

"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".

Hele Matter

For further information please visit:

www.psoriasis-association.org.uk

or call: 01604 251620

The Psoriasis Association Registered Charity Numbers 257414 and SC039886





The Psoriasis Association is an independent charity established in 1968 and remains committed to the original aims...

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

The Psoriasis Association is proud of its commitment to research, continuing to support PhD Studentships and small grants. In addition to funding our own research, we recognise the importance of working collaboratively with others carrying out research into this complex condition. In 2016 we initiated and funded a Priority Setting Partnership (PSP) – a collaborative partnership between patients, carers and clinicians to identify and prioritise future research projects.

#### To raise awareness about psoriasis

The Psoriasis Association aims to raise awareness of psoriasis to the widest audience possible, from the general public and healthcare professionals to Members

of Parliament and government bodies. Direct engagement has increased with the growth of our social media channels and improved website experience. Opportunities to engage face-to-face occur throughout the year with an in-depth focus during Psoriasis Awareness Week.



...whatever

I choose

to make

of it...

# Chairman's Report

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.

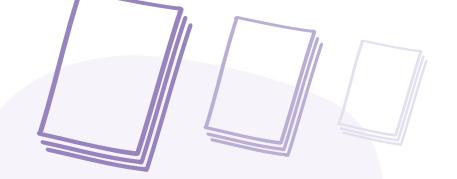
From our foundation The Psoriasis Association

Looking back at 2016 I have been struck by a sense of 'business as usual.' In a year that has been characterised by upheaval and shock nationally and internationally the Association's agenda has been an oasis of calm! That is not to say that it has been a year free of challenge – the absence of our chief executive on maternity leave, the reassessment of our research strategy, the further exploration of a Priority Setting Partnership, and the awareness of the Association's forthcoming fiftieth anniversary have all occupied the Trustees, alongside the 'usual business' of leading the organisation and overseeing our day to day services. In all of this our staff team have been outstanding and I am grateful to them.

Last year I reported the Trustees decision to pursue the establishment of a 'Priority Setting Partnership', a project designed to identify priorities for future research, jointly agreed between patients, carers, and expert clinicians. Through the past year we have undertaken a tendering process aimed at identifying an organisation with the expertise to undertake this work for us, and I am delighted to say that a contract has been signed with a consortium led by the University of Manchester. I hope this project will be a major step forward in determining priorities for research, not just for the Association but more widely.

Supporting research into the causes, treatment and impact of psoriasis remains a core part of our work. How we do it is reviewed regularly, with the aim of both ensuring we get the best value for the money we have available, and checking that we are addressing the areas where money from other sources is lacking. The five-year review undertaken this year benefited from input from several Trustees as well as from the group of expert advisors who give their time and experience to supporting our research programme. Our strategy of funding PhD Studentships, enabling us to invest in both research and in supporting the next generation of experts in the field, was strongly supported as the way to continue. Alongside this we have instituted a means by which researchers can apply for support for work addressing areas which emerge from the work of the Priority Setting Partnership, and a mechanism which will enable PhD students to apply for help with travelling costs associated with their research.

The popularity of web-based social media continues to increase and is now an essential and growing part of our communication with patients and carers - our various websites received well over 600.000 'hits' during the year and our engagement with various social media sites continues to grow. Calls to our telephone advice line and email requests for information and help continue to arrive. The level of need amongst patients and carers remains as strong as ever and we continue to look for ways of meeting it.



As I said in my report last year, inevitably all of this needs money. In a year that has seen considerable and prolonged upheaval in the financial world our finances remain stable. This is a testament to the expertise and commitment of our finance committee and those who advise them, but also reflects the continued support of our members and the wider community. As our fiftieth anniversary as an organisation approaches, we have much for which to be thankful, but also much to do. I look forward to continuing to work with our staff. members and supporters.



### Endorsements of Psoriasis PhD Programme

The Psoriasis Association PhD studentship has had a significant impact on the research activity of my group. Over the years, it has enabled us to recruit some very talented PhD students, who have brought fresh energy and enthusiasm to our team. Their hard work and dedication has allowed us to identify novel disease genes and better understand the differences and commonalities between rare and common forms of psoriasis. More recently, the studentship has enabled us to establish a multi-disciplinary collaboration, which is making use of advanced computational methods to dissect the causes of psoriasis.

Importantly, the award has also had a substantial impact on the career of the students, who have gone on to take post-doctoral positions in prestigious institutions and continued to investigate the genetic causes of conditions such as psoriasis. Thus, our experience illustrates how the Psoriasis Association studentship is advancing our understanding of the disease, while also helping to train a new generation of researchers.

#### Dr Francesca Capon King's College London

The Psoriasis PhD programme provides support for Early Career Researchers to probe detailed questions to advance our understanding of the condition. These prestigious awards address key questions and are awarded subject to peer review by external experts in the relative fields of study. Many of the projects involve access to patient related material, so experience in ethical applications for research, Good Clinical Practice, informed patient consent and public engagement literature relating to the project provides students with a broad underpinning in addition to their individual research areas.

**Dr Patricia Martin Department of Life Sciences Glasgow Caledonian University** 

# Providing information, advice and support

The Psoriasis Association was awarded the Information Standard in 2011, and is re-assessed annually. This NHS-run scheme ensures that the Psoriasis Association's information production processes are of high quality, and that the information produced is reliable, balanced, and evidence-based.

Information, advice and support are available through our helpline services, with enquirers receiving information tailored to their needs. Pso, the official magazine of the Psoriasis Association, ensures that members are kept informed of developments regarding the treatment and management of psoriasis and psoriatic arthritis.

The Psoriasis Association maintains a main website and a website intended for under-21s, Psoteen. Both of these websites were refreshed in 2016 to offer a number of key improvements, including:

- 'mobile-friendly' optimisation to allow the websites to be accessed to their full potential on mobile devices (such as phones and tablets) as well as desktops;
- a complete forum overhaul, making them tidier, easier to moderate and easier to use;
- a more modern and efficient function for donating, becoming a member and renewing membership;
- a refreshed 'look and feel', incorporating the images of Psoriasis Association members and supporters that were gathered during our 2015 photoshoot;
- and even more information content than was previously available.



### Research

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



As a patient organisation, the Psoriasis Association is keen to understand the treatment uncertainties surrounding psoriasis for patients, carers and clinicians. In 2016 The Board of Trustees agreed to pursue the concept of a Priority Setting Partnership (PSP), looking to address treatment uncertainties in psoriasis. Dr Helen Young, from the University of Manchester, was appointed as the study lead, under the guidance of the James Lind Alliance (JLA), who developed the PSP methodology, as 'questions about treatments that cannot be answered by existing research'.

A PSP is unique in that, unlike other methodologies used to determine research priorities, it moves away from the conventional approach of researchers, pharmaceutical companies and doctors deciding priorities. A PSP asks patients and carers to submit their views about what is important also.

MANCHESTER 1824

The University of Manchester

The Psoriasis Association is extremely grateful for the time dedicated to reviewing the applications by the Medical and Research Committee and External Peer Reviewers.

The psoriasis PSP will be led by a steering group chaired by a JLA advisor, who will ensure that the process is carried out in a fair and transparent way bringing together patients, carers and clinicians to identify and prioritise uncertainties or 'unanswered questions' about the effects of treatments that they collectively agree are most important. Once uncertainties have been analysed, a systematic review will be carried out in order to eliminate areas where the answers to the questions are already known. The identified uncertainties will be prioritised to produce a final Top 10 list of jointly agreed research priorities which will then be widely publicised and made available for researchers and funders to access.

The Psoriasis Association sees the Priority Setting Partnership as a fantastic opportunity to give those most affected by psoriasis the chance to influence future research.

The Psoriasis Association has awarded over £5 million in grants and PhD Studentships over the years. The projects that have been funded range from genetic research, through to psychological interventions to help people cope with the impact of psoriasis on everyday life. The Psoriasis Association is a member of the Association of Medical Research Charities (AMRC), and therefore abides by their conditions of membership. Each grant application is assessed by the Medical and Research Committee of the Psoriasis Association, in addition to external reviewers.

amrc

Here are the lay summaries of the grant applications that have been funded by the Psoriasis Association in 2016:-

Dr C. Elise Kleyn: An innovative mixed methods study investigating altered emotional processing in psoriasis patients.

#### **University of Manchester**

Psoriasis is a chronic inflammatory skin disease which affects 2-3% of the UK population. As a result of the appearance of their skin, patients with psoriasis commonly experience negative social interactions and reactions from others including facial expressions of disgust.

Our group were the first to use brain scanning (magnetic resonance imaging) to demonstrate that patients with psoriasis process facial expressions of disgust differently to individuals without skin disease. It was demonstrated that patients with psoriasis have a diminished signal in the insula, an area of the brain known to be important in disgust processing. This differential response may reflect a coping mechanism, adopted by patients to 'block out' the aversive reactions of others and protect themselves from stressful emotional responses. More recent, (unpublished) work, by the group suggests that an individual's response to disgust may vary depending on the length of time a patient has had psoriasis and the age at which they were diagnosed. However, it is not known when this mechanism develops, or its wider implications on patients' quality of life.

This novel study will pilot the integration of different techniques, including in-depth patient interviews and state-of-the art brain scanning, to further understanding of this proposed coping mechanism in psoriasis. Addressing this current gap in knowledge will inform the development of personalised clinical and psychological interventions to support people living with psoriasis.

Dr Timothy M. Millar: - Not just skin deep: circulating lipids in a "localised" disease.

#### **Southampton General Hospital**

People with psoriasis have a greater risk of clogged arteries and heart disease than the general population. People with psoriasis show more bad cholesterol and less of the good kind circulating in the blood. This can lead to fatty plaques growing on the inside of the blood vessel wall which are filled with white blood cells. Plaque psoriasis shows large numbers of white blood cells in the skin and an over growth of blood vessels. We believe that the plaque form of psoriasis and the fatty plaques seen in the blood vessels have striking similarities. From our earlier research, we have shown that some types of fat found in the blood can control new blood vessel growth.

New blood vessel growth is part of how plaques form in psoriasis and more blood vessels mean more white blood cells. These white blood cells in turn can cause blood vessels to grow causing a vicious circle of continued plaque flares. We have also shown that some white blood cells have the potential to be activated by blood fats and that when fats are removed, more white cells die. While some current treatments for psoriasis show effects on blood lipids they still have side effects which could be improved on. Together with other chemicals which are raised in psoriasis, these blood fats could provide a simple target to help treat the skin disease and also reduce the risks from clogged arteries.

What we hope to find out: Building on our early project we hope to show which fats are the most important in causing blood vessel growth. We also aim to show that blood fats in psoriasis cause blood vessel growth when combined with chemicals already found in the disease. We know that white blood cells can be affected by blood fats and we will describe how that happens. Finally, we expect to be able to show that removing blood fats or stopping them switching on blood vessel cells and white cells could lead to possible additional therapies.

## Raising awareness

The Psoriasis Association raised awareness of psoriasis in a variety of ways during 2016.

Psoriasis Awareness Week ran from 29th October to 5th November 2016. This year's main theme was the 'PsoriaslS' campaign, where we encouraged members, supporters and other psoriasis stakeholders (including healthcare professionals, researchers and pharmaceutical companies) to share what psoriasis is to them. The aim of this campaign was to encourage conversations about psoriasis, creativity and engagement amongst the psoriasis community, particularly online. All Psoriasis Association members, as well as corporate members, research collaborators and recent fundraisers were contacted to encourage them to take part in the campaign. All of the contributions received were, and remain, viewable in the 'Awareness' section of the main website.

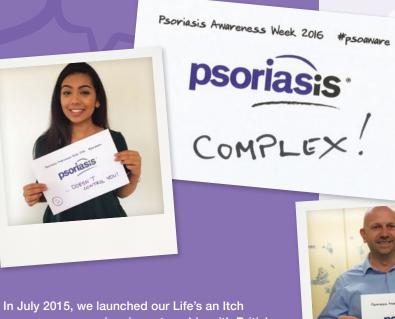
Psoriasis is becoming an ever-more frequently covered subject in the media, although headlines can sometimes be misleading and information inaccurate. It's great when we are given the opportunity to contribute to a media story, and raise awareness of psoriasis in an accurate way. This vear, we have given interviews to media outlets including Bella Magazine, the Huffington Post, OK! Magazine, Regional Birmingham BBC News, BBC Radio West Midlands, and BBC Radio 5 Live.





Psoriasis Association staff also had articles published in the British Journal of Dermatology, and the British Journal of Family Medicine. Throughout the year, staff represented the Psoriasis Association at a number of locations giving opportunity for valuable face-to-face communication with both the general public and healthcare professionals. Events attended included the British Association of Dermatologists Annual Conference, the Royal College of GPs Annual Conference, and the Psoriasis Shout Out Roadshow. Staff also presented on the patient experience of psoriasis to Dermatology Masters students at the University of Hertfordshire, and the PSORT Partner Meeting.

The Psoriasis Association continues to take an active role on the Advisory Group of the All Party Parliamentary Group on Skin and key involvement in a number of external networks including Skin Conditions Campaign Scotland. Cross Party Group on Skin and Associated Rheumatic Conditions, Dermatology Council for England, Skin Care Cymru, the ALLIANCE, and membership of the Association of Medical Research Charities, National Council of Voluntary Organisations. National Voices and the Patient Information Forum. The Psoriasis Association regularly engages with the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC) to raise awareness of the needs of people with psoriasis and psoriatic arthritis when assessing treatments and making recommendations that are relevant to the conditions.





awareness campaign, in partnership with British Dermatological Nursing Group and Celgene. 95% of people who were surveyed on our website said that itch was a problem for them. In 2016, the Life's an Itch collaboration was keen to not only highlight the fact that itch is an under-recognised and undertreated symptom of psoriasis, but also to suggest solutions to the issue. The Itch Discussion tool was developed to actively encourage healthcare professionals to ask people with psoriasis about their itch, and encourage people with psoriasis to talk about their itch. This tool was launched at our Annual Conference in 2016, and is available on the Psoriasis Association website.



psoriasis

awareness

tiring

frustrating

unknown to the majority (9)

painful

## Financial highlights

This information is a summary of the full accounts of the Psoriasis Association for the year ended 31st December 2016.

Income and endowments	2016 (£)	2015 (£)
Donations (including, for example, membership subscriptions, fundraising by individuals, Gift Aid, donations in memory)	102,749	101,931
Legacies	372,132	232,663
Income from investments	150,355	135,078
Income from Charitable Activities (including, for example, corporate sponsorship, charitable trust donations, Pso advertising, grant payments)	37,851	57,210

Total Income for the Year	663,087	526,882

Expenditure	2016 (£)	2015 (£)
Raising Funds	59,959	61,608
Charitable Activities	504,901	455,881
Investment Management Costs	29,755	29,636
Total Expenditure for the Year	594,615	547,125

If you would like the full financial statements, Trustees' annual report and Auditor's report please contact The Psoriasis Association.

Total Net Assets	2016 (£)	2015 (£)
At 1st January	5,192,057	5,194,980
Add Incoming Resources	663,087	526,882
Deduct Net Resources Expended	(594,615)	(547,125)
Gains/losses on Investment Assets	291,909	17,320
Gains on revaluation of Fixed Assets	196,000	Nil
At 31st December	5,748,438	5,192,057
The total assets are made up as follows	2016 (£)	2015 (£)
Endowment funds for research and educational work	3,543,239	3,356,508
Restricted funds for research	377,346	492,911
Restricted funds for Scotland	109,401	146,217
Unrestricted funds - General charitable work	247,141	186,572
Unrestricted funds - Designated funds	981,311	715,849
Unrestricted funds - Property fund (this reflects the value of the property purchased in 2007)	490,000	294,000
TOTAL	5,748,438	5,192,057

556.381

(2,923)



Our members and supporters

People who fundraise on our behalf and their donors

Individuals who leave legacies to the Psoriasis Association

#### **Our Board of Trustees**

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



Professor Jonathan Barker, Dr Tony Bewley, Professor Chris Griffiths, Professor Eugene Healy and Dr Julia Schofield

#### **External Peer Reviewers**

Dr John Ingram, Dr Elise Kleyn, Professor Anthony Ormerod and Professor Nick Reynolds

Trusts and Foundations who supported our work in 2016

CE & MM Campin Trust, Cecil King Foundation, Coulthurst Trust, Davis Rubens Charitable Trust, and the Salamander Charitable Trust

Companies who supported our work in 2016 via membership or unrestricted educational grants

Abbvie, Celgene, Dermal Laboratories, Eli Lilly, Galderma UK, LEO Pharma Ltd and T&R Derma.

research

...Thankyou!







Change in assets