



# 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.

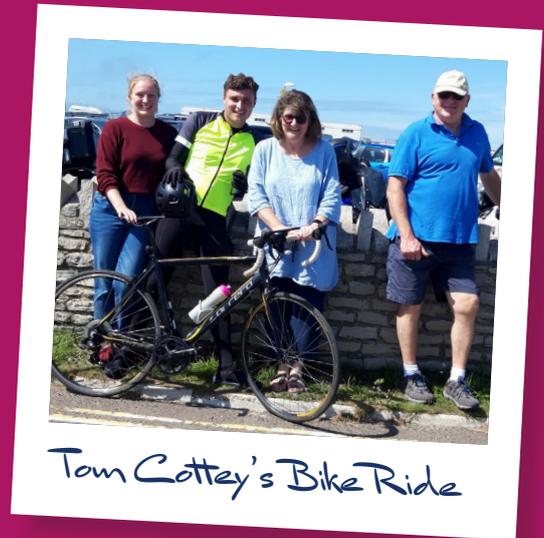
APS can cause low-grade symptoms including headaches and migraines, memory problems, joint pain and fatigue. It can also trigger potentially fatal symptoms such as deep vein thrombosis (DVT), blood clots on the lung, strokes and heart attacks.

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. ”

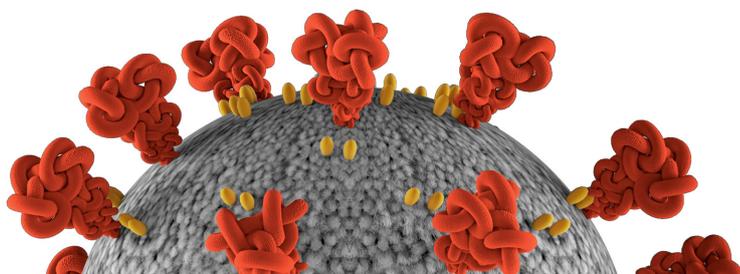
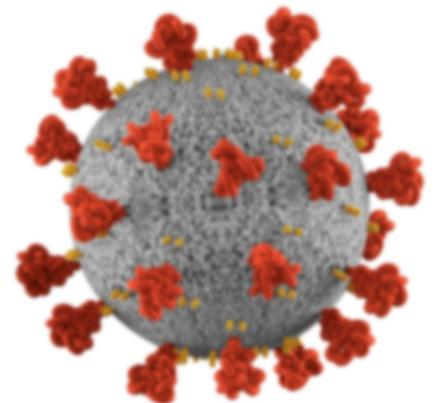
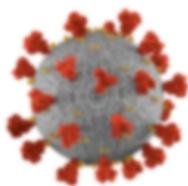
As with the previous year, there was a lot of confusion in 2021 as to whether APS patients needed to shield, which was exacerbated by the pausing and re-starting of shielding guidelines.

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, Sjogrens 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.



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 sniffly, 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 click on the logos to the right to learn more.

#### 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?

- 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 bodies 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.




# 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

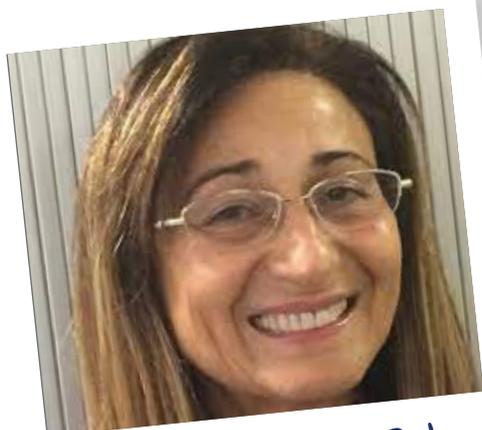
### APS Research Fund 2021 Peer Review Panel

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. ”

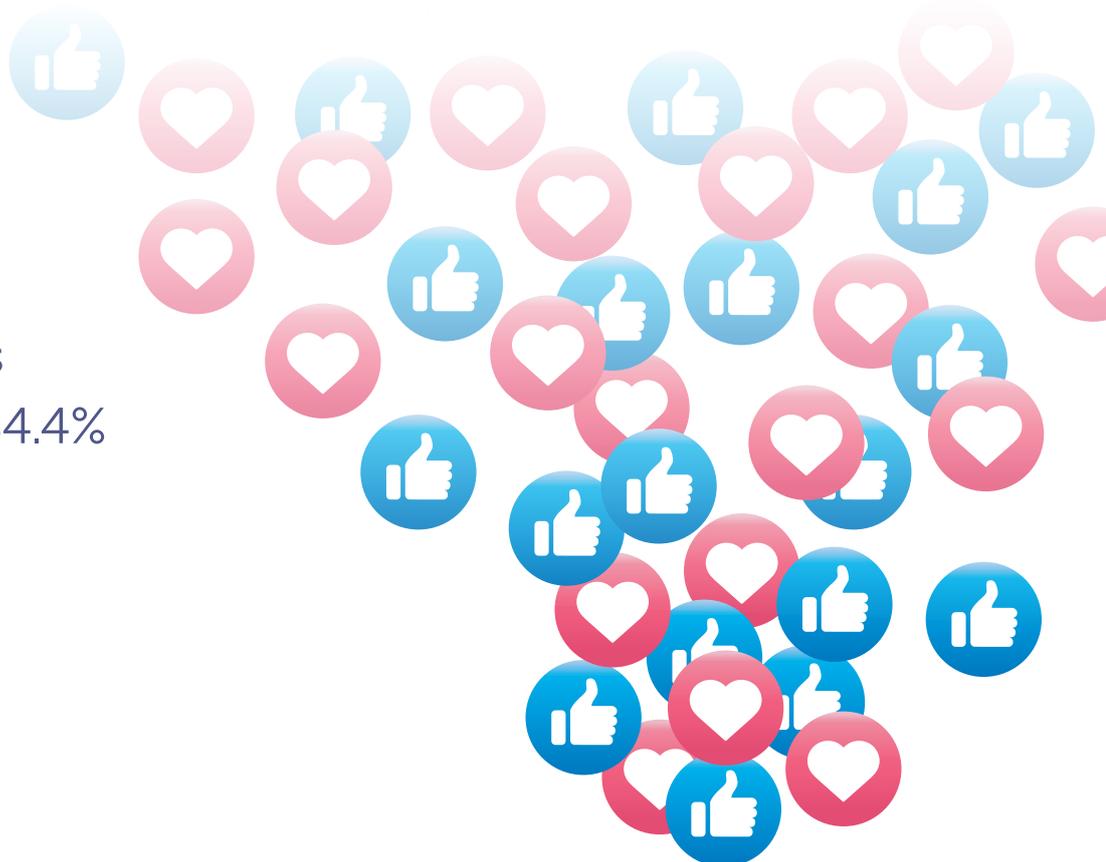
“ Thank you...everyone at APS Support UK - for people with antiphospholipid syndrome for all the work you have done and continue to do for us all with APS! ”

“ 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



Melts 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.

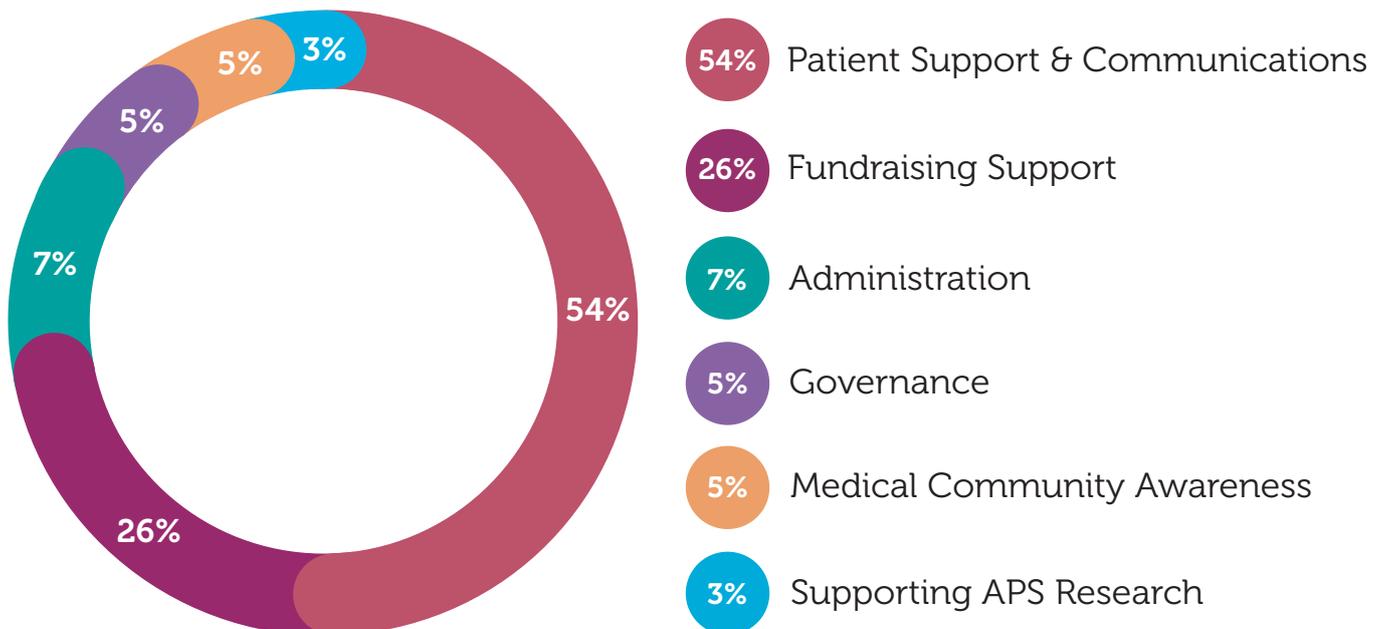
## Supporting patients through charitable activities

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](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
<b>TOTAL INCOME</b>	<b>3</b>	<b>£96,305</b>	<b>£31,730</b>	<b>£128,035</b>	<b>£127,590</b>

### 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
<b>TOTAL EXPENDITURE</b>	<b>4</b>	<b>£58,334</b>	<b>£7,940</b>	<b>£66,274</b>	<b>£92,020</b>

### NET INCOME / (EXPENDITURE) FOR THE PERIOD

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

### FUNDS

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

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
<b>TOTAL INCOME</b>	<b>3</b>	<b>£119,507</b>	<b>£8,083</b>	<b>£127,590</b>

#### EXPENDITURE

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

#### NET EXPENDITURE FOR THE PERIOD

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

#### FUNDS

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

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	
		<b>£274,982</b>		<b>£215,183</b>	

### CREDITORS

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

### FUNDS

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

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
<b>TOTAL</b>	<b>£63,433</b>	<b>£31,730</b>	<b>£95,163</b>	<b>£98,840</b>

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
<b>TOTAL</b>	<b>£31,894</b>	<b>-</b>	<b>£31,894</b>	<b>£27,930</b>

Investment Income	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
Bank Interest	£978	-	£978	£803
<b>TOTAL</b>	<b>£978</b>	<b>-</b>	<b>£978</b>	<b>£803</b>

Other Income	Unrestricted Funds	Restricted Funds	2021 TOTAL	2020 TOTAL
Sundry Income	-	-	-	£17
<b>TOTAL</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>£17</b>

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

## 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
<b>TOTAL</b>	<b>£1,024</b>	-	<b>£1,024</b>	<b>£1,494</b>

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
<b>TOTAL</b>	<b>£57,310</b>	<b>£7,940</b>	<b>£65,250</b>	<b>£90,526</b>

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

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
<b>TOTAL</b>	<b>£49,535</b>	<b>£53,827</b>

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
<b>TOTAL</b>	<b>£36,873</b>	<b>£31,730</b>	<b>(£7,940)</b>	-	<b>£60,663</b>

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
<b>TOTAL</b>	<b>£93,000</b>	-	-	-	<b>£93,000</b>

### 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)
<b>NET ASSETS</b>	<b>£60,663</b>	<b>£93,000</b>	<b>£120,112</b>	<b>£273,775</b>

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)
<b>NET ASSETS</b>	<b>£36,873</b>	<b>£93,000</b>	<b>£82,141</b>	<b>£212,014</b>

### 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.