



psoriasis  
association

# Our 2014 Achievements

*"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*

Helen McAteer - Chief Executive

For further information please visit:

[www.psoriasis-association.org.uk](http://www.psoriasis-association.org.uk)

or call: 08456 760 076



psoriasis  
association

The Psoriasis Association  
Registered Charity Numbers  
257414 and SC039886

Design by [www.spoken-image.com](http://www.spoken-image.com)

## Providing information, advice and support

The Psoriasis Association is committed to providing high quality, reliable, up-to-date information, and so was proud to be awarded the prestigious NHS England-run Information Standard in 2014, for every single piece of information we provide.

Our information provision has evolved over the years, reflecting the changes in technology and people's preferences. We continue to provide printed literature, and launched seven new leaflets during 2014, along with continuously updating existing resources. Our membership magazine, Pso, is also a printed publication.

The new leaflets were titled; What is psoriasis, Treatments from a GP, Scalp psoriasis, Sensitive areas, Treatments from a Specialist, Biologic treatments and Psoriatic arthritis.

The third most asked about topic on our helplines relates to how to get a referral to see a Dermatologist. We work with government bodies such as the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC) when they are assessing new treatments for psoriasis and psoriatic arthritis regarding their suitability for the NHS.

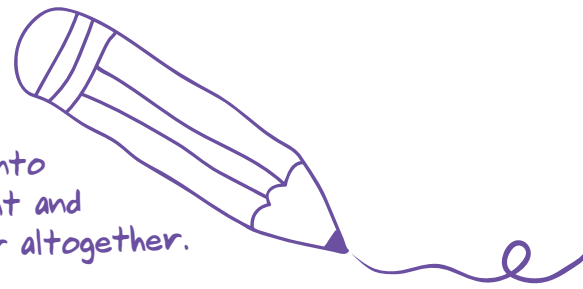
We also work with NICE and the SMC when they are developing guidelines for the assessment and management of psoriasis and / or psoriatic arthritis. During 2014 the Psoriasis Association was involved in the development of a guideline on Seronegative Spondyloarthropathies, and technology appraisals for Apremilast to treat psoriasis and psoriatic arthritis and Secukinumab to treat psoriasis with NICE, and Ustekinumab and Certolizumab Pegol to treat psoriatic arthritis with the SMC. Our Chairman contributed to the work of the European Development Group of Dermatological Experts, who produced updated Guidelines for the Systemic Treatment of Psoriasis throughout the European Union.

Peer-to-peer support is important to many people, and our online resources continued to go from strength to strength in 2014. We welcomed an additional **321** people to our Facebook Group, where **1,638** people now exchange hints and tips and offer advice to others. There are now **4,060** people signed up to the forum on our main website and **560** people signed up to the forum on Psoteen.org.uk.



# 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.



In 2014 once again we provided funds to the best research teams who presented projects to us. We also invested in PhD studentships for bright young postgraduates at the early stages of their research careers, who wished to pursue specific lines of enquiry in psoriasis-related areas. This has been a priority set by the Trustees following advice and guidance from our Medical and Research Advisory Committee. It is important not just for the results from their particular projects which we all hope to see, but also for the training in methods and techniques which should provide the foundation for continuing development over years to come. We have become a significant contributor to the education of those who will represent the future of psoriasis research in the UK, and The Psoriasis Association has received applause from the research community and Dermatology more widely for our distinctive role in this respect.

There is no doubt that excellent work is being done towards unravelling the complex puzzles still posed by psoriasis. But there is still some way to go. This year has seen the publication of major international reports reviewing what is known and not known, understood and not understood about the condition. Sadly they reveal that some research over the years could have been better, and some of the evidence which should underpin approaches to treatment is neither as sound nor as strong as we would like. But they also document progress, and importantly put forward proposals prioritising what should be done in the future.

Alongside this both here in the UK and Europe-wide Guidelines for clinicians (and those who commission and fund care) have been published for ensuring that the treatment made available to patients does indeed rest upon a firm basis of genuine, reliable evidence.

In all of this there has been provision for patients to make their contribution, based upon experience and the concerns and needs they themselves judge to be important. These views have been regarded with the seriousness they deserve. Members of the Association have played a significant part in these processes.

The provision of accurate and reliable information and guidance has also been a feature of what the Association has regarded as a role and responsibility. We have made giant strides in recent years. In 2014 once again we have received official recognition and a seal of approval for what we do. The social media have become a key feature of the work, expanding at a rate justifying the appointment of an additional member of staff who includes responsibilities in this area of activity. There is no doubt that we shall continue to be one of the most trusted resources of information and support for all those who are concerned for the wellbeing of everyone with psoriasis.

We are careful to scrutinise and evaluate coverage in the press and broadcast media concerning psoriasis, supposedly explaining psoriasis, offering suggestions about dealing with it, and in some cases offering "a cure". Setting the record straight is part of our job, ensuring that the public is not misled and crucially that patients are not drawn into something expensive, useless, and possibly harmful.

In doing so we cooperate with health professional bodies and the relevant regulatory bodies who deal with medicines and "treatments".

Every year unfortunately we find ourselves having to report that the NHS is stretched and services are under pressure. This year it remains the case that Dermatological services remain in question. There is a shortage of specialised staff, and some parts of the country have difficulty in appointing to Dermatology posts. Waiting times for seeing consultants are of course controlled, but continue to be longer than they ought to be. Patients are still reporting that they feel their GPs could do better; and indeed GPs themselves do recognise that their undergraduate medical education and continuing professional training for helping patients to manage psoriasis and other common skin conditions is lacking.

As an Association we have been trying to address these issues, both singly but also in partnership with other patients organisations and the relevant professional bodies, with support where appropriate from the pharmaceutical industry. In this regard the All-Party Parliamentary Group on Skin has played a significant role, opening doors and seeking to identify listening ears. The need to engage in what is in effect "lobbying" has become a fact of life for patients' organisations like ours.

None of the year's progress across the wide range of our efforts, with the positive impact it is making, would be possible without a firm foundation of sound finances. The Annual Financial Statement provides insight into our current position, and is reassuring. We are fortunate in the generosity of our members and supporters, in their contributions and the impressive sponsored activities and events in which they engage. Being remembered in legacies has also become an important feature of our financial accounts, a moving reminder that what we stand for and try to do is recognised and appreciated by so many as worthy of this distinctive gesture of support.

The Association is fortunate in its staff for their professionalism, and for their personal commitment which goes way beyond contract. Without their dedication we would be able to achieve far less.

Ray Jobling

Chairman,  
Psoriasis Association



# Raising awareness

The Psoriasis Association aims to raise awareness of psoriasis and the conditions that may be associated with it to the widest audience possible.

Our reach starts with the general public and extends to healthcare professionals, Members of Parliament and government bodies. Social media resources such as Twitter and Facebook are used to raise awareness across all areas.

In 2014 we attracted a further **1,154** followers on Twitter giving a total of **4,284** followers from individuals to clinical commissioning groups, journalists and professional bodies.

Twitter followers  
**4,284**  
(that's 37% more than in 2013!)



## General public

During 2014 the Psoriasis Association raised awareness of psoriasis in a variety of ways:-

### Online presence:

We are consistently high in search engine results (such as Google) and increased our social media outputs.

### Media:

Opportunities to engage with the media occur throughout the year, with an in-depth focus during Awareness Week each year (1st – 8th November). During 2014 members, the Chief Executive and the Information and Communications Manager all gave numerous radio interviews, with the Chairman being interviewed on the BBC Radio 4 programme You and Yours. The Chief Executive appeared on the lunchtime magazine programme on London Live TV and the Psoriasis Association had features in the Daily Mail, Glamour Magazine and health magazines Ask the Doctor with Dr Christian Jessen and Dear Doctor, with Dr Chris Steel.

### Face-to-face:

We had information stands at Well Being events and in supermarkets, along with our information being displayed at venues during the Manchester Psoriasis Shout Out, such as the Trafford Centre and Media City. Presentations were also given to Ladies groups.

## Healthcare professionals

The Psoriasis Association raised awareness with healthcare professionals in a variety of ways, from speaking at educational and conference events, through to having information stands at conferences and publications in peer reviewed journals. During 2014, the 2009 membership survey was published in the journal Primary Health Care Research and Development, and the analysis of the Dear Psoriasis... postcards was published in the British Journal of Dermatology.

## Members of Parliament

The Psoriasis Association takes an active role in the All Party Parliamentary Group on Skin, attending and presenting evidence at meetings in 2014. The Chairman and Chief Executive also took part in a parliamentary round-table meeting exploring the barriers to work for people with skin conditions.

We also communicate with the Scottish Parliament Cross Party Group on Skin and related Rheumatic conditions, and are active within the Dermatology Council for England.

## 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.



# 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 four External Peer Reviewers extensively reviewed all submissions received in the 2013 call for PhD Studentship and Small Grant Applications.

**The Medical and Research Committee recommended the Trustees funded four PhD Studentship Projects:-**

## 1) Psoriasis and sleep deprivation

**Dr Chris Bundy – University of Manchester**

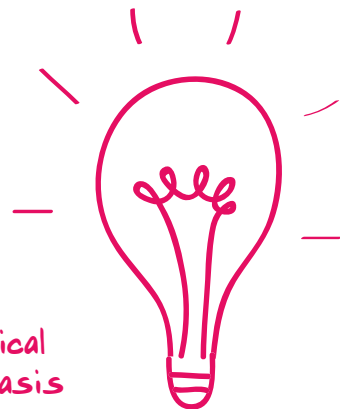
“Psoriasis is a chronic inflammatory skin disease that affects 1 in 50 people in the UK. It occurs as red, scaled patches particularly on the scalp, elbows and knees and is currently incurable. Stress is known to both trigger and worsen psoriasis in some patients. The appearance of psoriasis and the scaling can be very distressing; some patients say the itch and soreness of plaques stops them sleeping well. We don’t know how widespread the problem is. Lack of sleep can affect mood and ability to work and function in the day time. This aspect of psoriasis is under-recognised by health care staff and consequently is poorly managed. This project will: (1) comprehensively assess whether sleep disturbance is a significant problem in people with psoriasis; and (2) test an existing online method to improve sleep quality in people with psoriasis.”

## 2) Neuropsychological morbidity in psoriasis

**Dr Elise Kleyn – University of Manchester**

“Psoriasis is a chronic skin disease for which there is currently no cure. It afflicts far more than the skin and there is limited knowledge of the mechanisms or way in which psychological effects as well as other brain effects are caused.

We were the first to use brain scanning techniques to show that patients with psoriasis process facial expressions of disgust differently to individuals without skin disease. This PhD project will use state-of-the-art brain scanning, questionnaires and laptop-based tasks to investigate whether treating psoriasis lesions effectively will change altered processing of disgust in patients. Patients’ reactions to pictures of their own psoriasis lesions and those of others will also be studied in a separate group of patients who have had psoriasis for varying lengths of time. Understanding the brain-skin connection is key to developing new approaches to help treat the psychological and other brain effects of psoriasis.”



## 3) Functional characterisation of genetic susceptibility to psoriasis

**Dr Julian Knight – Oxford University**

“Recent genetic advances offer unique opportunities to improve our understanding of the causes of psoriasis and improve patient care. There is now evidence of association between particular genetic differences between people and risk of disease. However these associations do not tell us which genes are associated with disease, how genetic variants act and how this is relevant to patients.

This studentship will aim to carry out research to address these questions using cutting-edge techniques applied to patient samples. The longer-term aim will be to provide a better understanding of psoriasis and identify pathways that could serve as drug targets or biomarkers for diagnosis and prognosis. The studentship provides a unique training opportunity for a future research leader in the field, building research capacity. The research supervisors, Julian Knight and Graham Ogg are both clinical academics at the University of Oxford with research expertise spanning genetics and the biology of psoriasis.”

## 4) An investigation into genetic factors which discriminate psoriasis from psoriatic arthritis

**Dr Richard Warren – University of Manchester**

“Psoriasis is complicated by an arthritis, known as psoriatic arthritis (PsA) in approximately 25% of cases. It is well known that patients who have psoriasis affecting the skin and those who go on to develop the joint problems often have affected family members, what we would call a genetic predisposition to the condition. What is not understood is which genetic factors (small changes in an individual’s DNA code) influence who will develop psoriasis that remains confined to the skin versus those individuals who will also develop the arthritis.

This study will involve a large scale genetic investigation comparing and contrasting the genetic makeup of individuals from these two sub-groups. A greater understanding of the genetic factors which influence these two potential outcomes would be very helpful in: 1 – trying to devise ways to prevent the onset of PsA and 2 – target specific individuals with more appropriate treatments.”



**There are three ongoing Psoriasis Association funded PhD Studentships:-**

## 1). The molecular genetic basis of generalised pustular psoriasis

**Dr Francesca Capon – Kings College London**

## 2). Oxidised lipids and their role in the immunopathology of psoriasis

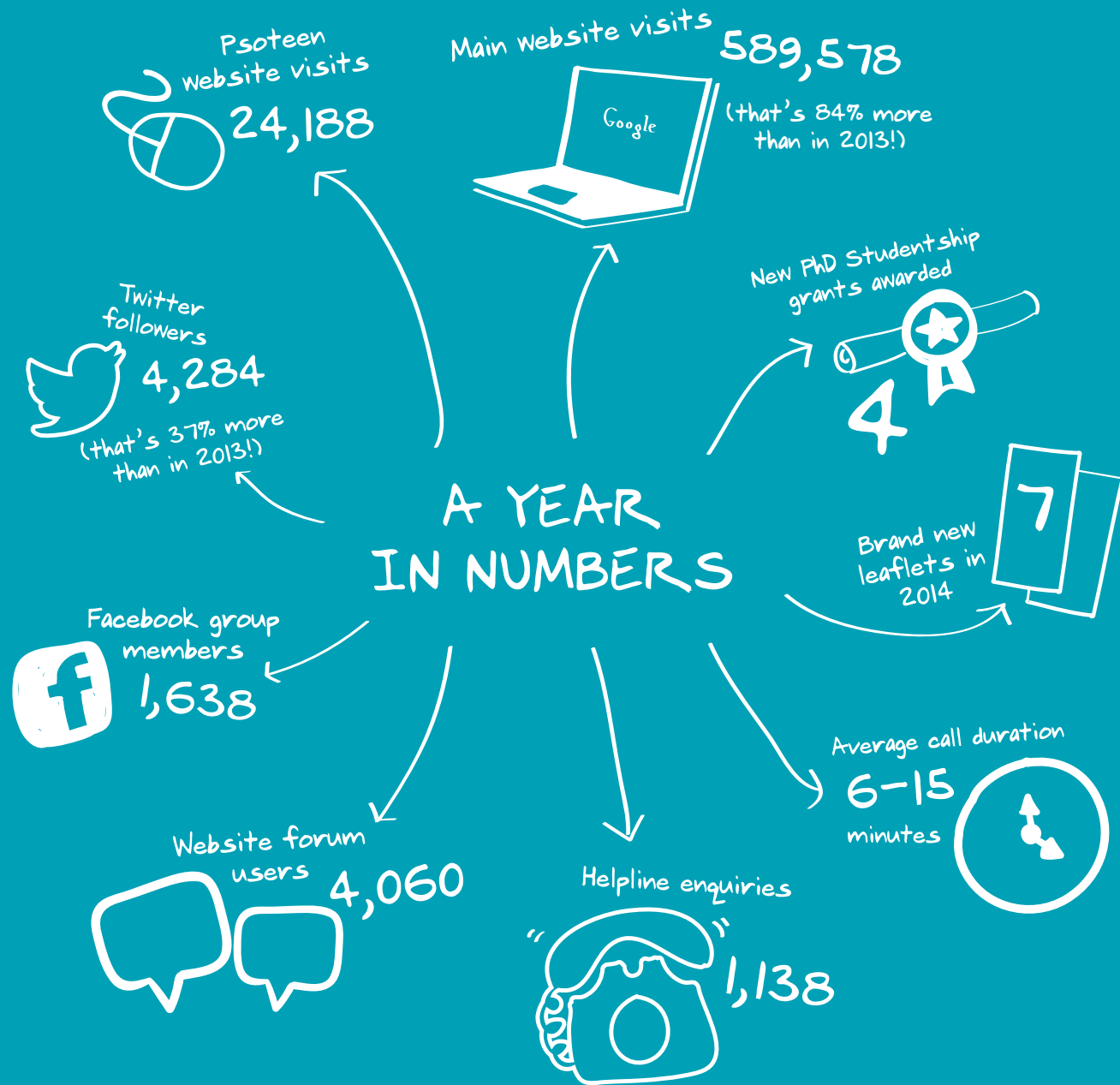
**Dr Tim Millar – University of Southampton**

## 3). The role of exercise on cardiovascular disease risk in psoriasis

**Dr Helen Young – University of Manchester**

The Psoriasis Association is extremely grateful for the time dedicated to reviewing the applications by the Medical and Research Committee (Professor Jonathan Barker, Dr Tony Bewley, Professor Chris Griffiths, Professor Eugene Healy, Ray Jobling and Dr Julia Schofield) and External Peer Reviewers (Professor Alex Anstey, Dr Elise Kleyn, Dr Tony Ormerod and Professor Nick Reynolds).





For helping us to have a successful 2014...

**Our members and supporters**

**People who fundraise and donate on our behalf**

**People who leave legacies to the Psoriasis Association**

**Our Trustees**

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

**Our Medical and Research Committee**

Professor Jonathan Barker, Dr Anthony Bewley, Professor Christopher Griffiths, Professor Eugene Healy, Dr Julia Schofield MBE and Ray Jobling MBE

**External Peer Reviewers**

Professor Alex Anstey, Dr Elise Kleyn, Dr Anthony Ormerod, Professor Nick Reynolds

**Trusts and Foundations who supported our work in 2014**

CE and Campin Trust, Cecil King Memorial Foundation Trust, The Coulthurst Trust, Davis Rubens Trust and Salamander Charitable Trust

**Companies who supported our work in 2014**

**via membership or unrestricted educational grants**

Abbvie, Celgene, Dermal Laboratories Ltd, Forest Laboratories UK Ltd, LEO Pharma Ltd, Novartis, T and R Derma

... Thank you!