APS Support UK
For people with antiphospholipid syndrome


Ana's 300,000 Steps!


Phil embraced Zoom


Danny's Static 500km

Annual Report 2020

Overview

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

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

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

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

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

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

Ana's 300,000 Steps!

In Memory of Sarah

Introduction and Message from the Chair

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

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

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

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

The charity board of trustees expanded further in 2020 when Chris Mansbridge was invited to join us as our Digital Media Marketing Trustee. Chris is a highly professional Digital Media Content expert and we have no doubt that his skillset and expertise will bring a lot to our board table; he has already worked wonders with our website and search engine optimisation.

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

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

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

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

Estelle

Baroness Estelle Morris
Chair of APS Support UK

Our Mission

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

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

Early diagnosis **saves lives**

Our Objectives

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

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

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

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

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

Public Benefit

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

Phil Godfrey

Are You Aware of APS?

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

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

1 IN 6 STROKES
under the age of 50 are caused by APS

1 IN 6 HEART ATTACKS
under the age of 50 are caused by APS

3 YEARS
is the average time it takes for a diagnosis of APS

34 YEARS
the average age a person is diagnosed with APS

3 MISCARRIAGES
before women are tested for APS

5 TIMES
the increased risk of stillbirth for a woman with APS

EARLY DIAGNOSIS
can prevent devastating consequences

LUPUS
is commonly associated with APS

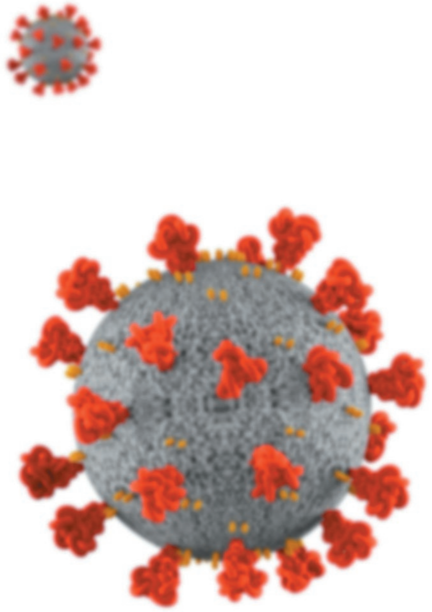
COVID-19 Impact in 2020

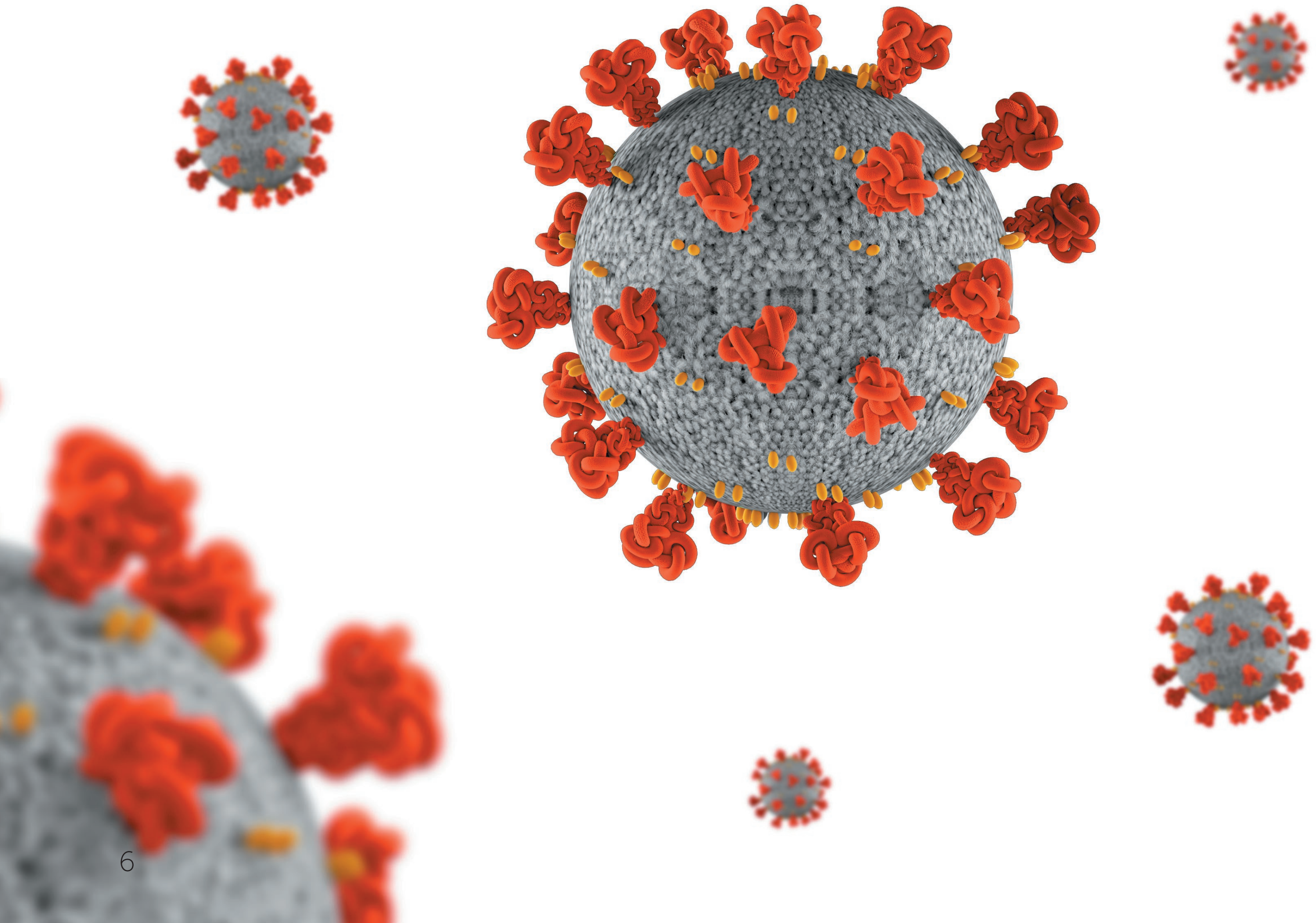
In March 2020, the unprecedented global COVID-19 outbreak affected our future plans, restricted our ability to raise funds and was the busiest year the charity has ever known since it began.

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

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

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





Charity objectives achieved in 2020

Raising awareness of APS in the medical community

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

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

Aberdeen Royal Infirmary Early Pregnancy Unit

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

Royal College of GPs online APS course

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

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

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

RCGP Royal College of General Practitioners

How we achieved our objectives:

Offering information and understanding to anyone affected by APS

COVID-19 patient enquiries

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

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

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

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

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

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

“ Should anyone with APS be a keyworker? ”

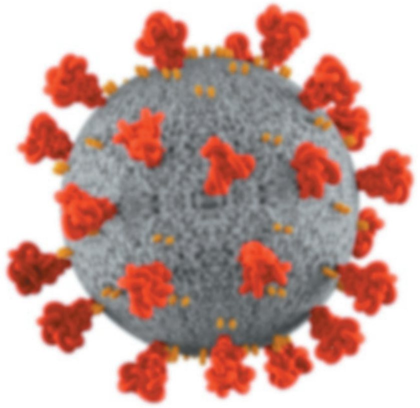
“ Is hydroxychloroquine an immunosuppressant? ”

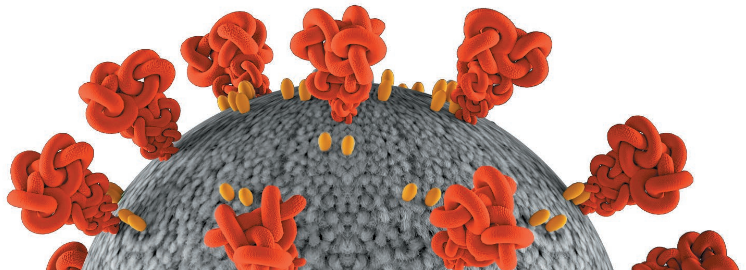
Throughout the pandemic in 2020 there was a lot of confusion as to whether APS patients needed to shield, and this uncertainty, understandably, generated a lot of enquiries from worried patients. The queries varied over time to match the ever-changing government and NHS guidance in this unique and emerging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

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

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

“ Should APS patients self-isolate? ”





How we achieved our objectives:

Offering information and understanding to anyone affected by APS

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

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

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

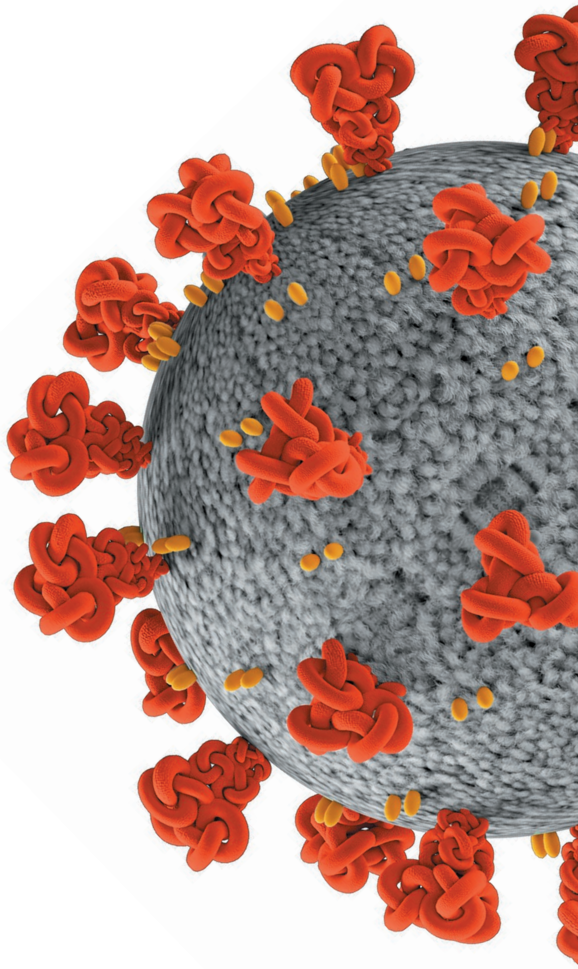
“ Is APS considered to be a vulnerable condition and can I go back to work? ”

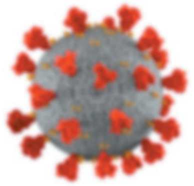
After contacting the relevant authorities, we discovered that APS is not listed as a clinically extremely vulnerable medical condition, so we were able to share this with the APS community.

COVID-19 website and social media updates

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

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





How we achieved our objectives:

Offering information and understanding to anyone affected by APS

The UK Medicines and Healthcare products Regulatory Agency (MHRA)

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

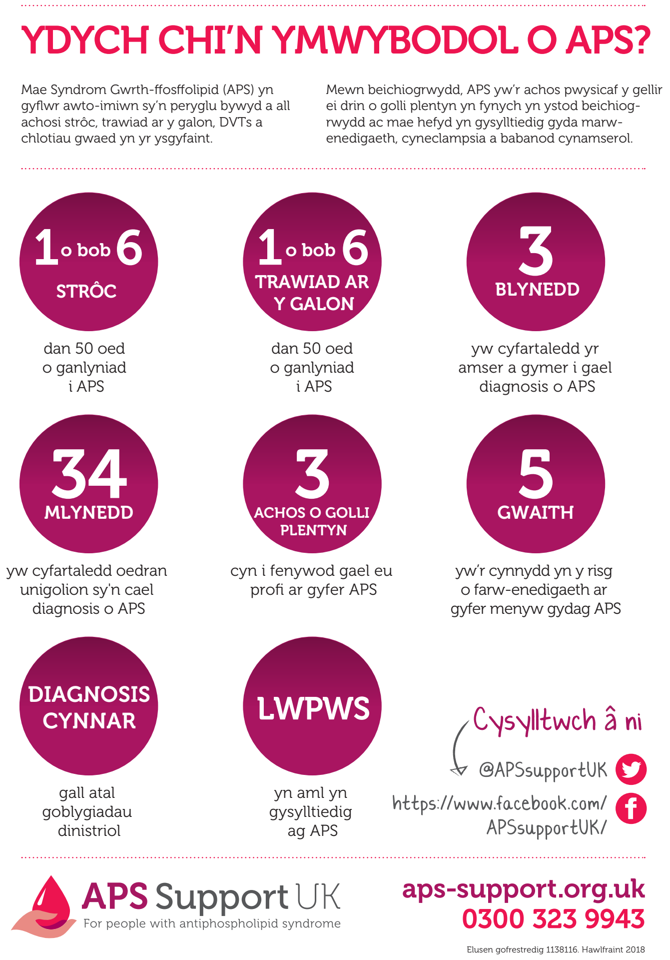
We received a deluge of enquiries about the suitability of these new COVID-19 vaccines for people with APS. We, therefore, contacted the MHRA directly in December 2020 to ask whether both the Pfizer/BioNTech and Oxford/AstraZeneca COVID-19 vaccines were considered to be suitable for anyone with antiphospholipid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

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

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

Welsh language APS poster

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



YDYCH CHI'N YMWYBODOL O APS?

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

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

1 o bob 6 STRÔC
dan 50 oed o ganlyniad i APS

1 o bob 6 TRAWIAD AR Y GALON
dan 50 oed o ganlyniad i APS

3 BLYNEDD
yw cyfartaledd yr amser a gymer i gael diagnosis o APS

34 MLYNEDD
yw cyfartaledd oedran unigolion sy'n cael diagnosis o APS

3 ACHOS O GOLLI PLENTYN
cyn i fenywod gael eu profi ar gyfer APS

5 GWAITH
yw'r cynnydd yn y risg o farw-enedigaeth ar gyfer menyw gydag APS

DIAGNOSIS CYNNAR
gall atal goblygiadau dinistriol

LWPWS
yn aml yn gysylltiedig ag APS

Cysylltwch â ni
@APSsupportUK
https://www.facebook.com/APSsupportUK/

APS Support UK
For people with antiphospholipid syndrome

aps-support.org.uk
0300 323 9943

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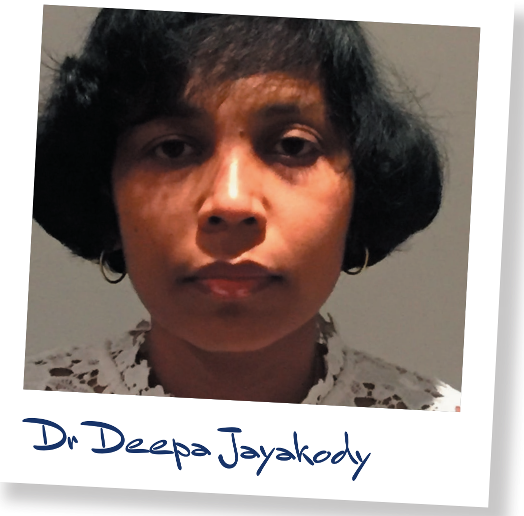


Dr Deepa Jayakody

How we achieved our objectives:

Supporting research into APS

APS Support UK Research Fund

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

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

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

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

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

Dr Jennifer Tamblyn

Dr Maria Efthymiou

How we achieved our objectives:

Supporting research into APS

UCB partnership with Patient Advisory Board

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

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

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

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

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

Fatigue and physical activity in APS patients

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

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

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

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

Our Impact in 2020

Our Impact in 2020

Website

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

57,834 website visits

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

42% of all website visits

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

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

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

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

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

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

Our Impact in 2020

Social media

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

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

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

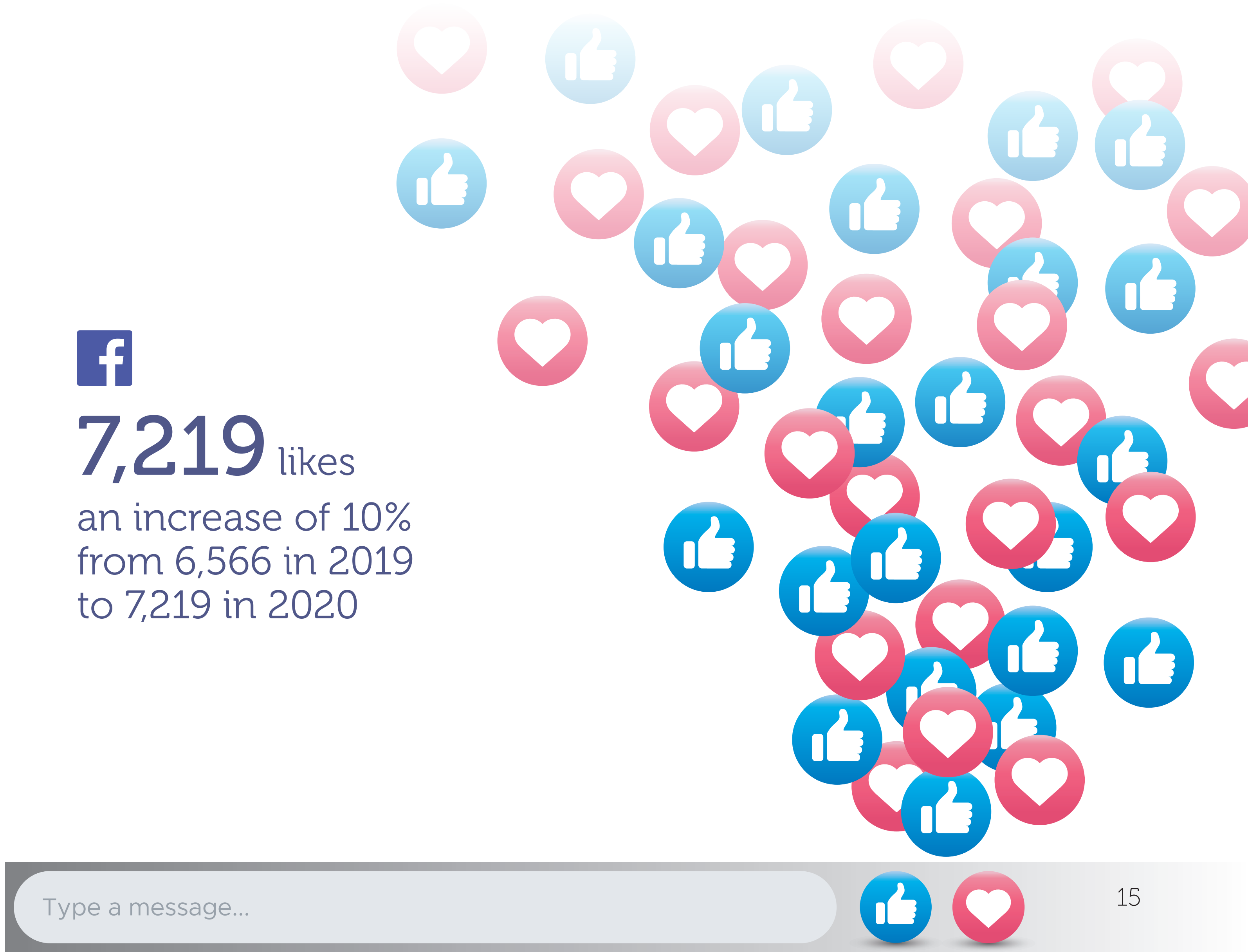
> “There is a lot of useful and interesting information provided.”

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

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

7,219 likes

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



Our Impact in 2020

Volunteers

We are very fortunate to have two world-leading APS experts as our Medical Vice-Chairs who write all our medical material, update the GP online module, help with complex enquiries and can contact their peers, if necessary, on specific APS subjects.

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

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

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

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

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

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

Pauline Bain

Pauline's SmartMedal!

Our Impact in 2020

Search Engine Optimisation

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

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

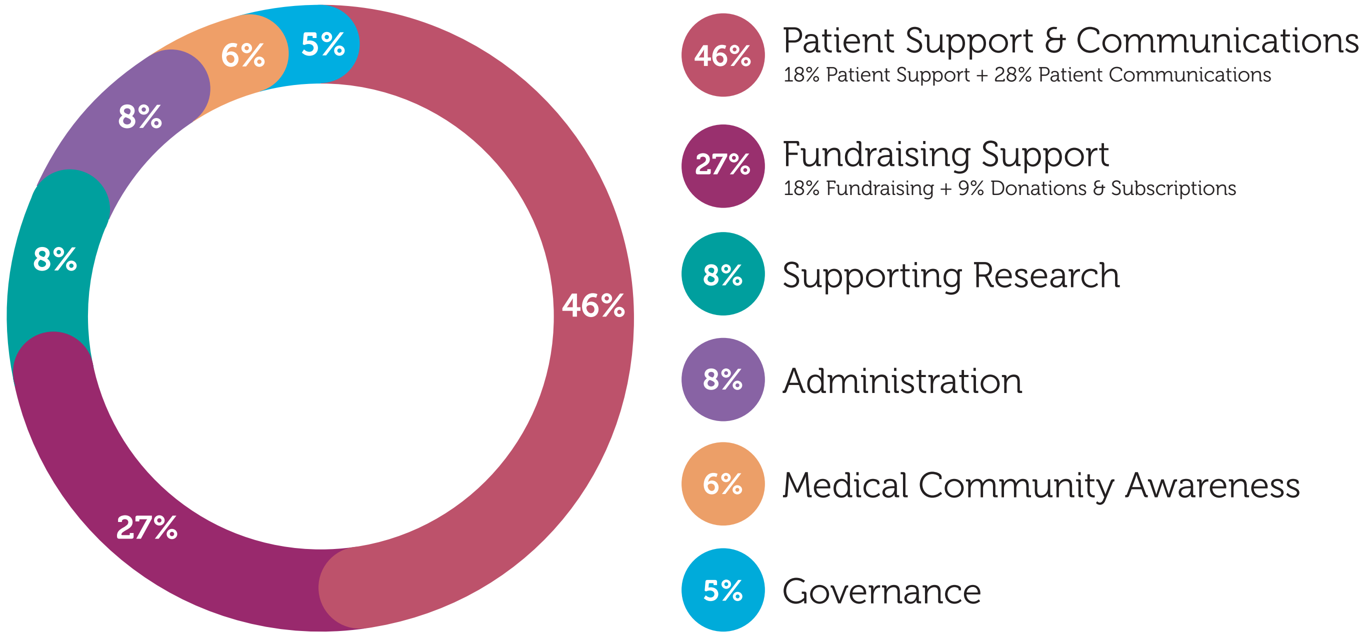
Supporting patients through charitable activities

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

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

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

Charity's staff activity breakdown 2020



Our Impact in 2020

APS in the news 2020

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

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

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

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

Collaboration

As we are such a small charity, our impact is increased through collaboration with other charities, campaigns and organisations. We are grateful for the following organisations generosity in sharing information and working with us during 2020:

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

LUPUS UK

Baby Loss Awareness Week

Different Strokes
Reclaiming lives after stroke

Thrombosis UK

Thanks for all your Help and Support

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

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

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

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

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

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

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

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

Future plans for 2021

Online Midwives course

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

APS Research Fund awards

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

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

APS Research Fund peer review panel

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

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

Google Ads campaigns

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

Dr Thomas McDonnell

Our SEO Guru

Legal and Administrative Information

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

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

Charity Registration Number:	1138116
Company Registration Number:	07268671
Date of Incorporation:	2010
Financial Year:	1st January 2020 - 31st December 2020
Registered Office:	The Orchard White Hart Lane Basingstoke Hampshire RG21 4AF
Trustees/Directors of the Organisation:	Baroness Morris of Yardley (Chair) Dr John Wolffe Professor David D'Cruz Professor Anisur Rahman Dr Andrew Pearson Mr James Turner Dr Michael Shipley Mr Christopher Mansbridge (appointed 1st January 2020)
Bankers:	NatWest Lambeth North Branch 91 Westminster Bridge Road London SE1 7ZB
Independent Examiner:	Knight Goodhead Limited 7 Bournemouth Road, Chandler's Ford, Eastleigh, Hampshire, S053 3DA

Governance and Management

Governing Document

The charity operates under a Memorandum and Articles of Association.

Appointment, retirement and training of the Trustees

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

Governance of the Charity

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

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

Risk Assessment

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

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

Update on Coronavirus 2020

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

Financial Review

Statement of responsibilities of the trustees

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

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

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

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

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

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

Results for the Year

For the financial year ended 31 December 2020 the charity made a surplus of £35,571 (2019: £28,432). Income totalled £127,590 (2019: £110,212) with expenditure of £92,020 (2019: £81,780).

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

Reserves Policy

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

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

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

I report to the charity trustees on my examination of the accounts of the company for the year ended 31 December 2020, which are set out on pages 23 to 31.

Responsibilities and basis of report

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

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

Independent examiner's report

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

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

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

Statement

Financial Activities for the year ended 31st December 2020

INCOMING RESOURCES

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

EXPENDITURE

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

NET INCOME / (EXPENDITURE) FOR THE PERIOD

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

FUNDS

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

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

Comparative statement of financial activites year ended 31 December 2019

Including Income and Expenditure Account

INCOME

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

EXPENDITURE

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

NET EXPENDITURE FOR THE PERIOD

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

FUNDS

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

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

Balance sheet as at 31 December 2020

CURRENT ASSETS

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

CREDITORS

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

FUNDS

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

For the financial period ended 31 December 2020, the company was entitled to exemption from audit under section 477 Companies Act 2006; and no notice has been deposited under section 476. The directors acknowledge their responsibilities for ensuring that the company keeps accounting records, which comply with section 386, and preparing accounts, which give a true and fair view of the state of affairs of the company as at the end of the period and of its income and expenditure for the financial period, in accordance with the requirements of section 394 and 395, and which otherwise comply with the requirements of the Companies Act 2006 relating to accounts, so far as applicable to the company.

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

Approved by the board of trustees on 27 September 2021
and signed on its behalf by

J Turner
Trustee

Notes to the accounts for the year ended 31 December 2020

1. ACCOUNTING POLICIES

a) Accounting convention

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

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

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

b) Income

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

Grants and donations are only included in the SOFA when the charity has unconditional entitlement to the resources.

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

Investment income is included in the accounts when receivable.

c) Expenditure

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

d) Fund accounting

Funds held by the charity are either:

Unrestricted general funds

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

Designated funds

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

Restricted funds

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

e) Tangible fixed assets

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

2. LEGAL STATUS

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

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

Notes to the accounts for the year ended 31 December 2020

3. INCOMING RESOURCES

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

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

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

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

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

Notes to the accounts for the year ended 31 December 2020

4. EXPENDITURE

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

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

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

The independent examination fee included in accountancy amounted to £1,123 (2019: £1,020).
Grants of £5,000 were paid as part of the Louise Gergel Fellowship Project.
Grants of £4,967 were paid to Imperial College, £13,999 to University College London and £4,782 to individuals.

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

5. EMPLOYED STAFF COSTS AND NUMBERS

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

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

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

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

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

Notes to the accounts for the year ended 31 December 2020

6. MOVEMENT IN FUNDS

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

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

RESTRICTED FUNDS

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

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

DESIGNATED FUNDS

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

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

Notes to the accounts for the year ended 31 December 2020

7. ANALYSIS OF NET ASSETS BETWEEN FUNDS

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

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

8. RELATED PARTY TRANSACTIONS

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

9. IMPACT ON GOING CONCERN - COVID 19

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

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

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

10. LEGACY

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

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APS Support UK
For people with antiphospholipid syndrome

Charity Registration Number: 1138116

Company Registration Number: 07268671

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

Telephone: 0300 323 9943

Email: info@aps-support.org.uk

Social Media:
www.facebook.com/apssupportuk
@apssupportuk
@apssupportuk

Annual Report 2020