



"We rely on the generosity of people like you..."

Each year the Psoriasis Association helps thousands of people whose lives have been affected by psoriasis via our websites, telephone and email helplines and by raising awareness amongst the general public, healthcare professionals and Members of Parliament.

We rely on the generosity of people like you to help us continue our vital work in supporting people, raising awareness and funding research".

Helen McAtteer - Chief Executive

For further information please visit:

www.psoriasis-association.org.uk

or call: 01604 251620

@PsoriasisUK



The Psoriasis Association
Registered Charity Numbers
257414 and SC039886

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Our Achievements 2017



Chairman's Report

From our foundation The Psoriasis Association has made a commitment to supporting research into the causes and impact of psoriasis, its treatment, and ultimately finding a way of eliminating the disorder altogether.

As we approach the beginning of our fiftieth year the Association's agenda seems to be as busy as ever. Our three main areas of work – supporting research into the causes and treatment of psoriasis, the provision of information, advice and support for those affected by the condition, and raising awareness of its impact – have dominated the work of both our staff and Trustees over the past year and remain at the heart of all that we do.

Our research programme remains very much to the fore in the Trustees' discussions and continues to thrive. Eight PhDs are ongoing, and during 2017 we provided funding enabling three new PhD studentships to start, as well as a grant to support a project in Newcastle, researching the use of narrow-band UVB phototherapy.



The research environment in the United Kingdom is vigorous, and another ten applications for grants for potential funding in 2018 have been received and are being assessed by our expert advisors.

Last year I announced that the Association had commissioned a consortium led by the University of Manchester to undertake a Priority Setting Partnership, a project designed to identify priorities for future research, jointly agreed between patients, carers, and expert clinicians. This work is now well under way, with input from over 600 patients and carers. We hope to see preliminary results published in the autumn of 2018, helping us and other funding bodies to better target future spending on research projects.

Communication with our members and others affected by psoriasis remains core business. Our websites recorded over 600,000 visits, and our social media presence continues to expand, with further developments being planned in 2018. In the digital age the significance of such systems is ever more important but the Trustees are conscious of the need to use all means possible to engage with those who seek our advice and support. The telephone advice line remains well used and a new logging system will enable us to better analyse the calls we receive and our response to them. The quarterly newsletter to members continues to be central to our communications.

Engaging with healthcare professionals and the regulatory authorities continues to be an important part of our staff team's work. The presence of our staff at annual conferences for dermatologists, specialist nurses and general practitioners during the year has provided a patient voice.

We have engaged with the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium, contributing to their appraisals of various treatments for psoriasis and psoriatic arthritis.

The changing regulatory environment for charities in the United Kingdom has made significant demands on staff time and 2017 has seen much work done in preparation for the advent of the General Data Protection Regulations in May 2018. The Association holds and uses personal information on its members and supporters and it is essential that all of our partners feel fully confident in our custody and use of their data.

The Trustees have given much consideration as to how best to mark our fiftieth anniversary. Whilst there is much to celebrate there remains much to do, and a range of initiatives aimed at stimulating and supporting further research, encouraging improvements in the provision of healthcare services, and raising the profile of psoriasis and its impact are being pursued. Further details at the AGM as our fiftieth year gets under way!

As I have said in previous years, all of this needs money. The skilful management of our resources by our finance committee and those who advise and support them helps us to achieve our aspirations, but so too does our membership and the wider community. Thank you to you all for your continued support. I look forward to continuing to work with you.



"Thank you to you all for your continued support. I look forward to continuing to work with you."

Nick Evans
Chairman,
Psoriasis Association

Introduction

We are so grateful for all the efforts, donations, grants and legacies we receive from our fabulous members, supporters and fundraisers. When you donate to the work of the Psoriasis Association, an exciting journey can begin, taking in the sites of our three objectives along the way:-

From joining the Psoriasis Association to climbing Ben Nevis, a sponsored slim to completing the London Marathon, the ways in which people support our work are varied and sometimes extreme... so what can your donation achieve... and how do we go about it?

Raising awareness

Providing information, advice and support

Funding and supporting research... and telling people the results of that research.



Fundraising



Information

At the heart of our support network are people whose lives are affected in some way by psoriasis. Carla Renton heads our information and communications department, but the following all feed in to ensuring our information is reliable, accurate, up-to-date and relevant:-

Members - willing members help to review information resources



Medical Journals such as the British Journal of Dermatology help to keep our information up-to-date



Involvement in key networks, working groups and guideline development groups – such as the All Party Parliamentary Group on Skin, Cross Party Group on Skin and Patient Support Group meetings hosted by the British Association of Dermatologists



Carla Renton

Healthcare professionals - help to review information resources and speak at the Annual Conference. Sessions from the Annual Conference are filmed and uploaded to the Psoriasis Association YouTube channel, where they were viewed 2,320 times in 2017



Attendance at relevant healthcare professional conferences



Regulatory bodies such as the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC) issue Guidelines, Quality Standards and Technology Appraisals into which the Psoriasis Association gives evidence, but also uses to help inform people of their rights to treatment



This network then goes full circle with all the information being used on the helpline to guide and signpost those who contact the Psoriasis Association.



Support

Supporting people whose lives are affected by psoriasis spans all staff job roles. At the heart of answering the helpline and membership queries is Laura Bell with a listening ear and knowledgeable answers to the rich and varied number of questions put to her. We received 850 enquiries via telephone, email and letter during 2017 which varied greatly in terms of topic and amount of support required. Almost three-quarters of telephone calls have a duration of between 6 and 30 minutes. Discussions around stress, depression and difficulty in coping are much more commonly received via email than the telephone. This may in part be due to people finding this means of communication easier to use owing to the more private nature. With this in mind, in 2018 we intend to launch a WhatsApp messaging service allowing people the freedom and anonymity to contact the Psoriasis Association in this way.

Laura Bell



'We received 850 enquiries via telephone, email and letter during 2017 which varied greatly in terms of topic and amount of support required.'



Raising Awareness

During 2017 the Psoriasis Association raised awareness of psoriasis in a variety of ways.

Raising awareness of psoriasis spans so much of the work of the Psoriasis Association, and increasingly our digital presence is essential for this purpose. People fundraising on behalf of the Psoriasis Association play a vital role in raising awareness by training and competing in our branded t-shirts. This year, supporters of the Psoriasis Association covered a distance the equivalent of running from the office in Northampton to Rome! This does not even take into account those who climbed Mount Kilimanjaro!

Our Digital Communications Officer, Dominic Urmston works tirelessly behind the scenes ensuring our digital presence across the internet and social media remain as relevant as possible. It's a busy job with two websites and five social media accounts to keep active and maintain the high standards people using our services expect.



Psoriasis is a condition that can affect almost any age; recognising the condition and getting a diagnosis is such an important time, but this is the start of a journey of highs and lows and so the Psoriasis Association strives to raise awareness to all ages, via a variety of means. Our printed literature is available free of charge to all Dermatology and Rheumatology Departments in the UK and the membership magazine Pso continues to be a great resource.

Instagram followers

1,685



Twitter followers

9,462



1,983,100 total impressions (tweet views)

Spotlight on Psoriasis Priority Setting Partnership

The first stage of the Psoriasis Association funded Priority Setting Partnership was launched in July 2017 where members, patients, carers, families, clinicians and researchers were asked to submit questions they had on psoriasis and psoriatic arthritis they felt were currently unanswered. Over 2,000 questions were submitted which will be checked against existing literature and research on psoriasis to identify the questions that remain unanswered. Participants will then be asked to rank the remaining questions to establish a "Top 10". These will be submitted to the National Institute of Health Research (NIHR) for future funding calls. The Psoriasis Association will also be calling for applications to address some of these questions.

The Psoriasis Priority Setting Partnership is funded by the Psoriasis Association and is being undertaken by the University of Manchester with support from the University of Nottingham. It uses the principles as set out by the James Lind Alliance and is due for completion by the end of 2018.



Research

'To promote and fund research into the causes, nature and care of psoriasis and to publish and disseminate the results of that research'



Sarah Hartwell

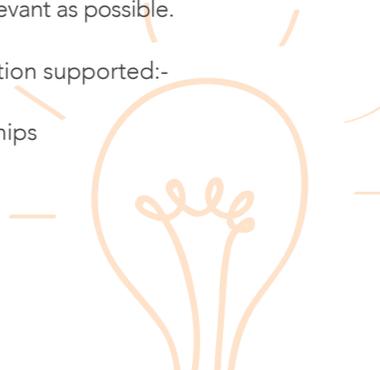
Co-ordinating our research efforts is our newest member of staff, Sarah Hartwell.

Feeding into Sarah's work in 2017 to ensure donations to research achieve maximum potential are:-

- 6 members of the Medical and Research Committee (Prof Jonathan Barker, Dr Tony Bewley, Steve Churton, Prof Chris Griffiths, Prof Eugene Healy and Dr Julia Schofield).
- 4 External Peer Reviewers (Dr John Ingram, Dr Elise Kleyn, Prof Nick Reynolds and Prof Hywel Williams)
- Our vision for 2018 is to develop a panel of lay reviewers to support our existing approach to reviewing grant applications, in order to ensure that the research funded by the Psoriasis Association remains as relevant as possible.

In 2017 the Psoriasis Association supported:-

- 8 ongoing PhD Studentships
- 3 new PhD Studentships



These three PhD Studentships were:-

1) The role of IL-1 and IL-36 in Palmar Plantar Pustulosis (PPP)

Palmar plantar pustulosis (PPP) is a severe form of psoriasis manifesting with the appearance of painful pustules on the palms and soles. These lesions can be preceded or accompanied by plaque psoriasis and/or psoriatic arthritis. PPP is a disabling condition that has a profound effect on quality of life, as affected individuals can find it very difficult to walk or carry out everyday tasks. At the same time, very little is known about the causes of the disease, which as a consequence is extremely difficult to treat.

The aim of our research is to achieve a better understanding of the causes of PPP, as that is essential for the development of effective treatment. Our group has already discovered two genes that malfunction in affected individuals, causing excessive production of an inflammatory molecule known as IL-36. Importantly, we also demonstrated that IL-36 drives the release of a protein called IL-1, which can be blocked by existing drugs. This was a breakthrough, which suggested that PPP could be treated with known IL-1 inhibitors.



It is important to bear in mind, however, that the genetic defects we have discovered are only found in 10-15% of individuals with PPP. Therefore, it is still not clear whether abnormal release of IL-36 and IL-1 is a general feature of the disease.

With this project, we plan to identify novel PPP genes and to establish whether they also cause excessive IL-36 and IL-1 production. If we find that the newly identified defects do not alter IL-36/IL-1 levels, we will seek to clarify what are the alternative mechanisms whereby they cause disease.

2) Mutation burden of narrowband UVB

Ultraviolet radiation (UV) in sunlight is an effective treatment for psoriasis. Narrowband UVB (NB-UVB) is a form of "artificial sunlight" which is used widely by dermatologists to treat patients with psoriasis. It is known that UV can cause skin cancer, but the long-term safety of NB-UVB in relation to skin cancer development is unknown. It has been highlighted that, in order to determine the long-term safety of NB-UVB, large studies in multiple dermatology centres involving several thousand new patients per year would need to be conducted and that those patients would need to be followed up at least for 10 years or more.

In the meantime, patients with psoriasis and dermatologists do not know what is a suitable safe limit of NB-UVB treatments for people with psoriasis to have over the course of their lifetime.

All of the cells in our body contain the genes that we are born with. These genes are written in the DNA in all our cells, including our skin cells. Exposure of the skin to UV causes specific damage to the DNA in skin cells and leads to mutations (i.e. errors in the DNA) that affect the ability of the genes to work properly. When a skin cell divides these changes are passed on to its daughter cells. Over time, these daughter cells and their descendants (which are collectively known as a clone) may eventually accumulate thousands of mutations which may cause the skin cells to become abnormal and form skin cancers. Recent advances in genetic technology have allowed scientists to map groups of cells carrying altered genes which drive the formation of cancer in normal skin. In the proposed study, we plan to use this technology (called next generation sequencing) to detect how many groups of cells carrying DNA changes linked to cancer are induced by NB-UVB treatment for psoriasis. Based on these findings, we will calculate the additional risk of cancer in a psoriasis patient resulting from multiple courses of NB-UVB and thus estimate the long-term safety of NB-UVB.

3) The risk of cancer in psoriasis patients treated with biologic therapies compared with conventional systemic therapies: results from BADBIR

Patients with severe psoriasis (more than 10% of the body surface affected) are often offered two broad types of long-term systemic treatment: conventional systemic treatments, such as methotrexate, ciclosporin and acitretin; and biologics, such as Humira, Stelara, and Enbrel. Biologic therapies target the immune system and may affect the body's ability to fight cancer. It is not known whether being treated with biologic therapies carries an increased risk of cancer in psoriasis patients compared to treatment with conventional systemic treatments. Very few studies have compared the safety of these two treatment options and have been limited by short duration with only small numbers of patients. As cancers develop relatively rarely, we need to compare large groups of psoriasis patients receiving biologic and conventional systemic treatments respectively.

- 2 ongoing small grant programmes
- 1 new small grant programme. This was a pilot study to compare the response of psoriasis to narrow-band UVB phototherapy in the morning and afternoon

Psoriasis is a very common skin disease. We often think of psoriasis as a disease of just the skin, but research shows that people who have psoriasis may have different body clock rhythms from the general population.

We know that people without psoriasis are more sensitive to phototherapy with ultraviolet B light at different times in the day. What we don't know is if this is also true for people who have psoriasis.

The main aim of this research question is to see if patients' psoriasis is more sensitive to ultraviolet light at different times of the day.

We also aim to see whether the participants in our study have different body clock (circadian) rhythms to the general population. We will do this in multiple ways, such as looking at the levels of a few chemicals in the body that respond to body clock rhythms (melatonin and cortisol), asking questions about participants' sleep (by questionnaire), measuring sleep (with a wrist-worn motion sensor), and asking the patients to fill in questionnaires about depression.

We will recruit 15 patients who have been prescribed phototherapy for the treatment of their psoriasis. The study will last nine days per patient and after this they will proceed to their prescribed course of phototherapy.

- 1 Psoriasis Priority Setting Partnership in which over 2,000 research questions were asked about psoriasis. The top ten research priorities will be announced in 2018.

The Psoriasis Association supported research in 7 UK centres in 2017 (University of Manchester, Oxford University, Kings College London, Glasgow Caledonian University, Southampton General Hospital, University of Edinburgh and the Royal Victoria Infirmary Newcastle).

The breadth of research supported by the Psoriasis Association is wide and ranges from genetic factors to impact on sleep, in addition to covering plaque psoriasis, psoriatic arthritis and generalised pustular psoriasis.

How donations fund research

£ Funds Available

Donations specifically for research are invested whilst we attract relevant applications. We then calculate each year the resources available.

Call for Applications

Researchers, academics and clinicians are invited to apply for PhD Studentship Grants (or small grants up to 2017)

Review and Recommendation

All applications are reviewed by our Medical and Research Committee and External Peer Reviewers. The Medical and Research Committee then make their recommendations to the Trustees as to which applications they feel should be funded.

Grants Awarded

Grants are awarded to successful applicants. We only fund research we feel will increase our understanding of psoriasis, or lead to better treatment. Funding is paid in instalments upon receipt of satisfactory progress reports.

Patient Impact

The findings from our research feed into bigger research projects in order to influence better treatments and clinical practice.

Progress Report and Thesis

An end of grant report is issued along with a bound copy of the PhD thesis and any publications from peer reviewed journals.

Research Priorities for 2018

- Explore ways to best involve and inform members and patients of research funded by or supported by the Psoriasis Association.
- Agree new research awards for 2018 and continue to support and monitor existing grants.
- Support the Psoriasis Priority Setting Partnership.

Financial highlights

This information is a summary of the full accounts of the Psoriasis Association for the year ended 31st December 2017.

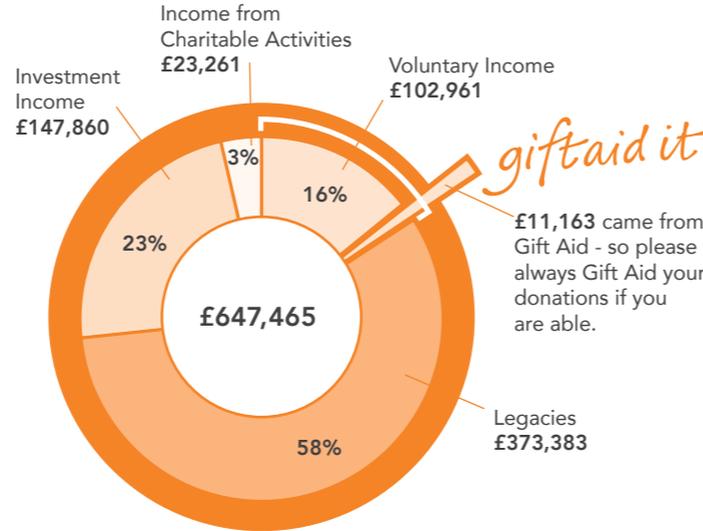
If you would like the full financial statements, Trustees annual report and Auditor's report please contact The Psoriasis Association or visit www.psoriasis-association.org.uk/who-we-are/funding

Income	2017 (£)	2016 (£)
Voluntary Income (including, for example, membership subscriptions, fundraising by individuals, Gift Aid, donations in memoriam)	102,961	102,749
Legacies	373,383	372,132
Investment Income	147,860	150,355
Income from Charitable Activities (including, for example, corporate sponsorship, charitable trust donations, Pso advertising)	23,261	37,851

Total Income for the Year 647,465 663,087

Total Net Assets	2017 (£)	2016 (£)
At 1st January	5,748,438	5,192,057
Add Incoming Resources	647,465	663,087
Deduct Net Resources Expended	(474,755)	(594,615)
Gains/losses on Investment Assets	304,215	291,909
Gains on revaluation of Fixed Assets	-	196,000

At 31st December 6,225,363 5,748,438



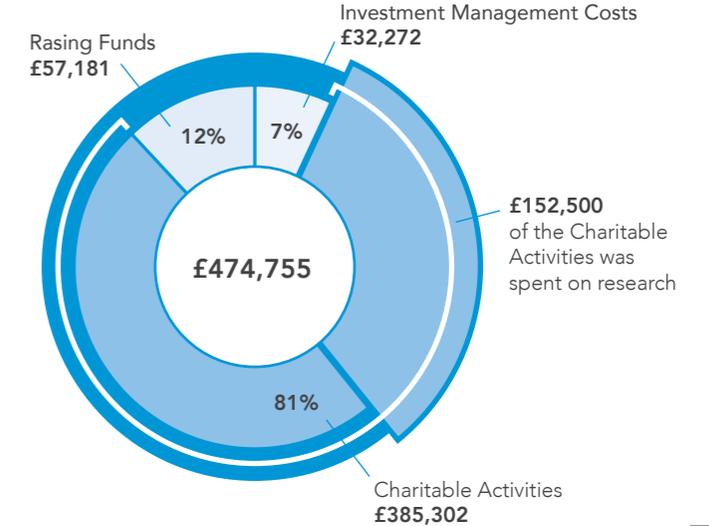
The total assets are made up as follows	2017 (£)	2016 (£)
Endowment funds for research and educational work	3,824,540	3,543,239
Restricted funds for research	473,813	377,346
Restricted funds for Scotland	74,837	109,401
Unrestricted funds - General charitable work	269,281	247,141
Unrestricted funds - Designated funds	1,092,892	981,311
Unrestricted funds - Property fund (this reflects the value of the property purchased in 2007)	490,000	490,000

TOTAL 6,225,363 5,748,438
Change in assets 476,925 556,381

Expenditure	2017 (£)	2016 (£)
Raising Funds	57,181	59,959
Charitable Activities	385,302	504,901
Investment Management Costs	32,272	29,755

Total Expenditure for the Year 474,755 594,615

Busy working to ensure the Psoriasis Association gets best value for money on a range of activities is our Finance Officer, Polly Matthews. Please remember to Gift Aid your donations whenever possible – in 2017 we received £11,163 from Gift Aid alone.



Watch this space...

...it's our 50th Anniversary in 2018!

We aim to better support people with psoriasis by offering a WhatsApp messaging service.

We will continue to support research to better understand and treat psoriasis by supporting the 5th year of the Psoriasis Stratification to Optimise Therapy (PSORT) programme.

Celebrate the rich history of the Psoriasis Association and embrace the original vision of a more holistic approach to treating people with psoriasis by empowering healthcare professionals by granting access to accredited PsoWell training (as developed by the National Institute of Health Research (NIHR) funded Identification and Management of Psoriasis Associated Co-Morbidity (IMPACT) project).

50



For helping us to have a successful 2017...

Our members and supporters

People who fundraise on our behalf and their donors

People who leave legacies to the Psoriasis Association

Our Trustees

Nick Evans, Brian Murkin, Jonathan Swift, Steven Astaire, Thomas Ball, Steve Churton, Chris Dyer, Gill Hynes, Michael Israel, Susan Morgan, Dr Julia Schofield MBE, Matthew Swift

Our Medical and Research Committee

Professor Jonathan Barker, Dr Anthony Bewley, Professor Christopher Griffiths, Professor Eugene Healy, Dr Julia Schofield MBE, Steve Churton and Helen McAteer

External Peer Reviewers

Dr John Ingram, Professor Hywel Williams, Dr Elise Kleyn, and Professor Nick Reynolds

Our Staff

Helen McAteer, Laura Bell, Tessa Farnsworth, Sarah Hartwell, Polly Matthews, Carla Renton, Dominic Urmston

Trusts and Foundations who supported our work in 2017

Cecil King Memorial Foundation Trust, The Coulthurst Trust and Davis Rubens Trust

Companies who supported our work in 2017 via membership or unrestricted educational grants

Abbvie, Celgene, Dermal Laboratories Ltd, Eli Lilly, LEO Pharma Ltd, T & R Derma, UCB, and Janssen

...Thank you!