



*Kathryn's Scilly Swims*



*The First Tee...*



*Our best Ambassador!*



*And the dog came too!*



*In Memory of Mum Becky*

# 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.



## Introduction and Message from the Chair

2019 has been an exciting year for all the team here at APS Support UK. We have launched two new initiatives which will help the charity to have an even greater impact on the future treatment of APS.

The first of these was the launch of the APS Research Fund at the very beginning of the year. At the end of 2018, as a result of generous donations and the extraordinary fundraising efforts of one supporter in particular, the charity was in a position to set up a new fund to award small grants of up to £5,000 specifically for APS research.

This year, we were delighted to award three APS Research Fund grants to projects that should make a difference to all APS patients in the future.

This builds on the long-standing work of the trustees of our memorial fundraising sub-committee, the Louise Gergel Fellowship. Due to their dedication and generosity, we have, since 2002, committed over £500,000 to support research into APS.

The second initiative was the unique opportunity to hold a Patients' Day during the 16th International Congress on Antiphospholipid Antibodies in Manchester, UK in September 2019. This global conference is very significant to the medical APS community and we were delighted to be invited to be involved by the lead organiser, Professor Ian Bruce. The Patients' Day was a huge success and fulfilled the aim of doctors and specialists learning directly from patients about unmet needs to enable them to prioritise future APS research.

The charity board of trustees expanded further in 2019 when we invited rheumatologist, Dr Michael Shipley to join us. Mike was Honorary Secretary of the British Society for Rheumatology from 1985-1989,

and acting Chief Executive, then Medical Director of the Middlesex and University College Hospitals. We have no doubt that his skillset and expertise will bring a lot to our board table. Following the successful recruitment of our highly professional Treasurer, James Turner, via Reach Volunteering in 2018, we are now actively seeking a new trustee to assist with Digital Marketing and hope to recruit a suitable professional in 2020 using the Reach platform again.

We may be a small charity but thanks to our supporters, volunteers and team, we continue to make solid progress to improve the lives of anyone affected by APS.

I would, on behalf of the trustees, like to thank our Manager, Kate Hindle, and Support Officer, Anne Sykes for all their work and commitment. I would also extend my own thanks to the trustees who bring their time, expertise and commitment to the charity. Without all these people our work really would not be possible.



A handwritten signature in blue ink that reads "Estelle". The signature is fluid and cursive.

**Baroness Estelle Morris**  
Chair of APS Support UK

## Our Mission

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

Although we are a small charity, we punch well above our weight and have achieved much so far; we always to 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.



*Pure Gold!*

## 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

# Charity objectives achieved in 2019

## Raising awareness of APS in the medical community

### International APS Congress 2019 - Patients' Day

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

This important conference attracted over 400 doctors and scientists to Manchester with a comprehensive programme that reviewed many exciting and evolving topics that are of great relevance across a range of APS subspecialties including rheumatology, haematology, obstetrics and neurology.

Our charity was delighted to be offered the opportunity to hold two patients' sessions on the Friday by the lead Congress organiser, Professor Ian Bruce. We were also invited to have an exhibition stand throughout the conference.

The organisers felt it was important that both these sessions were entirely patient-led and requested that patients set the agenda for the morning session. We, therefore, set up an online survey to discover the topics patients wanted to be discussed in this education session and, after receiving over 300 responses, we liaised with Professor Bruce to find experts to talk about these topics.

We were also requested to find Patient Speakers for the afternoon session with the aim of specialists learning from patients about unmet needs, so they can prioritise future APS research. We were very fortunate to find four excellent Patient Speakers who were willing to share their stories in front of an audience of around 100 patients, plus doctors and scientists who were learning from them.

Thanks to a pro bono audio visual expert, all the APS Expert and Speakers' talks are now freely available on our [YouTube channel](#).

Overall, the event was a great success and we were frequently asked when we would be holding another Patients' Day. The feedback from both patients and doctors was overwhelmingly positive, and APS experts from India, Sweden and France asked for advice about setting up national APS patient groups.



*APS Congress 2019*



*Interviewee Extraordinaire*

# Charity objectives achieved in 2019

## Raising awareness of APS in the medical community

### Royal College of GPs online APS course

Following extensive research with patients, other small charities and practising GPs, we launched the first-ever Royal College of GPs (RCGP) eLearning course on antiphospholipid syndrome in March 2017.

APS Support UK funded the £19,404 online course which could be accessed freely by all healthcare professionals, medical trainees and students throughout the UK for two years.

Due to the success of this online GP course, with over 300 doctors and healthcare professionals completing the module by the end of 2018, the trustees decided to extend the hosting for a further three years at a cost of £6,000.

In 2019, the RCGP was in a better position to market their eLearning courses and made our APS module 'course of the month' in April, and also included it in their April 2019 Learning Newsletter. As a result, the uptake of the APS course increased to over 500 by the end of December 2019, with knowledge increasing from 48% to 85% on course completion: the latter highlights the impact this course will have on APS diagnosis.



*Jade's Brighton Marathon*

# How we achieved our objectives:

## Offering information and understanding to anyone affected by APS

### Fact Sheet series

Following on from the initiative we started in 2018, we continued to update, redesign and produce further Fact Sheets on different aspects of APS for patients and healthcare professionals to download, print or share for free from our website.

The Fact Sheet series was compiled with expert help from the APS Support UK Medical Advisors and Professor Beverley Hunt from Thrombosis UK who received an OBE in 2019.

The Fact Sheets produced and made freely available on our website in 2019 include: -

- Associated conditions: the autoimmune family of disorders
- Antiphospholipid syndrome and women's health
- How to inject yourself with heparin
- INR and self-testing with APS
- Driving with antiphospholipid syndrome
- APS: employment and benefits
- Family and friends: helping people understand APS
- Travelling with APS: advice and tips

### Life insurance for people with APS

Over the years, we have come to understand that one of the most arbitrary and unfair issues APS patients face is the almost impossibility of finding an insurance company that is prepared to offer them a life insurance policy.

This reason for this appears to be the lack of evidence about the nature and outcome of APS and, therefore, it is classed as 'unknown' by insurance companies and deemed too high risk. This stance seems extremely unfair given that many APS patients manage their condition well, are capable of working and paying taxes, having families and taking out mortgages. It can make life difficult when trying to secure a mortgage, and also means that many people would be unable to look after their families financially if they did have a clotting event.

Towards the end of 2019, we were approached by a specialist advisory company, Cura Insurance, who offer life insurance and mortgage solutions for people with pre-existing medical conditions. We are now working with them to provide advice and options for people with APS through both our website and Cura's in the future.



Danny Lloyd

# How we achieved our objectives:

## Offering information and understanding to anyone affected by APS

### The UK Medicines and Healthcare products Regulatory Agency (MHRA)

In June 2019, we contacted the MHRA as they had issued new advice concerning the use of direct oral anticoagulants (DOACs) in patients with APS.

Rivaroxaban (a DOAC) had been approved to treat some APS patient in August 2016 following a multi-centre trial. The London-based [Rivaroxaban in APS \(RAPS\) study](#) found that rivaroxaban could be an effective, safe and convenient alternative to warfarin in some patients with antiphospholipid syndrome.

The trial organisers stipulated that, as the study only investigated patients with APS who had venous blood clots, such as deep vein thromboses (DVTs) and pulmonary emboli (PEs), requiring standard intensity warfarin - those with an INR range of between 2.0-3.0 - the results did not apply to other groups of patients, such as those with venous blood clots who have an INR range over 3.0, and those with arterial blood clots such as stroke.

However, in June 2019, we were alerted to the fact that the manufacturer of rivaroxaban had sent letters directly to GPs who were taking their APS patients off direct oral anticoagulants as instructed; worryingly, patients told us they were not being prescribed a substitute anticoagulant such as warfarin.

We contacted the MHRA and were told that the advice had changed due to recent evidence from the [TRAPS trial](#) which was halted prematurely due to adverse results. Although the RAPS and TRAPS trials are not truly comparable, the advice was now that warfarin was preferred to DOACs for patients with APS until more evidence is available.

As this was such a serious change of policy, we made sure we reached the entire APS community via all our communication channels immediately with the following advice for patients:

- If you are taking warfarin, carry on with your treatment as normal.
- If you are already taking a DOAC do not stop taking it until you have started an alternative blood-thinning agent such as warfarin. Remember that the highest risk of having a clot would be to take no blood-thinning agent at all. Your GP should not stop your DOAC without discussing it with your haematologist and local anticoagulation clinic first.
- If you are changed from a DOAC to warfarin you will need to start having regular INR blood tests and may need to take heparin injections until the warfarin starts to work and you reach your INR target range.

We also informed patients that a number of medical specialist and patient groups in the UK were currently discussing this advice and we will be posting the outcome of those discussions when it is available.

# How we achieved our objectives:

## Supporting research into APS

### APS Support UK Research Fund

Having launched the APS Research Fund at the end of 2018, we created a new [Research section](#) on our website in January 2019 offering small grants of up to £5,000 for research projects and travel awards specifically concentrating on antiphospholipid syndrome.

We promoted the APS Research Fund on our website, social media channels, 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 grant applications was 31st March 2019 and three were submitted by this deadline. They were reviewed by the trustees in July 2019 and, as the applications were very different, the trustees decided it was unnecessary to send them for peer-review because they would be impossible to compare.

All three were considered valid and worthwhile so the following grants were awarded in 2019:

- Dr Thomas McDonnell from University College London was awarded £3,999.08 to work on the project: 'The structure and function of Beta-2-Glycoprotein I: why do we get APS and how does it work?' Dr McDonnell was also awarded a fellowship in 2019 by the Medical Research Foundation to further study B2GPI for the next three years.
- Dr Doruk Erkan, one of the Founding Members of APS ACTION, the international group for collaborative research into APS, was awarded £5,000 to work on the project: 'A lupus anticoagulant testing protocol for anticoagulated patients'.
- Dr Maria Efthymiou from University College London was awarded a £1,000 travel grant to the International Society on Thrombosis and Haemostasis (ISTH) in Melbourne in 2019. One of Dr Efthymiou's abstracts was a top poster winner in the APS session at this international meeting.

### Bursaries awarded at the International APS Congress 2019

As 2019 was a special year in that the International APS Congress was being held in the UK in September for the first time in 34 years, and this meant that charity representatives could attend the conference, it was decided to grant two bursaries of £1,000 for outstanding research posters. We liaised with the lead organiser, Professor Ian Bruce, and the British Society of Rheumatology and selected the following:

- Dr Mynhi Dang from Imperial College was awarded a bursary for her poster about Plasma Von Willebrand Factor (VWF) and ADAMTS13 profiles in antiphospholipid syndrome and lupus.
- Dr Maria Efthymiou from University College London was awarded a bursary by our memorial fundraising sub-committee, the Louise Gergel Fellowship for her research paper at the International Society on Thrombosis and Haemostasis (ISTH) in Melbourne. The paper looked at the comparison of Local and Core Laboratory Lupus Anticoagulant Results from the APS ACTION Database/Repository.



*Dr Thomas McDonnell*

# How we achieved our objectives:

## Supporting research into APS

### External APS research support

In addition to funding APS research, our charity also provided support to external research projects including:

#### *Rivaroxaban in Stroke and APS trial*

As with the 2016 Rivaroxaban in APS (RAPS) trial, our Charity Manager agreed to be the layperson on the Trial Steering Committee for this research project led by Professor Hannah Cohen from University College London. The trial was due to start in 2018 and the charity would be assisting with the recruitment process. However, following the new advice in June 2019 from the MHRA that direct oral anticoagulants were mainly unsuitable for people with APS, an extraordinary meeting was called to discuss the future of the trial. The consensus was the trial should aim to continue following Ethics Approval and our charity reviewed all the amended Patient Information Sheets.

#### *APS BioBank*

Our Charity Manager agreed to join the Review Committee for the BioBank being set up at St Thomas' Hospital, London by Professor Beverley Hunt OBE. The aim of the BioBank is to provide researchers with samples of plasma, serum and DNA from people with APS. The other main role of the charity will be to raise awareness of the BioBank and to recruit willing patients.

#### *The prevalence and impact of fatigue and physical inactivity in people with primary antiphospholipid syndrome*

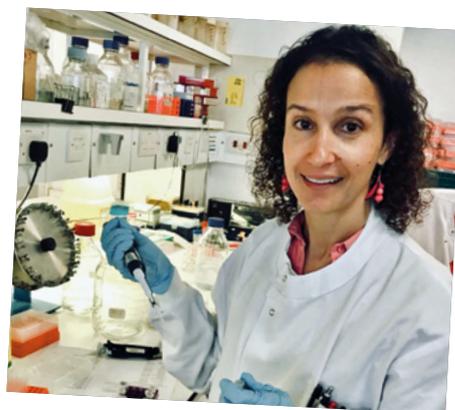
In 2017, the charity assisted with this study by liaising with our patient group and the researchers and, in 2019, an abstract for the paper was accepted at EULAR. We had further talks with the researchers and hope to help them take this work further by working with our patient group to design a self-management programme that will help people with APS to better understand and manage their fatigue.

#### *APS and B-cell chimeric autoantibody receptor T-cell (CAAR-T) therapy*

A researcher from Imperial College London was applying for a grant for this proposed study and requested that we review the lay summaries.

#### *The occupations of women with APS*

This was a project undertaken by a student studying for an Occupational Therapy Masters degree at the University of Cumbria. We facilitated by publicising this project to our patient group via our communications channels so the necessary number of patient interviews could be conducted.



*Dr Vera Ripol*

## Our Impact in 2019



# Our Impact in 2019

## Website

In 2019 we had 18,858 website visits from 123 countries. 57% of these came from the UK, while 24% came from the United States. In terms of demographics, the majority of visits were from female users aged between 35-44. Additionally, over 50% of all website visits were accessed on a mobile device.

**18,858** website visits

## Social media

Throughout 2019, our Facebook Likes grew from 5,867 to 6,570, an increase of 12%, and our Facebook Followers increased from 5,734 to 6,476, a rise of 13%. We received favourable reviews throughout the year including:

“ I have read more information on this site than I have in the last 20 years of being diagnosed. ”

“ This is a supportive group and great source of information. ”

“ So very supportive, helpful with real people and real experiences. ”

“ Any information on here is good ... If you get the right treatment and learn how to manage the condition it helps us all understand how to look forward to the future, and I'm all for that. ”

Our Tweet Impressions on Twitter reached 139,840, an increase of 8% since the previous year. This was helped by the Awareness Month in June 2019 and the Patients' Day at the International APS Congress in Manchester.

The Homepage, Symptoms page and Factsheets, were the three most popular pages viewed in 2019, making up

**23%** of all website visits



**6,570** likes

an increase of 12%  
from 5,867 in 2018  
to 6,570 in 2019



**139,840** impressions

an increase of 8%  
from 2018

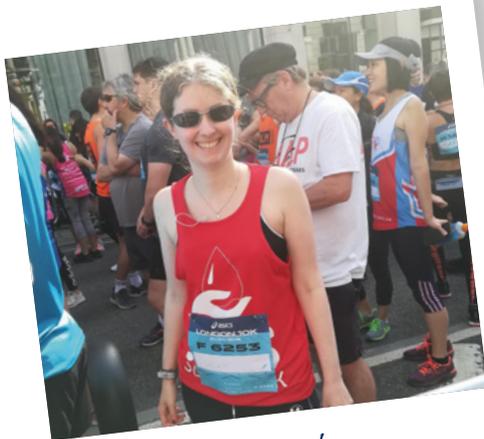
# Our Impact in 2019

## Shaping future research priorities in APS

APS Support UK was delighted to be invited to hold a Patients' Day during the 16th International APS Congress in Manchester, UK this year. This was a unique opportunity for APS patients to voice their opinions to world-renowned APS experts on the direction of future research priorities in a face-to-face setting.

The Question and Answer sessions following the APS Experts and Patient Speakers allowed doctors and scientists to learn about unmet needs directly from the patients. The feedback was extremely positive from the medical community and one of the Patient Speakers was invited to talk to a Canadian scientific group in 2020.

All the APS Expert and Patient Speakers' talks, plus Question and Answer sessions are now freely available on our [YouTube channel](#).



*London 10K Hero!*



**Today is World APS Day!**

Share this post and join APS Support UK and our friends around the world in raising awareness of antiphospholipid syndrome



## APS Awareness Month and World APS Day

June is APS awareness month and, in 2018, we had agreed with the APS Foundation of America to keep to a fixed date of 9th June for World APS Day from now on to create the maximum impact and reach.

This year, APS Support UK and the APS Foundation of America were joined by two other national APS patient groups to help promote World APS Day: the APS Foundation of Australia and the Spanish APS Association.

One of our pro bono graphic designers created a new image to reflect this year's collaboration and this graphic was shared with all four charities. It was very popular and was widely shared on social media channels throughout the world with our audience reach peaking at 20,000 on World APS Day.

As in previous years, we produced 30 infographics that were shared on our Facebook and Twitter accounts throughout June 2019.

# Our Impact in 2019

## 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.

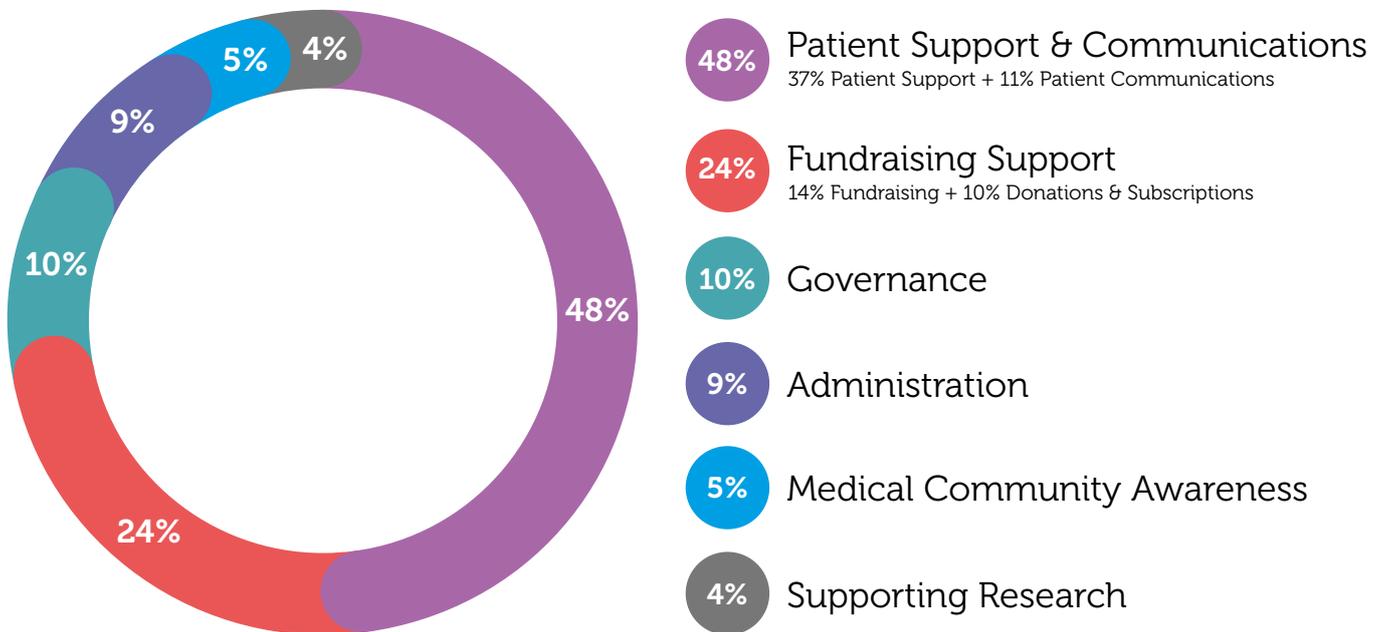
Thanks to our Treasurer, Jim Turner, who we recruited through Reach Volunteering in 2018, the two staff members of the charity were able to easily and quickly log the time they spend on charitable activities this year and the results for 2019 are as follows:

As this was the first year we have been in a position to record the activities of our one full-time and one part-time members of staff, we were pleased to see that supporting APS patients is our main activity; it means we are living up to the name APS Support UK.

Our website and social media channels provide people with up-to-date information about APS, allow them to ask questions and discuss their health concerns. Patients now predominantly contact us directly via email or social media, and we do our utmost to answer every single enquiry.

We also send out regular newsletters and e-shots, ensuring we prioritise important information that can impact patients' health.

Charity's staff activity breakdown 2019



# Our Impact in 2019

## APS in the news 2019

Throughout 2019, numerous articles about APS appeared in both the national and local media helping raise the profile of the condition; the most significant were the following:

The Medicines Discovery Catapult is a government funded initiative that aims to “help UK SME biotechs, academics and innovators have access to the laboratory facilities, knowledge, data, technologies and networks”. We were invited by their Chief Business and Strategy Officer to write a [blog to help promote awareness of APS](#) to researchers and scientists in the pharmaceutical and biotech industries.

In April 2019, the Daily Record reported on [APS patient, Kris Simpson](#), who was told he could not have heart treatment to save his life, despite his London consultant recommending he was eligible. Thanks to a crowd-funding appeal and lots of publicity, the decision to give 32-year-old Kris palliative care was reversed and the heart treatment is now going ahead. Our charity was able to help promote Kris’ plight and we are happy with the result.

The BBC ran an article about [miscarriage and APS](#) in June 2019. This was then picked up by other news agencies and was republished in the Times, the Independent, the Metro, the Evening Standard, the Mirror, the Daily Mail and even the New York Post, Fox News and the New Zealand Herald.

During the International APS Congress Patients’ Day in September 2019, our charity was contacted by the Manchester University NHS Foundation Trust who liaised with us to produce a number of press releases during the four-day event to help raise awareness of APS. They even produced a short video filming our Chair, Estelle Morris, and APS patients attending the event which was broadcast on the local television station ‘That’s TV Manchester’ during the four days the conference was taking place.

We would particularly like to thank APS patient, Krista Hoskinson, who bravely gave a spontaneous interview that was broadcast and later published on the [Manchester University NHS Foundation Trust website](#).

## Collaboration

As we are such a small charity, our impact is increased through collaboration with other charities, campaigns and organisations. We are grateful for their generosity in sharing information; in 2019 we were involved with the following:

- [Anticoagulation UK](#)
- [APS ACTION](#)
- [APS Foundation of America](#)
- [APS Foundation of Australia](#)
- [Babyloss Awareness Week](#) and the [Wave of Light](#) on 15th October 2019
- [British Society of Rheumatologists](#)
- [BUMP trial](#) – blood pressure monitoring in pregnancy
- [Chana – fertility network](#)
- [Different Strokes](#)
- [Eat on warfarin](#)
- [LUPUS UK](#)
- [Prescription Charges Coalition](#)
- [Spanish APS Association](#)
- [Stroke Association](#)
- [Thrombosis UK](#)
- [World Kidney Day](#)
- [World Stroke Day](#)
- [World Thrombosis Day](#)

# Thanks for all your Help and Support

We would like to say a huge thank you to everyone who has supported us throughout 2019. This includes generous donors, fabulous fundraisers and patients sharing information about their experiences to help raise awareness of APS.

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 2019, Dr Michael Shipley joined the board of trustees. Dr Shipley is a rheumatologist that has been practising since 1982 and was Honorary Secretary of the British Society for Rheumatology from 1985-1989. He was also acting Chief Executive, then Medical Director of the Middlesex and University College Hospitals. Mike is very widely published and his work has often focussed on the psychological aspect of chronic disease.

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, web designer and audio visual professional. These qualified people all have links to APS and save the charity thousands of pounds every year.

As we held an APS Patients' Day this year, we enlisted the help of four wonderful volunteer Patient Speakers: Cath Atkin, Danny Lloyd, Lucy Thomas and Yvonne Wren. Expert APS doctors also gave their valuable time to present talks and answer patient questions and we would like to thank Professor Ian Bruce, Dr Paul Fortin, Dr Clare Tower and Dr Stephane Zully for their pro bono work.

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 has spoken to over 100 Rotary Clubs throughout the UK and is a major fundraiser for our charity.



*Take your partners...*



*Greetings from Venice!*

## Future plans

### Royal College of GPs online APS course

In 2019 we decided to continue funding the Royal College of GPs online APS course for a further three year. The RCGP has informed us that the module is due to be reviewed in the spring of 2020, and they have asked us for our input regarding amendments and updates such as the new advice about direct oral anticoagulants and catastrophic APS.

### APS Research Fund awards 2020

We launched the APS Research Fund at the end of 2018 and have awarded five grants totalling approximately £12,000 in 2019.

We intend to continue offering small grants again in 2020 and we will be making the application process available on our website at the beginning of the year with deadline of 15th April 2020. We are looking forward to receiving grant applications and awarding funding to worthy projects in 2020.

### National APS Patients' Day 2020

Due to the overwhelmingly positive feedback following the APS Patients' Day this year, we intend to hold a similar national event in 2020. We are investigating venues in Birmingham and have arranged to meet the event organisers at IET Austin Court early in the year.

### Digital marketing trustee

At the end of 2019 we advertised for a Digital Marketing Trustee via Reach Volunteering. We are hoping to appoint a new trustee with knowledge and expertise to help our website's search engine optimisation and also to move forward with the Google Ad-Words grant and potential campaigns.



*The Outlaw Triathlon*



*The Future's Bright!*

## Legal and Administrative Information

The Trustees present their final report and the audited financial statements for the year ended 31 December 2019.

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 2019 - 31st December 2019

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 (appointed 26th November 2019)

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 2019 the charity made a surplus of £28,432 (2018: deficit of £28,011). Income totalled £110,212 (2018: £68,008) with expenditure of £81,780 (2018: £96,019).

Total funds at 31 December 2019 were £176,444 (2018: £148,012) of which £93,000 (2018: £93,000) relate to designated funds, with £57,538 (2018: £40,622) relating to restricted funds.

£73,000 of designated funds relate to the designated reserve explained in the reserve policy. General funds total £25,906 (2018: £14,390). 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 2019, 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 2019

### INCOMING RESOURCES

	Notes	Unrestricted Funds	Restricted Funds	2019 TOTAL	2018 TOTAL
Donations and legacies		£35,292	£30,938	£66,230	£42,246
Charitable activities		£42,715	-	£42,715	£24,460
Investment income		£1,011	-	£1,011	£1,021
Other income		£256	-	£256	£281
<b>TOTAL INCOME</b>	<b>3</b>	<b>£79,274</b>	<b>£30,938</b>	<b>£110,212</b>	<b>£68,008</b>

### EXPENDITURE

	Notes	Unrestricted Funds	Restricted Funds	2019 TOTAL	2018 TOTAL
Raising funds		£2,564	-	£2,564	£4,354
Charitable activities		£65,194	£14,022	£79,216	£91,665
<b>TOTAL EXPENDITURE</b>	<b>4</b>	<b>£67,758</b>	<b>£14,022</b>	<b>£81,780</b>	<b>£96,019</b>

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

	Notes	Unrestricted Funds	Restricted Funds	2019 TOTAL	2018 TOTAL
<b>TOTAL NET INCOME</b>		<b>£11,516</b>	<b>£16,916</b>	<b>£28,432</b>	<b>(£28,011)</b>

### FUNDS

	Notes	Unrestricted Funds	Restricted Funds	TOTAL 2019	TOTAL 2018
Funds at 1 January 2019		£107,390	£40,622	£148,012	£176,023
<b>FUNDS AT 31 December 2019</b>	<b>7</b>	<b>£118,906</b>	<b>£57,538</b>	<b>£176,444</b>	<b>£148,012</b>

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

## Comparative statement of financial activities year ended 31 December 2018

### Including Income and Expenditure Account

#### INCOME

	Notes	Unrestricted Funds	Restricted Funds	2018 Total
Donations and legacies		£29,062	£13,184	£42,246
Charitable activities		£24,460	-	£24,460
Investment income		£1,021	-	£1,021
Other income		£281	-	£281
<b>TOTAL INCOME</b>	<b>3</b>	<b>£54,824</b>	<b>£13,184</b>	<b>£68,008</b>

#### EXPENDITURE

	Notes	Unrestricted Funds	Restricted Funds	2018 Total
Raising funds		£4,354	-	£4,354
Charitable activities		£63,665	£28,000	£91,665
<b>TOTAL EXPENDITURE</b>	<b>4</b>	<b>£68,019</b>	<b>£28,000</b>	<b>£96,019</b>

#### NET EXPENDITURE FOR THE PERIOD

	Notes	Unrestricted Funds	Restricted Funds	2018 Total
<b>NET EXPENDITURE FOR THE PERIOD</b>		<b>(£13,195)</b>	<b>(£14,816)</b>	<b>(£28,011)</b>

#### FUNDS

	Notes	Unrestricted Funds	Restricted Funds	2018 Total
NET MOVEMENT IN FUNDS		(£13,195)	(£14,816)	(£28,011)
Funds at 1 January 2018		£120,585	£55,438	£176,023
<b>FUNDS AT 31 December 2018</b>	<b>6</b>	<b>£107,390</b>	<b>£40,622</b>	<b>£148,012</b>

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

## Balance sheet as at 31 December 2019

### CURRENT ASSETS

	Notes	2019		2018	
Gift aid recoverable		£5,252		£3,800	
Cash at bank and in hand		£173,238		£145,232	
		<b>£178,490</b>		<b>£149,032</b>	

### CREDITORS

	Notes	2019		2018	
Amounts falling due within one year Accruals		(£2,046)		(£1,020)	
<b>NET ASSETS</b>	<b>7</b>		<b>£176,444</b>		<b>£148,012</b>

### FUNDS

	Notes	2019		2018	
Restricted funds	<b>6</b>		£57,538		£40,622
Unrestricted funds					
General funds	<b>6</b>		£25,906		£14,390
Designated funds	<b>6</b>		£93,000		£93,000
<b>TOTAL FUNDS</b>			<b>£176,444</b>		<b>£148,012</b>

For the financial period ended 31 December 2019, 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 and signed on its behalf by

J Turner  
Trustee

## Notes to the accounts for the year ended 31 December 2019

### 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, 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 2019

### 3. INCOMING RESOURCES

Donations & Legacies	Unrestricted Funds	Restricted Funds	2019 TOTAL	2018 TOTAL
Donations	£30,105	£24,813	£54,918	£32,413
Gift aid recoverable	£5,187	£6,125	£11,312	£9,833
<b>TOTAL</b>	<b>£35,292</b>	<b>£30,938</b>	<b>£66,230</b>	<b>£42,246</b>

Charitable activities	Unrestricted Funds	Restricted Funds	2019 TOTAL	2018 TOTAL
Fundraising income	£32,972	-	£32,972	£14,339
Membership renewals	£8,149	-	£8,149	£7,651
Merchandise sales	£1,594	-	£1,594	£2,470
<b>TOTAL</b>	<b>£42,715</b>	<b>-</b>	<b>£42,715</b>	<b>£24,460</b>

Investment Income	Unrestricted Funds	Restricted Funds	2019 TOTAL	2018 TOTAL
Bank Interest	£1,011	-	£1,011	£1,021
<b>TOTAL</b>	<b>£1,011</b>	<b>-</b>	<b>£1,011</b>	<b>£1,021</b>

Other Income	Unrestricted Funds	Restricted Funds	2019 TOTAL	2018 TOTAL
Sundry Income	£256	-	£256	£281
<b>TOTAL</b>	<b>£256</b>	<b>-</b>	<b>£256</b>	<b>£281</b>

	Unrestricted Funds	Restricted Funds	2019 TOTAL	2018 TOTAL
<b>TOTAL INCOME</b>	<b>£79,274</b>	<b>£30,938</b>	<b>£110,212</b>	<b>£68,008</b>

## Notes to the accounts for the year ended 31 December 2019

### 4. EXPENDITURE

Raising funds	Unrestricted Funds	Restricted Funds	2019 TOTAL	2018 TOTAL
Fundraising costs	£2,390	-	£2,390	£2,801
Merchandise purchases	£174	-	£174	£1,553
<b>TOTAL</b>	<b>£2,564</b>	-	<b>£2,564</b>	<b>£4,354</b>

Charitable activities	Unrestricted Funds	Restricted Funds	2019 TOTAL	2018 TOTAL
Staff costs	£52,999	-	£52,999	£50,012
Insurance costs	£691	-	£691	£688
Office costs	£1,858	-	£1,858	£2,077
Publicity and advertising	£3,094	-	£3,094	£5,121
Rent	£4,044	-	£4,044	£3,955
Legal and professional fees	£349	-	£349	£250
Accountancy	£1,020	-	£1,020	£1,020
Grants paid	-	£14,022	£14,022	£28,000
Sundry expenses	£1,139	-	£1,139	£542
<b>TOTAL</b>	<b>£65,194</b>	<b>£14,022</b>	<b>£79,216</b>	<b>£91,665</b>

	Unrestricted Funds	Restricted Funds	2019 TOTAL	2018 TOTAL
<b>TOTAL EXPENDITURE</b>	<b>£67,758</b>	<b>£14,022</b>	<b>£81,780</b>	<b>£96,019</b>

The independent examination fee included in accountancy amounted to £1,020 (2018: £1,020).

Grants of £1,000 (2018: £28,000) were paid to University College London, as part of the Louise Gergel Fellowship.

Grants of £6,000 were paid to Royal College of General Practitioners, £5,022 to University College London and £2,000 to individuals.

## Notes to the financial statements for the year ended 31st December 2019

### 5. EMPLOYED STAFF COSTS AND NUMBERS

	2019 TOTAL	2018 TOTAL
Salaries and wages	£50,081	£47,861
Social security costs	£1,536	£1,276
Pension	£1,382	£875
<b>TOTAL</b>	<b>£52,999</b>	<b>£50,012</b>

No employee earned more than £60,000 during this or the prior period. The total number of employees during the period was 2 (2018: 2).

Key management were paid remuneration totalling £39,648 (2018: £38,569).

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

Trustees' indemnity insurance of £228 (2018: £228) for the Board of Trustees was paid during the year.

## Notes to the accounts for the year ended 31 December 2019

### 6. MOVEMENT IN FUNDS

Restricted funds	At 1 January 2019	Income	Expenditure	Transfers	At 31 December 2019
Louise Gergel Fellowship	£18,202	£313	(£1,000)	-	£17,515
Research and Projects Fund	£22,420	£30,625	(£13,022)	-	£40,023
<b>TOTAL</b>	<b>£40,622</b>	<b>£30,938</b>	<b>(£14,022)</b>	-	<b>£57,538</b>

Designated funds	At 1 January 2019	Income	Expenditure	Transfers	At 31 December 2019
Research and Projects fund	£20,000	-	-	-	£20,000
Designated reserve fund	£73,000	-	-	-	£73,000
<b>TOTAL</b>	<b>£93,000</b>	-	-	-	<b>£93,000</b>

### RESTRICTED FUNDS

#### *Louise Gergel Fellowship*

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

#### *Research and Projects Fund*

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

### 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 2019

### 7. ANALYSIS OF NET ASSETS BETWEEN FUNDS

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)
<b>NET ASSETS</b>	<b>£57,538</b>	<b>£93,000</b>	<b>£25,906</b>	<b>£176,444</b>

2018	Restricted funds	Designated funds	Unrestricted funds	2019 Total funds
Current assets	£40,622	£93,000	£15,410	£149,032
Current liabilities	-	-	(£1,020)	(£1,020)
<b>NET ASSETS</b>	<b>£40,622</b>	<b>£93,000</b>	<b>£14,390</b>	<b>£148,012</b>

### 8. RELATED PARTY TRANSACTIONS

During the year, no trustees were reimbursed expenses incurred on behalf of the charity (2018: £176).

### 9. POST BALANCE SHEET EVENT - COVID 19

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.