

HUGHES SYNDROME FOUNDATION
(Company limited by guarantee and not having a share capital)

TRUSTEES ANNUAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2018

Introduction

The Trustees present their final report and the audited financial statements for the year ended 31 December 2018.

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

Reference and administrative details

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

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

Registered Company Number 07268671

Registered Charity Number 1138116

Working name APS Support UK

Principal / registered address
The Orchard
White Hart Lane
Basingstoke
Hampshire
RG21 4AF

Directors / Trustees during the year and to date:
Baroness Morris of Yardley (Chair)
Dr John Wolffe
Mrs Lynne Kirwin (resigned 9 October 2018)
Professor David D’Cruz
Professor Anisur Rahman
Dr Andrew Pearson
Dr Giles Beattie (appointed 12 Jan 2018, resigned 9 Oct 2018)
Mr James Turner (appointed 4 May 2018)

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

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

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Structure 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 newsletter/website or professional organisation such as Reach.

Governance of the Charity

The Board of Trustees meet four 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.

Objects of the charity

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.

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.

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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 performance 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.

How we achieved our objectives in 2018

Raising awareness of APS in the medical community

• **Clinical Commissioning Group project**

Following the launch of the first-ever Royal College of GPs eLearning course on antiphospholipid syndrome in 2017, we decided to raise awareness of the training module in order to reach as many busy GPs as possible. To achieve this, we contacted all the Clinical Commissioning Groups (CCGs) in the UK and asked them to promote the online APS course to all the GPs and Practices under their jurisdiction.

We contacted 229 CCGs and received 110 positive responses. We kept contacting those who did not respond but stopped after three requests. The positive responses we received were extremely helpful and these CCGs helped promote the APS GP course on their websites, intranets, newsletters and bulletins.

We also made contact with the Community Education Provider Networks for North and South London, East Kent and Berkshire who agreed to promote the course on their intranets and e-bulletins.

As a result of this project, at the end of December 2018, the total number of GPs who had completed the course had risen from 159 to 312 – almost double the amount; pre-course GP knowledge of APS was recorded at 48% and this increased to 84% on course completion. This jump in knowledge of the disease demonstrates the benefit this online APS GP training module has for doctors and, ultimately, patients.

• **World Thrombosis Day APS collaborative campaign**

This year we took part in the first collaborative APS awareness campaign between the international research group, [APS ACTION](#), and two other national charities: the [APS Foundation of America](#) and the [APS Foundation of Australia](#).

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[World Thrombosis Day](#) is held every year on 13th October and we ran the APS collaborative campaign from the 1st-13th October to coincide with this. The goal was to increase awareness of APS among the thrombosis community and beyond.

The campaign was a great success. Our pro bono graphic designer created infographics and leaflets for all four organisations to share daily on our respective social media platforms, along with agreed statements. Patients were encouraged to ask questions throughout the campaign and these were answered online by the doctors at APS ACTION; these were collated into an online document at the end of the campaign which we shared with our patient groups.

- **APS Awareness Outreach**

Our part-time APS Awareness Outreach worker continued to talk to medical students around the country. In January 2018, she spoke to a large group of MSc Clinical Immunology students at Manchester University that also included NHS biomedical scientists, intercalating medical students and medical professionals from overseas and recent graduates undertaking postgraduate study.

The session was well appreciated and feedback comments included:

“Fantastic insight into how an autoimmune disease affects the patient. Learned so much from her.”

“Really interesting to hear the patient’s story.”

“Interesting patient story, good to see another perspective.”

“Different insight gained from patient perspective, really helpful lecture.”

Offering information and understanding to anyone affected by APS

- ***Fact Sheet series***

In 2018 we updated, redesigned and wrote a series of Fact Sheets on different aspects of APS for patients to download, print or share for free from our website.

The Fact Sheet series was compiled with help from APS experts and healthcare professionals, including Professor Beverley Hunt from Thrombosis UK.

The titles completed and uploaded in 2018 include: -

[What is antiphospholipid syndrome and how can it affect you?](#)

[What are the symptoms of antiphospholipid syndrome?](#)

[How is antiphospholipid syndrome diagnosed?](#)

[Antiphospholipid syndrome: treatment and medication](#)

[Talking to your doctor: how to get the best from your appointment](#)

[Visiting the dentist when you have APS](#)

[Going into hospital when you have APS](#)

[Medical identification: what to carry in case of emergency](#)

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- *APS poster*

Due to requests from people organising awareness days and fundraisers, we produced a new APS poster thanks to one of our pro bono graphic designers. The [poster](#) is available on our website and in hard copy by request.

- *Website*

In 2018 we made our website mobile-friendly. Data from Google Analytics showed that the majority of website visitors were now accessing our information via mobile or tablet rather than desktop.

As the charity aims to offer information to anyone affected by APS, we felt it was important that everyone has easy access to our website so made the mobile-friendly project a priority.

The new website and content management system went live in August 2018 and we had almost 30,000 visitors to the site in the year. We continue to receive positive feedback such as:

“The website you provide is fantastic. Thank you so much to all of the people involved.” – Zane

“Thank you for all the excellent support you provide to APS sufferers. The website is a mine of clear, concise information and advice.” – Margaret

Over half of our website visitors were based in the UK, but we also had visitors from America, Australia, Canada, France, India, Ireland, the Netherlands, Brazil and Germany

We were pleased to see that after the Symptoms of APS, the most accessed pages in 2018 were the new Fact Sheets series.

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Supporting research into APS

- ***APS Support UK Research Fund***

We were delighted to establish the first APS Research Fund at the end of 2018.

APS Support UK became 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 set up a new Research section on our website and now offer small grants of up to £5,000 for research projects specifically concentrating on antiphospholipid syndrome.

Applications will be considered for:

- Smaller pilot studies which will lead to applications to major funders for large-scale research trials
- Enabling grants for basic science support that would enable larger projects by providing essential data for large grant applications
- Support for organising medical meetings that would facilitate improvements to the understanding of the causes, prevention and treatment of APS, and its research (NB maximum grant £1000)
- Travel awards to enable scientists or clinicians in training to attend national or international meetings to present their own research. The maximum award will be £1000 and we will require a letter from the applicant's supervisor confirming that they are in training, and proof that their research has been accepted for presentation

APS Support UK is willing to work collaboratively with other charities where research interests overlap.

We promoted the APS Research Fund on our website, social media, newsletters and e-shots and also directly alerted the British Society of Rheumatologists, the British Haematology Society and the Royal College of Obstetrics and Gynaecology.

The closing date for applications was set at 31st March 2019 and they will be reviewed by the trustees in the summer with the aim of award the funding as soon as possible.

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- ***Jointly funded APS research at University College London with LUPUS UK***

Due to the efforts of our fundraising committee, the [Louise Gergel Fellowship](#), and matching funding from [LUPUS UK](#) our charity was able to support a year-long APS research project at University College London (UCL) carried out by Dr Vera Ripoll-Nunez by awarding £28,000.

Dr Ripoll-Nunez has been working at UCL since 2011, and played a key role in the 2010-2016 research programme funded by Arthritis Research UK that looked into the causes of APS.

Her new project builds on this earlier research and will look at a new biological target in the treatment of APS: an important process called autophagy in which the body's cells renew themselves.

Dr Ripoll-Nunez is aiming to prove that a malfunction in autophagy leads the immune system to attack the body itself causing symptoms of APS, and she has already obtained promising results indicating that APS-derived antibodies act to reduce autophagy.

She says: "With the Louise Gergel Fellowship, I propose to build on the exciting results generated from my previous research at UCL".

Autophagy is a hot topic in scientific research at the moment, and the 2016 Nobel Prize in Medicine was awarded for work on the subject.

One of the available drugs that act on autophagy, sirolimus, has been the subject of a [study](#) looking at kidney transplants in patients with APS and the UCL research team believe that pursuing the investigation of autophagy in APS could potentially help patients in the future.

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Our impact in 2018

- ***APS Awareness Month and World APS Day***

June is APS awareness month and a date of 8th June 2018 for World APS Day was agreed between our charity and the American APS Foundation.

We posted infographics daily on social media to help promote awareness of APS. These were produced by the charity office and a pro bono graphic designer and aimed to cover all aspects of the condition.

These were very popular, were shared widely on Facebook and Twitter, and increased traffic by 10% to our website during June.

As with the previous year, we produced pro bono infographics that were shared on social media as part of a global awareness campaign aimed at raising understanding of antiphospholipid syndrome and its impact on patients' lives.

However, the World APS Day did not have quite as much impact as in 2017, so we have agreed with the American APS Foundation to retain the date of 9th June regardless of what day it falls on.

- ***World Thrombosis Day APS awareness campaign***

The collaborative APS awareness campaign between ourselves, [APS ACTION](#), and two other national charities: the [APS Foundation of America](#) and the [APS Foundation of Australia](#) was a great success and our charity's audience reach on Facebook spiked at over 21,000 views on one day during the campaign.

- ***Social media***

Throughout 2018, our Facebook Likes rose from 5070 to 5866 – an increase of 16%, while our Tweet Impressions on Twitter reached 129,991 which is a huge increase of 89% from the previous year. This steep rise was mainly boosted by the APS Awareness Month in June and the World Thrombosis Day campaign in October.

We also played a pivotal role in an innovative social media project devised by APS doctors and scientists from University College London. The aim was to discover the opinions of APS patients on specific research projects so that scientists could assess which topics are of most interest to patients.

Our charity helped draft the questions and lay summary for an online survey, then made it available to patients on our website and social media channels. It received over 500 respondents and the most popular research topics for patients were treatment, genetics, triggers, diagnosis and mechanistic research.

Overall it proved it is possible to conduct short-term, valuable patient engagement at low cost, using an online survey and social media. The findings were published in *Rheumatology Advances in Practice*, March 2018: [Going viral in rheumatology: using social media to show that mechanistic research is relevant to patients with lupus and antiphospholipid syndrome](#).

- ***Supporting patients***

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 and support.

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Our website and social media pages provide people with up-to-date information about APS, allow them to ask questions and discuss their health concerns. Patients now tend to contact us directly via email or social media, but we do also receive telephone enquiries so are able to offer support in a variety of ways to suit everyone. We answered around 100-150 patient enquiries a month in 2018.

We also support patients by alerting them to important APS information. For example, in May 2018, the Royal College of Ophthalmologists (RCO) updated their guidelines regarding eye testing for patients taking hydroxychloroquine. We warned over 8000 people in our patient groups to be aware that, if they were treated with hydroxychloroquine, they will now need to be referred for screening at an eye hospital clinic.

- ***Newsletter and e-shot***

We send a newsletter three times a year to the 250 or so Friends of the charity, and a free e-shot containing important news and updates to a mailing list of around 2,200 at least six times a year.

- ***INR self-testing machines loan scheme***

We run a small loan scheme where we lend patients an [INR self-testing](#) machine for a number of months. This is because the machines may not always be suitable for people with APS and, therefore, could be an expensive wasted outlay at £350. The six machines in our scheme have all been donated thanks to other patients and their families.

- ***APS ambassador to Rotary Clubs***

One of our major fundraisers, [Phil Godfrey](#), is undertaking a Round Britain Rail Tour with the aim of raising awareness of APS to as many Rotary clubs in the UK as possible. By the end of 2018, he had visited 50 clubs, most of which generously sent donations following his talk and he also raised awareness of APS in the local media such as the [Orkney News](#).

- ***APS in the news***

In April 2018, BBC Radio Tees broadcast an in-depth radio interview with our medical advisor Anisur Rahman and APS patient, Lisa Forster. It was a very emotive and powerful interview talking about APS and the effect of baby loss; as a result, we received a spike in enquiries and interest on our medial channels.

In the Awareness Month of June 2018, the [National Blood Clot Alliance](#) worked with us to produce and publish an article about APS in their newsletter.

There were various other articles about APS appearing in the Daily Mail, Marie Claire and local newspapers around the UK.

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- ***Collaboration***

As we are such a small charity, our impact can be increased through collaboration with other charities, campaigns and organisations. In 2018 we were involved with the following:

- [Anticoagulation UK – real life challenges associated with anticoagulant management](#)
- [APS ACTION](#)
- [APS Foundation of America](#)
- [APS Foundation of Australia](#)
- [Babyloss Awareness Week and the Wave of Light on 15th October 2018](#)
- [Brazilian APS group – translation of our Fact Sheets](#)
- [BUMP trial – blood pressure monitoring in pregnancy](#)
- [Different Strokes](#)
- [Eat on warfarin](#)
- [HYPATIA trial – hydroxychloroquine in pregnant women with APS](#)
- [LUPUS UK](#)
- [Prescription Charges Coalition](#)
- [Spanish APS Association](#)
- [Stroke Association](#)
- [Thrombosis UK](#)
- [World Stroke Day](#)
- [World Prematurity Day](#)
- [World Thrombosis Day](#)

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 who are able to contact their peers, if necessary, on specific APS subjects.

In 2018, we advertised for a qualified Treasurer on Reach Volunteering, and were very fortunate in finding James Turner, a professional accountant, who now oversees APS Support UK's finances in line with the best practice and legal requirements.

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, Professor Beverley Hunt, a leading APS specialist, from Thrombosis UK wrote two of our Fact Sheets.

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

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Future plans

- **APS Congress 2019**

The APS medical and scientific community hold an international APS Congress every three years and, for the first time in 34 years, it is going to take place in the UK from 17th-20th September 2019.

This conference attracts over 400 doctors and scientists with an exciting programme that will review, discuss and debate many exciting and evolving topics that are of great relevance across a range of APS subspecialties including rheumatology, haematology, obstetrics and neurology.

The conference provides an ideal platform for scientists and clinicians from around the world and multiple disciplines to discuss recent innovative and important research to prioritise research questions, and to set a roadmap for further research in thrombosis and antiphospholipid syndrome.

The Congress has asked our charity to hold two patients' sessions on the Friday and we have been invited to have an exhibition stand throughout the conference. They have requested that patients set the agenda for the morning session, and have asked us to find patient speakers for the afternoon with the aim of specialists learning from patients about unmet needs so they can prioritise future APS research.

- **APS Research Fund grants**

Having launched the APS Research Fund at the end of 2018, we are looking forward to receiving grant applications and awarding funding to worthy projects in 2019.

Although we only offer small grants, these can still help start projects that can increase survival rates and reduce the effects that antiphospholipid syndrome can have on quality of life.

Financial review

For the financial year ended 31 December 2018 the charity made a deficit of £28,011 (2017: surplus of £13,917). Income totalled £68,008 (2017: £74,903) with expenditure of £96,019 (2017: £60,986).

Total funds at 31 December 2018 are £148,012 (2017: £176,023) of which £97,000 (2017: £77,000) relate to designated funds, with £40,622 (£55,438) relating to restricted funds. £77,000 of designated funds relate to the designated reserve explained in the reserve policy. General funds total £10,390 (£43,585). 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 emergency or other unexpected need of funds and illustrates to trustees, donors, creditors, employees, beneficiaries and other 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 with 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.

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Statement of responsibilities of the trustees

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

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

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

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

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

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

Approved by the trustees and signed on their behalf by: