

"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 McAteer - Chief Executive

For further information please visit:

www.psoriasis-association.org.uk

or call: 01604 251620

The Psoriasis Association Registered Charity Numbers 257414 and SC039886





## Our Objectives

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

### To provide information, advice and support to those whose lives are affected by psoriasis

The Psoriasis Association is committed to providing high quality, up to date, Information Standard accredited literature; offering a range of printed leaflets and supporting resources.

'We have found the literature and information that you provide extremely useful and informative. Many of our patients have commented on how useful the information has been to them. Individual leaflets on different sites of the body and different aspects of psoriasis make it easier for patients as they only need to read information relevant to their specific needs.'



## 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. In addition to funding our own research, we recognise the importance of working collaboratively with others carrying out research into this complex condition.

'The Psoriasis Association continues to attract PhD funding applications from high quality research teams. The projects chosen are important. They seek to help us understand the condition better so that we can then develop the right treatments. I am delighted to support the choice of research projects.'

Dr Julia Schofield MBE Consultant Dermatologist

### 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.

'I have suffered psoriasis and psoriatic arthritis since 1955. In my twenties, little seemed to be known about the condition, and the medical fraternity seemed to me somewhat indifferent to it - it wasn't glamorous or deadly enough to warrant much attention. How I wish the Psoriasis Association had existed then to give the sort of excellent information, advice and support available to members today. The enthusiastic work of the Association, since its inception in 1968, has been most helpful and instructive. Knowing there is that source of assistance and education relating to psoriasis available is reassuring, and even comforting.'

Gordon Kerr-Smith Member

## Chairman's Report

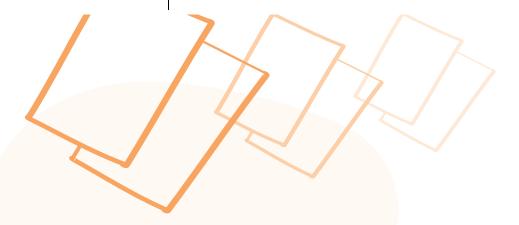
From our foundation The Psoriasis Association has made a commitment to supporting research into the causes and impact of psoriasis, its treatment and ultimately finding a way of eliminating the disorder altogether.

As I reflect on 2015 it seems to have been an odd mixture of change and familiarity for the Association. Change last May, as we said our farewells to Ray Jobling, our chairman for so many years, and change at the end of the year as we wished our Chief Executive, Helen McAteer, well for her forthcoming maternity leave. Nonetheless, the Trustees, guided and supported by our superb office team, have coped admirably with these potential upheavals, and the Association has remained focussed on its core business.

Research continues to be at the forefront of our activities. We have continued the policy established several years ago of funding PhD studentships, and guided by our expert Research Advisory Committee the Trustees were able to both continue support to seven students, and begin funding three additional projects. Not only does this work push forward knowledge and understanding of psoriasis, it also contributes significantly to the development of the next generation of experts in the condition. The way in which research is prioritised has been the subject of much discussion during the past year, and in the autumn the Trustees agreed in principle to take forward the commissioning of a 'Priority Setting Partnership', an approach which seeks to determine priorities for research jointly between patients, carers, and expert clinicians. The experience of other medical conditions that have used the approach suggests that the results will inform not just the Association's future research priorities, but also those of other research funding bodies.

The provision of high quality, reliable information and access to advice remain part of our day to day work. Sadly numerous people are newly diagnosed with psoriasis each year, but our printed leaflets and websites offer both high quality information and the opportunity to contact others. Our websites received approximately 800,000 'hits' during the year, and we distributed information leaflets on a variety of topics. The telephone and email helplines continued to be busy, with 1,085 enquiries being answered by the office staff. These can vary from simple requests for information to complex pleas for advice and help from patients and carers struggling with the impact of psoriasis on their lives.

The difficulties of accessing NHS dermatology services remain a major issue. There is considerable variation across the country and we have sought both directly and in partnership with other organisations to press for more investment, both in specialist services and in the education and training of GPs and medical students. There remains a need for long term investment in staff across the system if all patients are to have the care which is currently only available to some. Our engagement with the National Institute for Health and Clinical Excellence (NICE), our partnership with other charity and professional organisations in the All Party Parliamentary Group on Skin, our contacts with the pharmaceutical industry, our briefings for the general and specialist press, and our presence in the broadcast media over the past year have all served to raise the profile of psoriasis and to ensure that the patients voice is heard.



Inevitably all of this needs money. The Financial Statements reveal a continuing, solid financial foundation to the Association. The generosity of our members and supporters enables us to continue our existing work as well as developing new strands to what we do. The energy and imagination that we see in the pages of Pso is testament to the commitment of our membership, and the support that they inspire in the wider community. Legacies remain an important part of our income and it is perhaps a further reflection of the widespread recognition that our work commands. 2016 will of course bring its own challenges, but I am confident that the Association will rise to them.

The commitment and expertise of our staff team remains unbounded, and they continue to be at the heart of all that we do.

Nick Evans Chairman, Psoriasis Association

## What our supporters say about us...

'I would never have had this major advancement had it not been for you and the kindness you showed in listening to me today.'

> 'You've been very informative and helpful, and rest assured, I will contact you when I need more advice.'

'Just wanted to say how much I enjoyed the current edition of the magazine. In your head you know you are not alone suffering psoriasis, but it is so encouraging to hear how other people cope.'

'Thank you for the great information, your phone helpline gave me the confidence to go to my GP again.'

'I just loved your site, I have just been diagnosed and found your site very simple and easy to read.'

'You have been a tremendous help and gave my son all the information he needed. I can't thank you enough for taking the time to reply.'

'You will never know how much I appreciate your reply; I am eternally grateful for the advice you have sent.'



## Providing information, advice and support

The Psoriasis Association has been awarded the Information Standard which denotes that the charity's information production processes are of high quality, and the information produced reliable.

As a Community Dermatology Clinic we were very keen to partner with the Psoriasis Association to support our many patients. I'm pleased to say that the Psoriasis Association responded very quickly to our request and they have offered to provide many forms of literature to us as well as allowing us to promote the Psoriasis Association on our website. The additional support and information directly from the Association regarding this condition is of great help to our patients and clinicians.

Lucy Brockway
Community Dermatology Clinic
Basildon & Brentwood CCG and Thurrock CCG areas

Advice and support is available through our helpline services with enquirers receiving tailored information for their needs in addition to a general information pack when necessary. Both websites offer comprehensive information and peer-to-peer support. **Pso**, the official journal of the Psoriasis Association ensures that members are kept informed of developments regarding the treatment and management of psoriasis and psoriatic arthritis.

I spoke to the helpline on the phone, who I have to say were great! They gave me more information in 20 minutes than anyone else has put together in 18 months.



### Research

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











The Medical and Research Committee, along with External Peer Reviewers extensively reviewed all submissions received in response to the 2014 call for PhD Studentship and Small Grant Applications, recommending three PhD Studentships and one Small Grant.

The Trustees were pleased to support the following PhD Studentships and Small Grant:-

## 1) The role of mast cell tryptase in psoriatic itch

### Professor Silvia Bulfone-Paus – University of Manchester

Psoriasis is a chronic, frequently life-ruining skin disease in which itch is one of the least understood - but one of the most frustrating - symptoms. The sensation of itch in psoriasis patients is unique and different to that of other skin diseases: an intense burning / biting sensation, which is often enhanced by stress and can often be experienced in the absence of active skin disease. Additionally, scratching can lead to a worsening of disease. There is therefore a need to explore the origins of so called "psoriasis itch" to develop more effective treatment strategies. This PhD project will investigate chemicals produced by mast cells (a critically important cell type in psoriasis) and how they interact with other cells in the skin to produce the characteristic itching. This study promises to clarify the role of mast cells in psoriasis and may ultimately lead to more effective strategies for the management of psoriatic itch.

# 2) Characterisation of novel pathogenic pathways for generalised pustular psoriasis

### Dr Francesca Capon - Kings College, London

Generalised Pustular Psoriasis (GPP) is a rare, but potentially life-threatening variant of psoriasis that is notoriously difficult to treat. Our group has been leading the search for the genetic causes of GPP and has identified two genes, which account for a significant proportion of disease cases. We now plan to build on these exciting findings to gain a better understanding of the mechanisms that underlie the onset of GPP symptoms. We will achieve this objective through a multi-disciplinary approach integrating genetic studies and computational methods. This innovative strategy will allow us to uncover additional genes that are abnormally active in the immune cells of GPP patients and therefore play an important role in determining disease onset. These studies are expected to facilitate the identification of novel GPP genes and to shed new light on the mechanisms that can be targeted for the treatment of this severe disorder.

Nrlasis

research

# 3) A role for connexin-mediated signalling events in the pathogenesis of psoriasis

### Dr Patricia Martin - Glasgow Caledonian University

During psoriasis skin cells multiply and their ability to stick to one another is affected, resulting in 'flaky' skin and inflammation. A change in the bacteria that live on the surface of the skin during psoriasis may also influence this process. We will investigate how a family of proteins, the connexins, that enable skin cells to i) talk to one another and ii) stick to one another are modified during psoriasis and by microorganisms present on the skin. Connexin26 is found at very high levels in the skin of psoriasis patients yet the level of its sister protein Connexin43 is reduced. Agents that can 'block' overactive Connexin26 may decrease inflammation, and agents that stabilise Connexin43 may encourage skin cells to stick together thereby reducing the symptoms

of psoriasis. Skin cells isolated from

'normal' and 'psoriatic' skin samples

will be used. Such an approach may

identify new treatments for psoriasis.

Investigation of the roles of UVinduced nitric oxide and vitamin D in Narrow-band UVB phototherapy treated psoriasis patients

### Dr Richard Weller - University of Edinburgh

Psoriasis is a debilitating condition which affects 2-3% of the population. The causes are not fully understood. Many psoriasis patients improve in the sun, and one of the most effective medical treatments is ultraviolet therapy. We are searching for factors that might be responsible for the beneficial effect of phototherapy in psoriasis and how they correlate with response to treatment. Several possible psoriasis modulating mechanisms are influenced by UV. We suspect that UV-induced anti-inflammatory molecules including NO and vitamin D have direct effects on immune cells function and are partially responsible for the beneficial effects of phototherapy. We propose that the combined effect of NO and vitamin-D suppresses interleukin 22 (IL22) secreting T cells. These are closely related to the development and progression of psoriasis and affect regulatory T cells that suppress the activation of the immune system and thus improve psoriasis.

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

## Raising awareness

During 2015 the Psoriasis Association raised awareness of psoriasis in a variety of ways:

The main Psoriasis Association website and sister site Psoteen remain vital information resources for many people with psoriasis, complemented by the Psoriasis Association's two Social Media channels, Twitter and Facebook. Both websites have a forum for people to exchange experiences of living with and treating psoriasis and the presence of the Psoriasis Association on social networking sites helps to maximise our online outreach, achieving 'verified' status for our Facebook presence in 2015.



'It is the best website that I have seen for simple, clear information. Very informative and a good insight into what is available.'

Facebook group members
2,520
(54% more than last year!)



In 2015 the Psoriasis Association invited members and supporters to be part of a **photoshoot project** to build an image library of people living with psoriasis and psoriatic arthritis, which will be incorporated into resources such as websites, leaflets, exhibition stands and posters. A set of five new posters were produce and distributed to Dermatology and Rheumatology Departments nationwide.

The importance of recognising the symptoms of psoriatic arthritis was the key message during **Psoriasis Awareness Week**, in November. The Information and Communications Manager and a member of the Psoriasis Association were interviewed on BBC local radio; an article was published in the review-based journal Dermatology in Practice, and articles were also published on relevant websites including Patient, Talk Health, Treated.com, and Yours Magazine online. An article on a Psoriasis Association supporter was published in the Metro online. The launch of five A4 and A3 posters featuring the photoshoot participants supported this activity.

Efforts were concentrated on the Psoriasis Association's online and social media presence during Awareness Week, with five case studies of individuals with psoriatic arthritis being featured on the main website and across Facebook and Twitter, generating high levels of interest.

**Media** - opportunities to raise awareness throughout the year included interviews on BBC Radio Ulster and BBC Radio Foyle, inclusion in a Daily Mail article and a full page advertisement in the magazine Ask the Doctor with Dr Christian Jessen.

Staff and Trustees presented on the work of the Psoriasis Association along with the conditions psoriasis and psoriatic arthritis to MSC students in Dermatology, the Manchester Psoriasis Research User Group and Deutsche Bank, and papers were published in the Dermatological Nursing Journal and the Practice Nursing Journal.



Throughout 2015 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, the Annual Psychodermatology UK meeting, the British Society for Rheumatology and the Royal College of Nursing combined conference and the Primary Care Dermatology Society Annual 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 on the Association of Medical Research Charities, national council of Voluntary Organisation, National Voices and the Patient Information Forum.

**Government** - 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.







This information is a summary of the full accounts of the Psoriasis Association for the year ended 31st December 2015.

Income and endowments	2015 (£)	2014 (£)
Donations (including, for example, membership subscriptions, fundraising by individuals, Gift Aid, donations in memory)	101,931	119,822
Legacies	232,663	335,087
Income from investments	135,078	147,955
Income from Charitable Activities (including, for example, corporate sponsorship, charitable trust donations, Pso advertising, grant payments)	57, 210	40,739

Total Income for the Year 526,882	643,603
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Expenditure	2015 (£)	2014 (£)
Raising Funds	61,608	55,776
Charitable Activities	455,881	361,599
Investment Management Costs	29,636	23,525
Total Expenditure for the Year	547,125	440,900

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

Total Net Assets	2015 (£)	2014 (£)
At 1st January	5,194,980	4,943,007
Add Incoming Resources	526,882	643,603
Deduct Net Resources Expended	(547, 125)	(440,900)
Gains/losses on Investment Assets	17,320	49,270
At 31st December	5,192,057	5,194,980

The total assets are made up as follows	2015 (£)	2014 (£)
Endowment funds for research and educational work	3,356,508	3,319,101
Restricted funds for research	492,911	608,491
Restricted funds for Scotland	146,217	198,319
Unrestricted funds - General charitable work	186,572	168,915
Unrestricted funds - Designated funds	715,849	606,154
Unrestricted funds - Property fund (this reflects the value of the property purchased in 2007)	294,000	294,000

TOTAL	5,192,057	5,194,980
Change in assets	(2,923)	251,973





# For helping us to have a successful 2015...

### 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**

Ray Jobling MBE, Nick Evans, John Ford MBE, Jonathan Swift, Mike Andrews, Steven Astaire, Antony Bramley, Steve Churton, Chris Dyer, Michael Israel, Brian Murkin, Dr Julia Schofield MBE, Claire Strudwicke, Matthew Swift and Frank Wallder

#### **Our Medical and Research Committee**

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 2015

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

Companies who supported our work in 2015 via membership or unrestricted educational grants Abbvie, Celgene, Dermal Laboratories, LEO Pharma Ltd, Novartis and T&R Derma.



