



APS Support UK

For people with antiphospholipid syndrome



Sarah steps up for APS



Crazy hair for APS care!



Hyjek sisters run Brighton



In memory of Craig

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 Mazushla



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 reads "Estelle". The signature is fluid and cursive.

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.

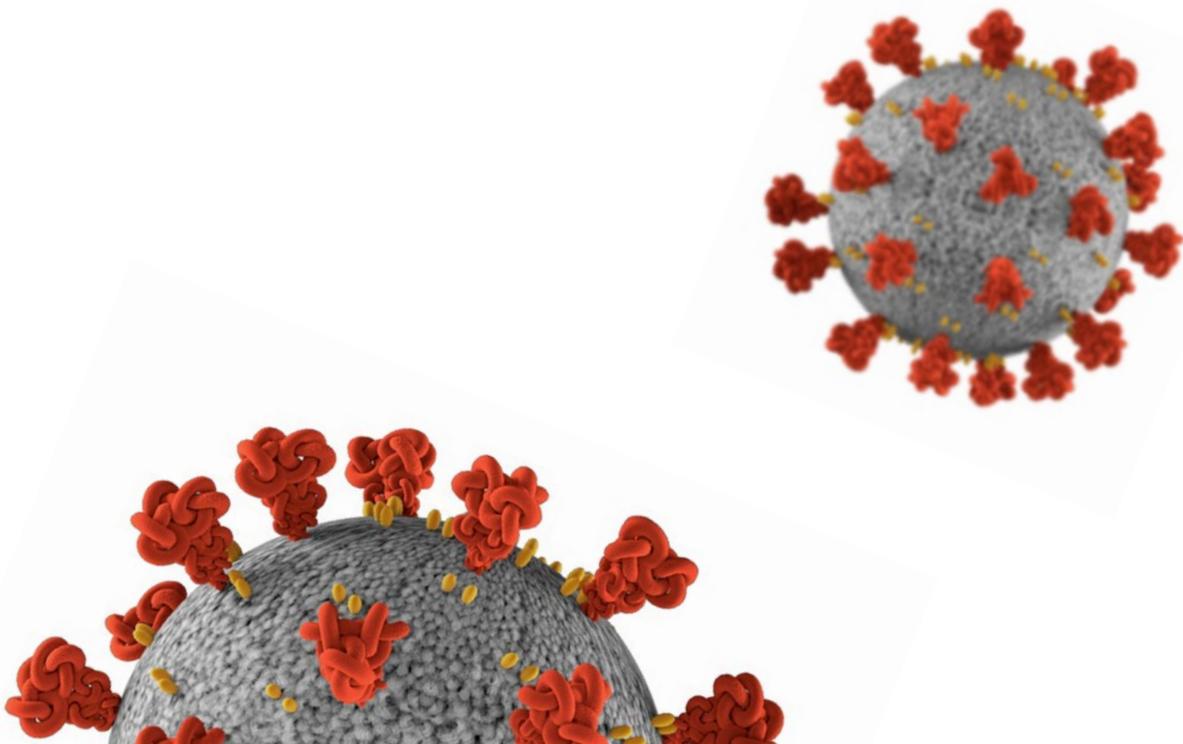
Fortunately, several scientific papers about APS and COVID were published in 2022 which made it clear the international research community is prioritising this subject; this helped us allay some of the worries of the APS community and reassured people that they are not being ignored.

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.

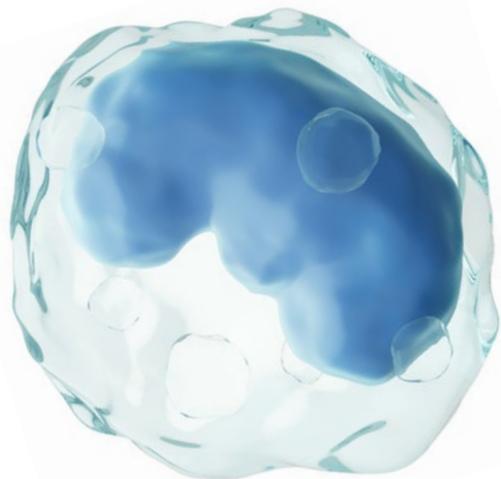
International Congress on Antiphospholipid Antibodies 2022

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.

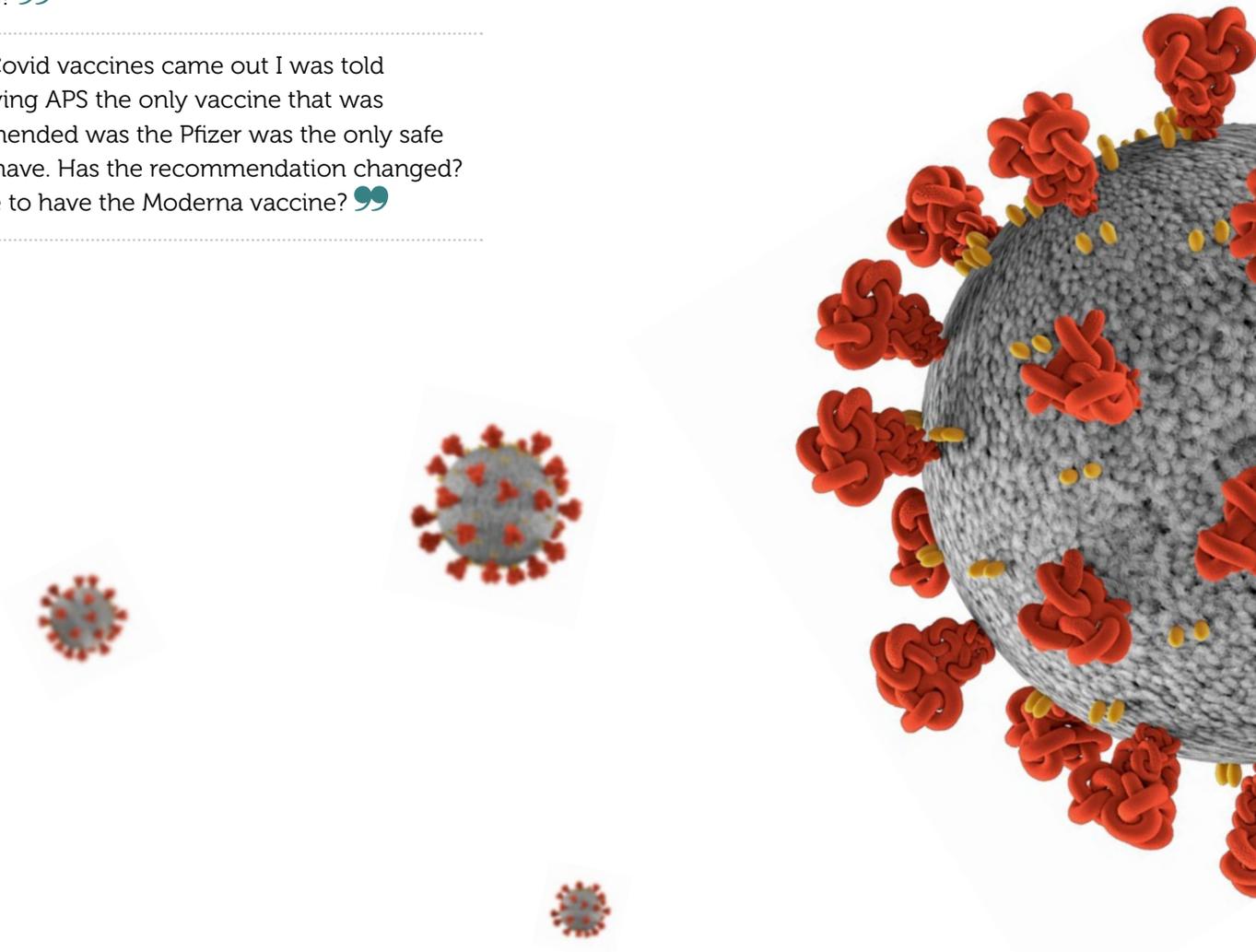
The following queries show a sample of the types of questions we received:

“ 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:

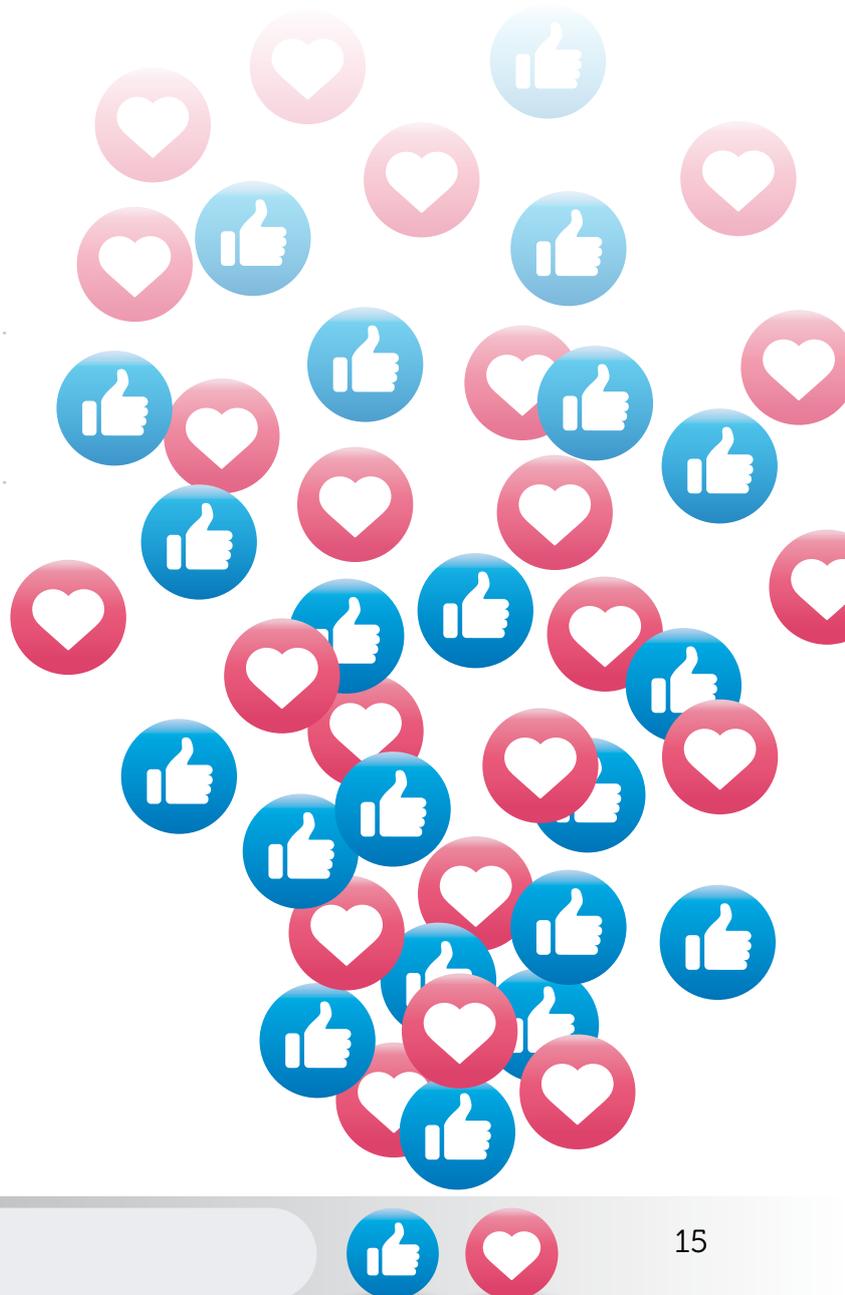
“ I’ve had APS for 10 years now, and catastrophic APS in 2020... Everything I’ve read on this site is 100% spot on. ”



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 Kilsby

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.

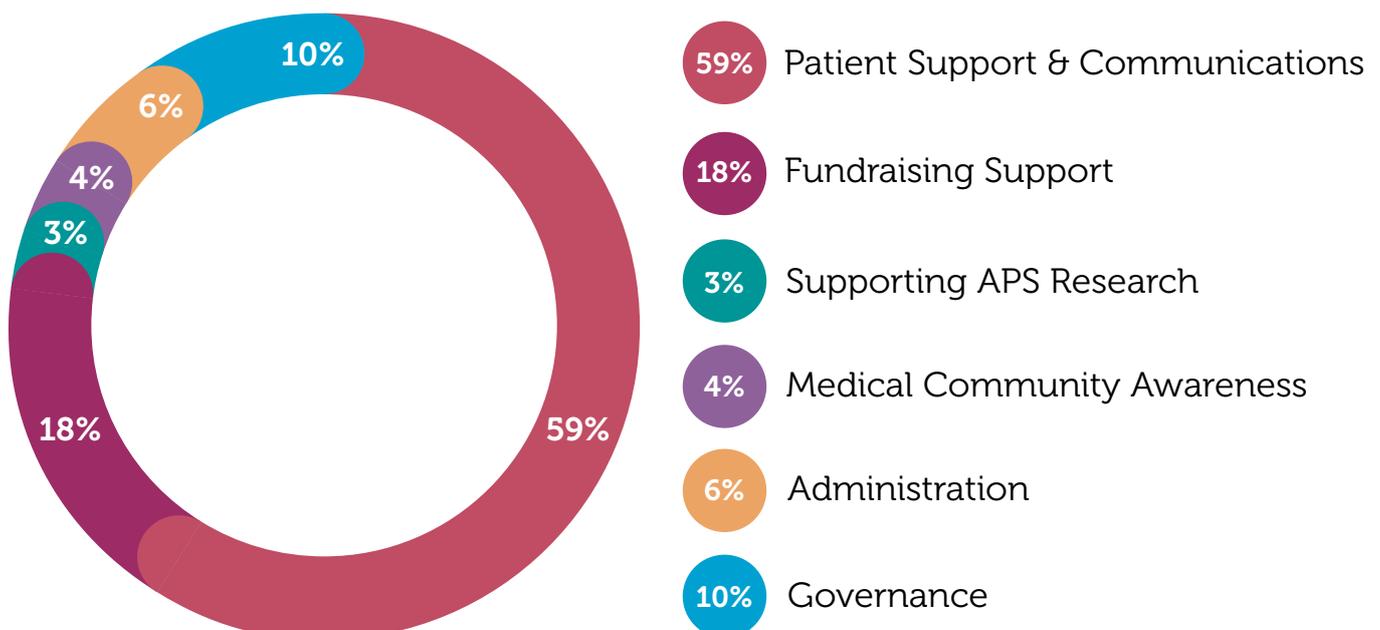
Supporting patients through charitable activities

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

