



APS Support UK

For people with antiphospholipid syndrome



APS ally Andy Tang



Joe rocks a kilt!



In memory of Annie Tang



Mindfulness meets charity with Dipan!

Overview

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

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

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

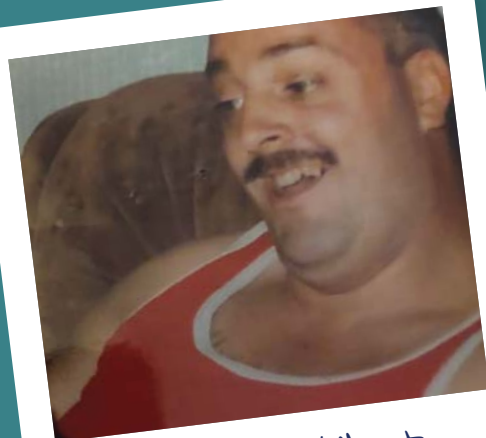
As of yet, we simply don't know why people develop APS, why some patients go on to have blood clots while others don't, why some women (but not all) have pregnancy problems and why some people are affected by symptoms more than others – vital research is needed before we can answer these questions.

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

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



Graeme with Mum



In memory of Albert

Introduction and Message from the Chair

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

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

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

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

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



Baroness Estelle Morris
Chair of APS Support UK

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

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

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

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

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



Our Mission

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

Although we are a small charity, we punch well above our weight and have achieved much so far; we always do our utmost to help those affected by antiphospholipid syndrome (APS).

Early diagnosis **saves lives**

Our Objectives

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

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

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

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

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

Public Benefit

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



Phil Godfrey

ARE YOU AWARE OF APS?

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

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

1 IN 6
STROKES

under the age of 50 are caused by APS

1 IN 6
HEART
ATTACKS

under the age of 50 are caused by APS

3
YEARS

is the average time it takes for a diagnosis of APS

34
YEARS

the average age a person is diagnosed with APS

3
MISCARRIAGES

before women are tested for APS

5
TIMES

the increased risk of stillbirth for a woman with APS

**EARLY
DIAGNOSIS**


can prevent devastating consequences

LUPUS

is commonly associated with APS

Connect with us

↪ @APSupportUK 

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



APS Support UK
For people with antiphospholipid syndrome

aps-support.org.uk
0300 323 9943

Registered charity 1138116. Copyright 2018

COVID-19 Impact in 2023

Since 2020, our charity has continually been impacted by the global COVID-19 pandemic and our services are still under great demand by our patient group. This is mainly because the issue of suitability of vaccines for people with APS is still being investigated by the research community so, understandably, we receive many patient enquiries regarding vaccine safety.

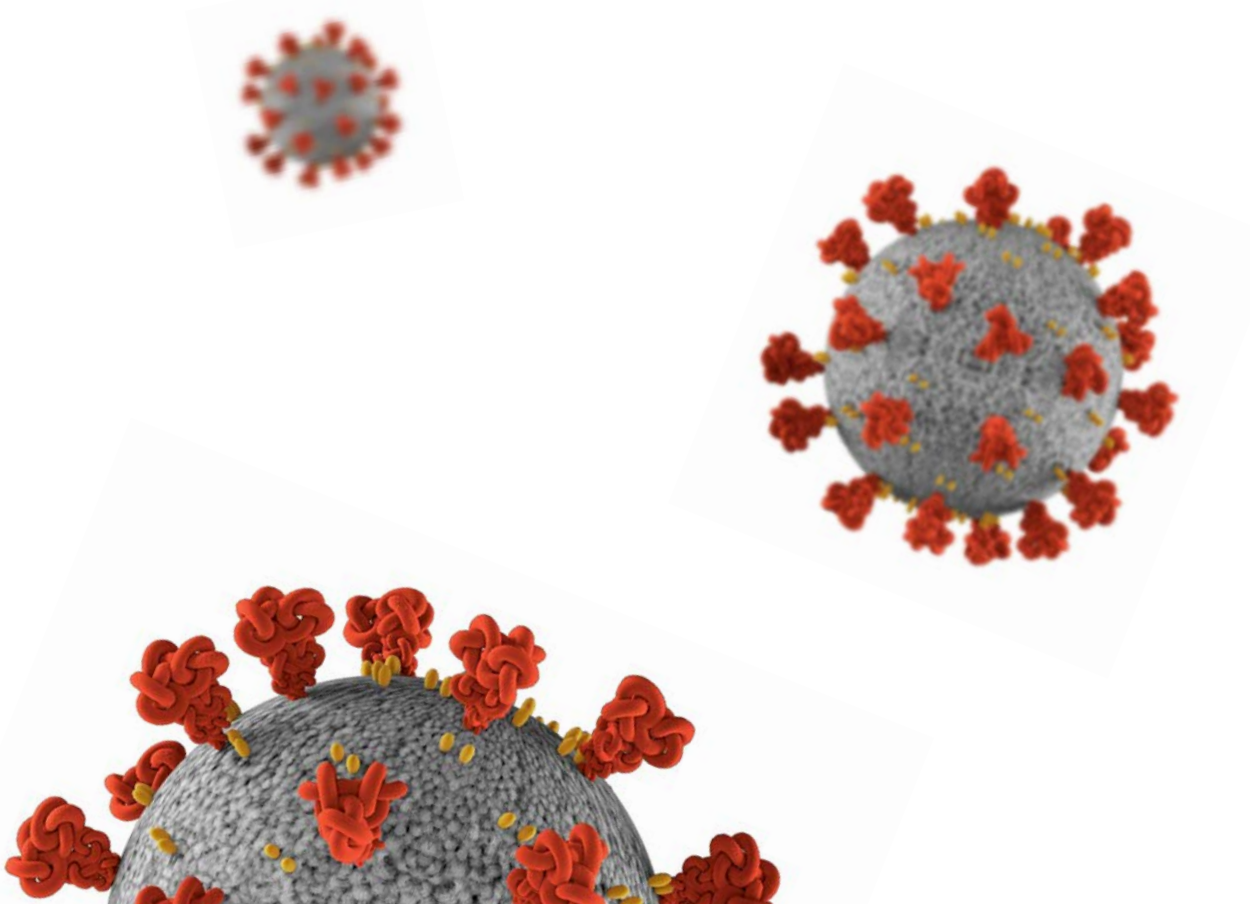
The other reasons our charity is still being affected by the pandemic is the apparent link between antiphospholipid antibodies and COVID-19 and what this potentially means for patients.

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

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

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

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



Charity objectives achieved in 2023

Raising awareness of APS in the medical community

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

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

APS ACTION Patients Engagement workgroup

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

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



Dr Thomas McDonnell

Dr Thomas McDonnell research achievements

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

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

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

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

One of our volunteer ambassadors, Yvonne Wren, is an APS Expert Patient and she kindly gave a talk entitled 'A Patient Journey – Living with Autoimmunity' to the Immunology post-graduate students at the Faculty of Biology, Medicine and Health at the University of Manchester in February 2023.

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

Tommy's

The pregnancy and baby charity

Charity objectives achieved in 2023

Raising awareness of APS in the medical community

Royal College of Midwives APS course

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

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

Royal College of GPs online course

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

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



Royal College
of Midwives
i-learn



Royal College of
General Practitioners

APS | ACTION 

How we achieved our objectives:

Offering information and understanding to anyone affected by APS

COVID-19 patient support

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

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

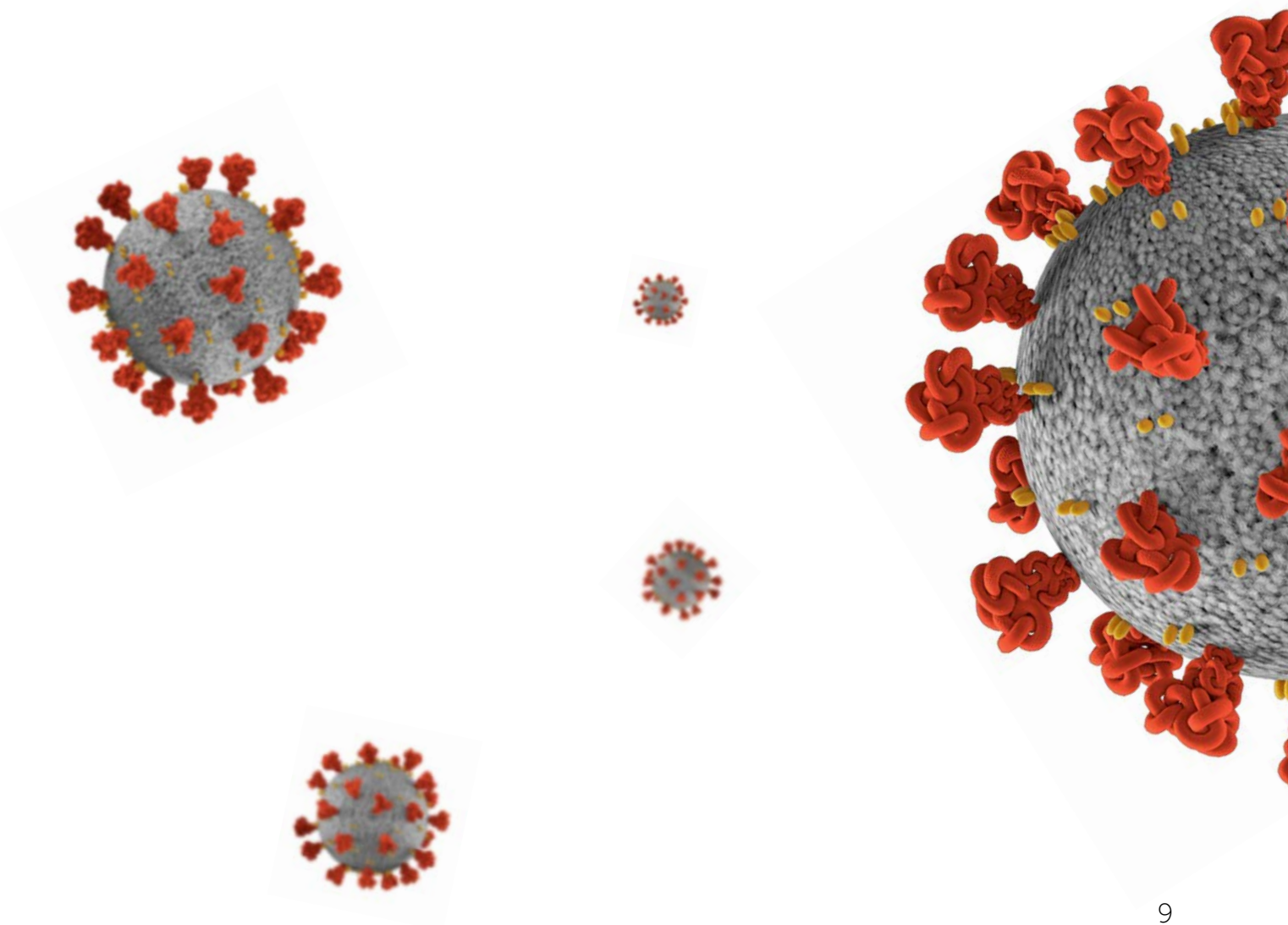
“Do people with APS qualify to get COVID tests sent out from the government?” - March 2023

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

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

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

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



How we achieved our objectives:

Offering information and understanding to anyone affected by APS

Baby Loss Certificates

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

Baby Loss Awareness Week campaign

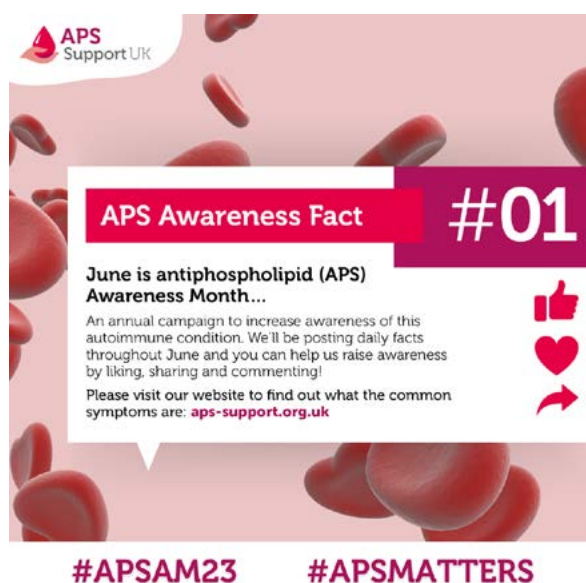
We have been involved in this national campaign for over ten years and there are now over 50 other charities involved, with SANDS and Tommy's Baby Charity as the lead groups. This year, we took a more active role by changing the banners on our social medial channels to 'pink and blue' and encouraged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

APS Awareness Month

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

Life Insurance for people with APS

We continued to partner with Cura Insurance in 2023 with the aim of helping people with APS obtain life insurance policies; Cura Insurance is a company specialising in pre-existing medical conditions. To try and reach the largest audience possible, we promoted our webpage: <https://aps-support.org.uk/self-help/living-with-aps/aps-and-life-insurance> with a QR code on our social media platforms and also sent direct e-shots and included articles in our hard copy newsletters to those who wish to receive information in this format.



How we achieved our objectives:

Funding and supporting research into APS

APS Support UK Research Fund

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

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

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

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

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

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

Self-management app for people with APS

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

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

Michigan (US) APS programme

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

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

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

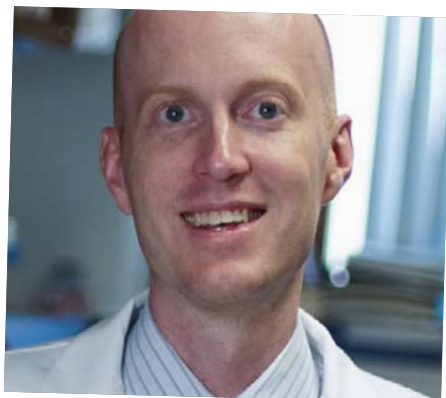
The recruitment went well, and the Michigan Group told us that they had "succeeded in obtaining surveys from 70 participants, 7 of whom found our study through you" and they thanked us and our patient group for all their help. They will be sharing the results once they have analysed them.

How we achieved our objectives:

Funding and supporting research into APS

Development and Validation of a EULAR disease activity index

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



Jason Scott Knight, MD, PhD

Swansea University Research project

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

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



Professor Lindsay Bearn



Yu (Ray) Zuo, MD, MSc

Our Impact in 2023



Our Impact in 2023

Website

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

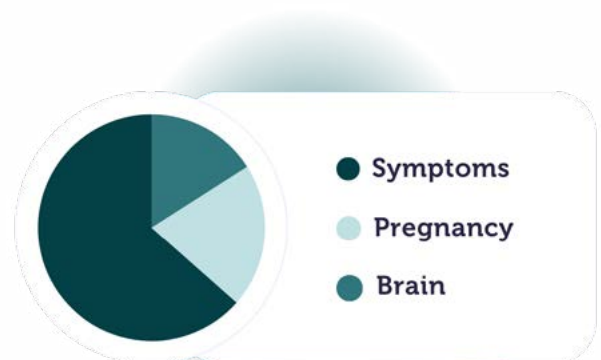
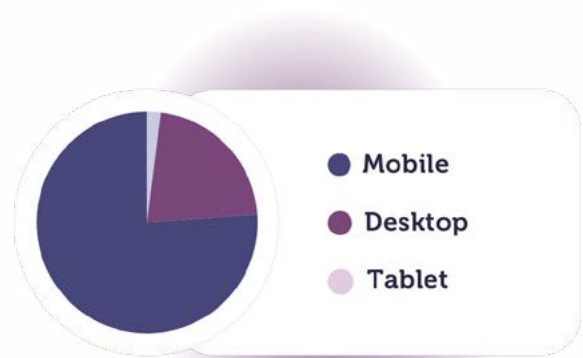
136% increase in page views

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

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

28% of all website visits

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



Our Impact in 2023

Social Media

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

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

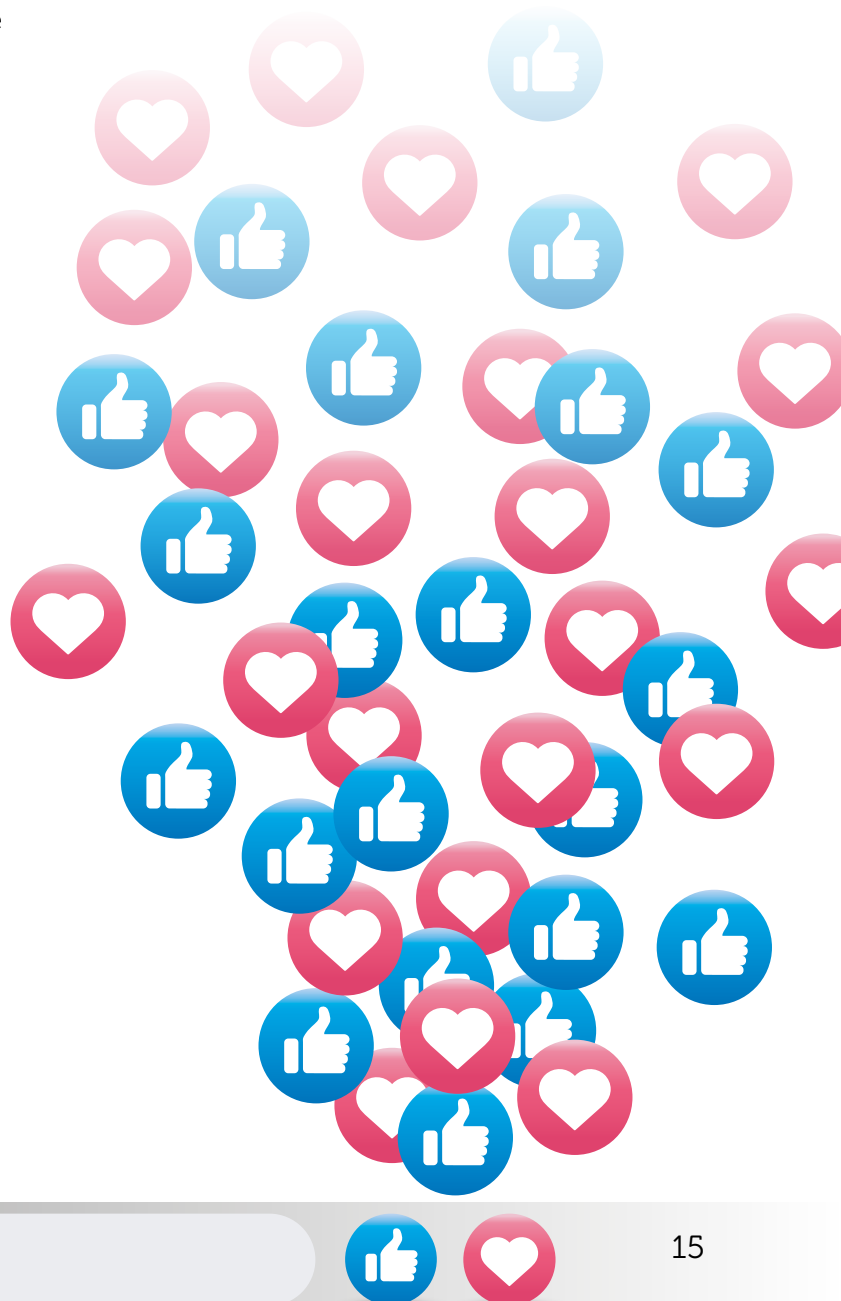
We were pleased to note that, this year, our Instagram account achieved a reach of 14.3K, an increase of 277% from the previous year. We also received 4.2K profile visits, an increase of 626%.



14.3k reach
an increase of 277%



35.5k page visits
an increase of 638%



Our Impact in 2023

Volunteers

We are very fortunate to have two world-leading APS experts as our Medical Vice-Chairs who write all our medical material, update the GP and midwife online course modules, help with complex enquiries and can contact their peers, if necessary, on specific APS subjects; for example, this year, we called upon the expert opinion of Professor Beverley Hunt OBE to review the APS Research Fund application.

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

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

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

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



Alex and Annie



Lydia Goodall

Our Impact in 2023

Search Engine Optimisation and Google Ads campaign

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

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

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

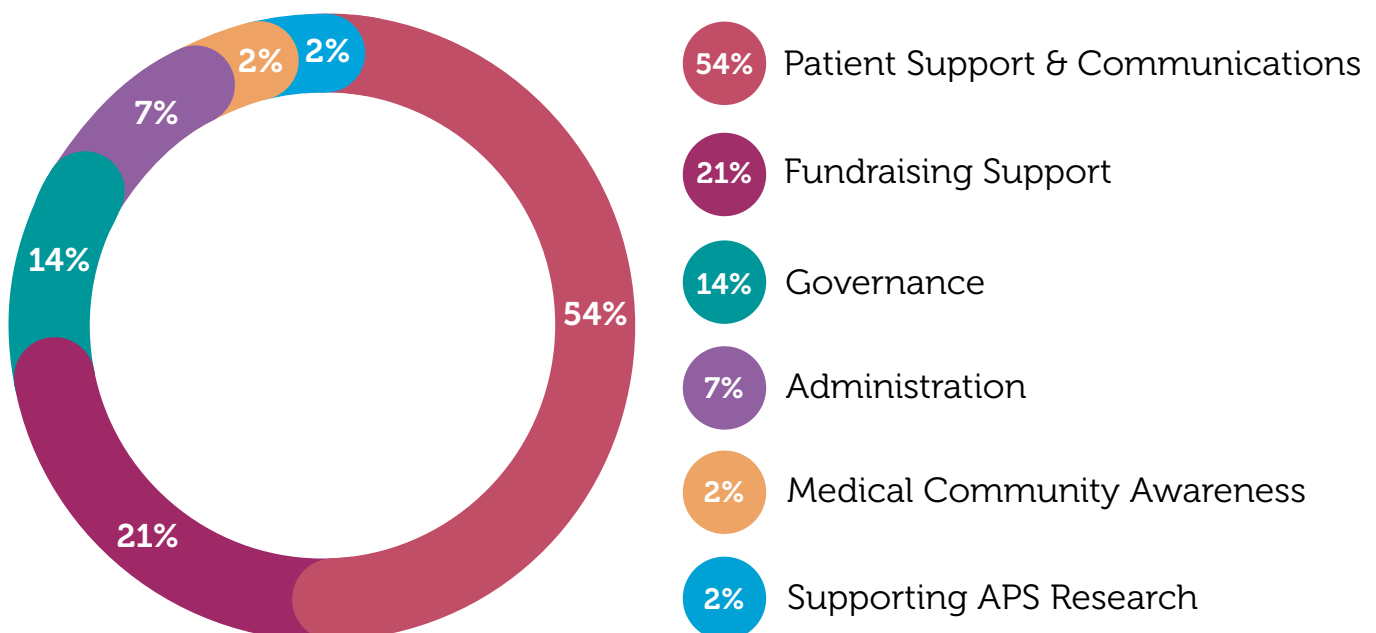
activities

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

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

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

Charity's staff activity breakdown 2023



Supporting patients through charitable

Our Impact in 2023

APS in the news 2023

As usual, there were lots of stories in the local press and online platforms involving patients and their families who were sharing their APS experiences, such as: <https://www.aberdeenlive.news/news/aberdeen-news/family-beloved-aberdeen-vet-who-8304191>

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

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



Collaboration

As we are a small charity, our impact is increased through collaboration with other charities, campaigns and organisations. We are grateful for the following organisations' generosity in sharing information and working with us during 2023:

- [APS ACTION](#)
- [APS Foundation of America](#)
- [APS Foundation of Australia](#)
- [Baby Loss Awareness Week](#)
- [Cura Life Insurance](#)
- [Different Strokes](#)
- [Eat on warfarin](#)
- [European Alliance of Associations for Rheumatology](#)
- [EURORDIS – Rare Diseases Europe](#)
- [German APS Support Group](#)
- [LUPUS UK](#)
- [Mama Academy](#)
- The [University Manchester Faculty of Biology, Medicine and Health](#)
- [Michigan University Medical School](#)
- [Philippines APS Support Group](#)
- [Prescription Charges Coalition](#)
- [Royal College of GPs](#)
- [Royal College of Midwives](#)
- [Spanish APS Association](#)
- [Thrombosis UK](#)
- [Tommy's Baby Charity](#)
- [World Thrombosis Day](#)



Thanks for all your help and support

As we look back on the remarkable year that was 2023, we want to express our heartfelt appreciation to our dedicated network of supporters, generous donors, volunteers, collaborators and passionate ambassadors.

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

It is with profound gratitude that we thank you for your staunch support. Your unwavering commitment has made a substantial difference in our fight against APS, and we are eager to embark on a brighter and yet another successful year 2024, with you by our side.



Professor Maria Tektonidou



Professor Heidi Lempp



Claire conquers the Cayman Islands

THANK YOU

Future plans for 2024

APS Nurse Specialist

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

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

PhD Studentship

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



Dr Ibrahim Tahidi-Esfahani

New website

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

APS Research Fund awards

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



Dr Hannah Bradford

Legal and Administrative Information

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

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

Charity Registration Number: 1138116

Company Registration Number: 07268671

Date of Incorporation: 2010

Financial Year: 1st January 2023 - 31st December 2023

Registered Office: The Orchard
White Hart Lane
Basingstoke
Hampshire
RG21 4AF

Trustees/Directors of the Organisation: Baroness Morris of Yardley (Chair)
Dr John Wolffe
Professor David D'Cruz
Professor Anisur Rahman
Mr James Turner
Mr Christopher Mansbridge

Bankers: NatWest
Lambeth North Branch
91 Westminster Bridge Road
London
SE1 7ZB

Independent Examiner: Knight Goodhead Limited
7 Bournemouth Road,
Chandler's Ford, Eastleigh,
Hampshire, S053 3DA

Governance and Management

Governing Document

The charity operates under a Memorandum and Articles of Association.

Appointment, retirement and training of the Trustees

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

Governance of the Charity

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

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

Financial Review

Statement of responsibilities of the trustees

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

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

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

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

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

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

Results for the Year

For the financial year ended 31 December 2023, the charity made a surplus of £92,184 (2022: £13,849). Income totalled £172,332 (2022: £91,541), with expenditure of £80,148 (2022: £77,692).

Total funds at 31 December 2023 are £379,808 (2022: £287,624), of which £93,000 (2022: £93,000) relate to designated funds, with £44,756 (2022: £50,182) relating to restricted funds. £73,000 of designated funds (2022: £73,000) relate to the designated reserve explained in the reserve policy. General funds total £242,052 (2022: £144,442). The trustees continue to keep the level of reserves under close review to ensure the needs of the charity can be met.

Reserves Policy

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

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

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

I report to the charity trustees on my examination of the accounts of the company for the year ended 31 December 2023, which are set out on pages 23 to 31.

Responsibilities and basis of report

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

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

Independent examiner's report

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

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

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

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

Statement

Financial Activities for the year ended 31st December 2023

Including Income and Expenditure Account

INCOMING RESOURCES

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

EXPENDITURE

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

NET INCOME / (EXPENDITURE) FOR THE PERIOD

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

FUNDS

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

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

Comparative statement of financial activities year ended 31 December 2022

Including Income and Expenditure Account

INCOME

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

EXPENDITURE

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

NET INCOME / EXPENDITURE FOR THE PERIOD

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

FUNDS

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

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

Balance sheet as at 31 December 2023

CURRENT ASSETS

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

CREDITORS

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

FUNDS

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

For the financial period ended 31 December 2023, the company was entitled to exemption from audit under section 477 Companies Act 2006; and no notice has been deposited under section 476. The directors acknowledge their responsibilities for ensuring that the company keeps accounting records, which comply with section 386, and preparing accounts, which give a true and fair view of the state of affairs of the company as at the end of the year and of its income and expenditure for the financial year, in accordance with the requirements of section 394 and 395, and which otherwise comply with the requirements of the Companies Act 2006 relating to accounts, so far as applicable to the company.

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

Approved by the board of trustees and signed on its behalf by:

James Turner
Trustee

Notes to the accounts for the year ended 31 December 2023

1. ACCOUNTING POLICIES

a) Accounting convention

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

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

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

b) Income

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

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

Income from tax reclaims are included in the Statement of financial activities at the same time as the gift to which they relate.

Investment income is included in the accounts when receivable.

c) Expenditure

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

d) Fund accounting

Funds held by the charity are either:

Unrestricted general funds

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

Designated funds

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

Restricted funds

Funds that can only be used for particular restricted purposes within the objects of the charity.

Restrictions arise when specified by the donor or when funds are raised for particular restricted purpose.

e) Tangible fixed assets

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

2. LEGAL STATUS

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

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

Notes to the accounts for the year ended 31 December 2023

3. INCOME

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

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

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

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

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

Notes to the accounts for the year ended 31 December 2023

4. EXPENDITURE

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

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

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

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

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

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

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

5. EMPLOYED STAFF COSTS AND NUMBERS

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

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

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

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

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

6. DEBTORS

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

7. CASH AT BANK AND IN HAND

Bank balances are held as follows:

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

Notes to the accounts for the year ended 31 December 2023

8. MOVEMENT IN FUNDS

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

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

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

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

RESTRICTED FUNDS

Louise Gergel Fellowship

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

Research and Projects Fund

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

APS Research Fund

One of our key aims is to support research into antiphospholipid syndrome (APS) and we have committed over £543,000, to-date, into research we believe will have a real impact on the APS community. APS Support UK is a grant making charity recognised by the National Institute for Health Research (NIHR) as a non-commercial partner funding research of clear value to the NHS as a result of open competition with high quality peer review. We aim to offer awards of £5,000 to APS-specific research projects on a yearly basis.

Digital Media Assistant

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

Notes to the accounts for the year ended 31 December 2022

8. MOVEMENT IN FUNDS - PRIOR YEAR FUNDS MOVEMENTS

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

Designated funds	At 1 January 2022	Income	Expenditure	At 31 December 2022
Research and Projects fund	£20,000	-	-	£20,000
Designated reserve fund	£73,000	-	-	£73,000
TOTAL	£93,000	-	-	£93,000

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

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

DESIGNATED FUNDS

Designated Reserve Fund

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

Research and Projects Fund

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

Notes to the accounts for the year ended 31 December 2023

9. RELATED PARTY TRANSACTIONS

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

10. ANALYSIS OF NET ASSETS BETWEEN FUNDS

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

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

