will help us raise the profile of APS and assist people when they are searching for symptoms.



Dr Thomas McDonnell



Our SEO Guru

Legal and Administrative Information

The Trustees present their final report and the audited financial statements for the year ended 31 December 2020.

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 2020 - 31st December 2020

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
Dr Andrew Pearson
Mr James Turner
Dr Michael Shipley
Mr Christopher Mansbridge (appointed 1st January 2020)

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 skills sets of trustees, to identify specific skills 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 meet 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.

Risk Assessment

The trustees actively review the major risks which the charity faces on a regular basis and believe that maintaining the free reserves stated, combined with the annual review of the controls over key financial systems carried out on an annual basis will provide sufficient resources in the event of adverse conditions.

The trustees have also examined the other operational and business risks which they face and consider the systems in place for the day-to-day operation of APS Support UK to be appropriate to our current size, but are aware that as the charity grows we will need to develop and implement procedures and reporting regimes to mitigate the risks associated with running a charitable company.

Update on Coronavirus 2020

In March 2020, the unprecedented coronavirus outbreak affected our future plans and restricted our ability to raise funds. We took steps to mitigate the impact to the charity and the trustees take the view that we hold sufficient bank reserves to carry us through, even if the pandemic continues for several more months and beyond. We are not considering any further cost cutting measures at the time of writing (September 2020), but we will be keeping the situation under close review.

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 in 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.

So far as the trustees are aware, there is no relevant audit information (information needed by the company's auditors in connection with preparing their report) of which the company's auditors are unaware. Each trustee has taken all the steps that they ought to have taken as a trustee in order to make themselves aware of any relevant audit information and to establish that the company's auditors are aware of that information.

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 2020 the charity made a surplus of £35,571 (2019: £28,432). Income totalled £127,590 (2019: £110,212) with expenditure of £92,020 (2019: £81,780).

Total funds at 31 December 2020 are £212,014 (2019: £176,444) of which £93,000 (2019: £93,000) relate to designated funds, with £36,873 (2019: £57,538) relating to restricted funds. £73,000 of designated funds relate to the designated reserve explained in the reserve policy. General funds total £82,141 (2019: £25,906). The trustees continue to keep 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 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.

The trustees acknowledge their general legal duty to spend income within reasonable time of receipt and to do so in the charity's best interest and hence it is not the charity's policy to hold excessive reserves above and beyond those that are prudent. Our reserve policy is in accordance with the provisions of CC19.

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 2020, 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

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).

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 2020

INCOMING RESOURCES

	Notes	Unrestricted Funds	Restricted Funds	2020 TOTAL	2019 TOTAL
Donations and legacies		£93,415	£5,425	£98,840	£66,230
Charitable activities		£25,272	£2,658	£27,930	£42,715
Investment income		£803	-	£803	£1,011
Other income		£17	-	£17	£256
TOTAL INCOME	3	£119,507	£8,083	£127,590	£110,212

EXPENDITURE

	Notes	Unrestricted Funds	Restricted Funds	2020 TOTAL	2019 TOTAL
Raising funds		£1,494	-	£1,494	£2,564
Charitable activities		£61,778	£28,748	£90,526	£79,216
TOTAL EXPENDITURE	4	£63,272	£28,748	£92,020	£81,780

NET INCOME / (EXPENDITURE) FOR THE PERIOD

	Notes	Unrestricted Funds	Restricted Funds	2020 TOTAL	2019 TOTAL
TOTAL NET INCOME		£56,235	(£20,665)	£35,570	£28,432

FUNDS

	Notes	Unrestricted Funds	Restricted Funds	2020 TOTAL	2019 TOTAL
Funds at 1 January 2020		£118,906	£57,538	£176,444	£148,012
FUNDS AT 31 December 2020	6	£175,141	£36,873	£212,014	£176,444

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 activities year ended 31 December 2019

Including Income and Expenditure Account

INCOME

	Notes	Unrestricted Funds	Restricted Funds	2019 Total
Donations and legacies		£35,292	£30,938	£66,230
Charitable activities		£42,715	-	£42,715
Investment income		£1,011	-	£1,011
Other income		£256	-	£256
TOTAL INCOME	3	£79,274	£30,938	£110,212

EXPENDITURE

	Notes	Unrestricted Funds	Restricted Funds	2019 Total
Raising funds		£2,564	-	£2,564
Charitable activities		£65,194	£14,022	£79,216
TOTAL EXPENDITURE	4	£67,758	£14,022	£81,780

NET EXPENDITURE FOR THE PERIOD

	Notes	Unrestricted Funds	Restricted Funds	2019 Total
NET EXPENDITURE FOR THE PERIOD		£11,516	£16,916	£28,432

FUNDS

	Notes	Unrestricted Funds	Restricted Funds	2019 Total
NET MOVEMENT IN FUNDS		£11,516	£16,916	£28,432
Funds at 1 January 2019		£107,390	£40,622	£148,012
FUNDS AT 31 December 2019	6	£118,906	£57,538	£176,444

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 2020

CURRENT ASSETS

	Notes	2020		2019	
Gift aid recoverable		£852		£5,252	
Prepayments and accrued income		£60,000		-	
Cash at bank and in hand		£154,331		£173,238	
		£215,183		£178,490	

CREDITORS

	Notes	2020		2019	
Amounts falling due within one year Accruals		(£3,169)		(£2,046)	
NET ASSETS	7		£212,014		£176,444

FUNDS

	Notes	2020		2019	
Restricted funds	6		£36,873		£57,538
Unrestricted funds					
General funds	6		£82,141		£25,906
Designated funds	6		£93,000		£93,000
TOTAL FUNDS			£212,014		£176,444

For the financial period ended 31 December 2020, 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 period and of its income and expenditure for the financial period, 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 27 September 2021
and signed on its behalf by

J Turner
Trustee

Notes to the accounts for the year ended 31 December 2020

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 SOFA when the charity has unconditional entitlement to the resources.

Income from tax reclaims are included in the SOFA at the same time as the gift to which they relate.

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 2020

3. INCOMING RESOURCES

Donations & Legacies	Unrestricted Funds	Restricted Funds	2020 TOTAL	2019 TOTAL
Donations	£27,246	£5,425	£32,671	£54,918
Legacies	£60,000	-	£60,000	-
Gift aid recoverable	£6,169	-	£6,169	£11,312
TOTAL	£93,415	£5,425	£98,840	£66,230

Charitable activities	Unrestricted Funds	Restricted Funds	2020 TOTAL	2019 TOTAL
Fundraising income	£16,073	£2,658	£18,731	£32,972
Membership renewals	£8,706	-	£8,706	£8,149
Merchandise sales	£493	-	£493	£1,594
TOTAL	£25,272	£2,658	£27,930	£42,715

Investment Income	Unrestricted Funds	Restricted Funds	2020 TOTAL	2019 TOTAL
Bank Interest	£803	-	£803	£1,011
TOTAL	£803	-	£803	£1,011

Other Income	Unrestricted Funds	Restricted Funds	2020 TOTAL	2019 TOTAL
Sundry Income	£17	-	£17	£256
TOTAL	£17	-	£17	£256

	Unrestricted Funds	Restricted Funds	2020 TOTAL	2019 TOTAL
TOTAL INCOME	£119,507	£8,083	£127,590	£110,212

Notes to the accounts for the year ended 31 December 2020

4. EXPENDITURE

Raising funds	Unrestricted Funds	Restricted Funds	2020 TOTAL	2019 TOTAL
Fundraising costs	£1,321	-	£1,321	£2,390
Merchandise purchases	£173	-	£173	£174
TOTAL	£1,494	-	£1,494	£2,564

Charitable activities	Unrestricted Funds	Restricted Funds	2020 TOTAL	2019 TOTAL
Staff costs	£53,827	-	£53,827	£52,999
Insurance costs	£693	-	£693	£691
Office costs	£1,510	-	£1,510	£1,858
Publicity and advertising	£1,068	-	£1,068	£3,094
Rent	£3,078	-	£3,078	£4,044
Legal and professional fees	£363	-	£363	£349
Accountancy	£1,123	-	£1,123	£1,020
Grants paid	-	£28,748	£28,748	£14,022
Sundry expenses	£116	-	£116	£1,139
TOTAL	£61,778	£28,748	£90,526	£79,216

	Unrestricted Funds	Restricted Funds	2020 TOTAL	2019 TOTAL
TOTAL EXPENDITURE	£63,272	£28,748	£92,020	£81,780

The independent examination fee included in accountancy amounted to £1,123 (2019: £1,020).

Grants of £5,000 were paid as part of the Louise Gergel Fellowship Project.

Grants of £4,967 were paid to Imperial College, £13,999 to University College London and £4,782 to individuals.

Notes to the financial statements for the year ended 31st December 2020

5. EMPLOYED STAFF COSTS AND NUMBERS

	2020 TOTAL	2019 TOTAL
Salaries and wages	£51,149	£50,081
Social security costs	£1,143	£1,536
Pension	£1,535	£1,382
TOTAL	£53,827	£52,999

No employee earned more than £60,000 during this or the prior period. The total number of employees during the period was 2 (2019: 2).

Key management were paid remuneration totalling £40,586 (2019: £39,648).

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

Trustees' indemnity insurance of £228 (2019: £228) for the Board of Trustees was paid during the year.

Notes to the accounts for the year ended 31 December 2020

6. MOVEMENT IN FUNDS

Restricted funds	At 1 January 2020	Income	Expenditure	Transfers	At 31 December 2020
Louise Gergel Fellowship	£17,515	£5,425	(£5,000)	-	£17,940
Research and Projects Fund	£40,023	£2,658	(£23,748)	-	£18,933
TOTAL	£57,538	£8,083	(£28,748)	-	£36,873

Designated funds	At 1 January 2020	Income	Expenditure	Transfers	At 31 December 2020
Research and Projects fund	£20,000	-	-	-	£20,000
Designated reserve fund	£73,000	-	-	-	£73,000
TOTAL	£93,000	-	-	-	£93,000

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 initiatives such as conferences etc.

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 initiatives such as conferences etc.

Notes to the accounts for the year ended 31 December 2020

7. ANALYSIS OF NET ASSETS BETWEEN FUNDS

2020	Restricted funds	Designated funds	Unrestricted funds	2020 Total funds
Current assets	£36,873	£93,000	£85,310	£215,183
Current liabilities	-	-	(£3,169)	(£3,169)
NET ASSETS	£36,873	£93,000	£82,141	£212,014

2019	Restricted funds	Designated funds	Unrestricted funds	2019 Total funds
Current assets	£57,538	£93,000	£27,952	£178,490
Current liabilities	-	-	(£2,046)	(£2,046)
NET ASSETS	£57,538	£93,000	£25,906	£176,444

8. RELATED PARTY TRANSACTIONS

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

9. IMPACT ON GOING CONCERN - COVID 19

The COVID pandemic has adversely impacted on our operations and on our financial performance in 2020. It was inevitable that fundraising activities reduced due to government regulations and donations also suffered due to the depressed economic climate.

During this and the prior year, no trustees were reimbursed expenses incurred on behalf of the charity. Charity activities were undoubtedly hampered, and we were not free to expand the charity's operations in the ways we would have wished. We made some cost savings in rent and in areas which we consider will cause the least harm. Overall costs excluding Grants and Education were reduced from £67,848 in 2019 to £63,272 in 2020. The fall in cash receipts in 2020 was offset by the £60,000 accrued legacy and resulted in our available funds increasing from £176,444 at the end of 2019 to £212,014 at the end of 2020.

Fortunately, we had sufficient cash reserves at the end of 2019 to weather the storm and we do not anticipate that the ongoing pandemic will lead to any long-term curtailment in either our activities or our ability to fund them.

10. LEGACY

A legacy of £60,000 was bequeathed on 2nd July 2020 from the estate of Arthur Ogden, who passed away in April 2020. Phil Godfrey who has been a most generous supporter and ambassador of our charity for many years, kindly varied Arthur's will (as an Executor, with approval of the other two Executors) for this money to come from Phil's part of Mr Ogden's Estate. This was carried out with the full agreement of Mr Ogden, prior to his death. This generous legacy was received into the charity accounts on 15th April 2021. The legacy is accrued in the accounts for the year ended 31st December 2020 as we were aware that the legacy was in probate during 2020.