



psoriasis
association

10 Year Impact Report
What a Difference a
Decade Makes

2010-2020

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"The Psoriasis Association provides good, relevant information in a positive way. They make me feel understood & less alone. The services all provide good information that allow me to make more informed decisions & make me feel more empowered in them and myself."

Felicity - London

"The Psoriasis Association team at HQ are amazing, always updating and keeping us informed with anything new or any problems, especially with medication. They have even helped me with information for school to help [my son] Callum. It's nice to know someone is always there if you need them and can give accurate information too."

Karen Lowe - Guildford, Surrey

"I don't know anyone else with psoriasis so it's nice to see other people's stories and know I'm not alone."

Anonymous

Welcome

In this report we look at the real difference that we have made to the lives of people with psoriasis and/or psoriatic arthritis over the last **10 years**. We explore the explosion of social media, the re-launch of our websites, our latest cutting edge research projects, and our ever growing Psoriasis Awareness Week.

Our aims:



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



To raise **awareness** of psoriasis.



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



Nick Evans

Chairman
Psoriasis Association

Founded over fifty years ago, the Psoriasis Association has grown to become the leading national charity and membership organisation for people affected by psoriasis in the United Kingdom. The Psoriasis Association's aims have remained unchanged and are as pertinent now as when it first began – to offer good quality and reliable independent information and advice, to raise awareness of psoriasis amongst those who lead the provision of services and the wider public, and fund and promote research into the causes, nature and care of people with the condition. I am privileged to introduce this review of our achievements over the past ten years and I hope that readers will find much in it to interest and inform.



Helen McAteer

CEO
Psoriasis Association

The Psoriasis Association is committed to helping people whose lives are affected by psoriasis. The advances in technology in the last ten years have seen us help individuals on a one-to-one basis, host conferences with hundreds of delegates and educate thousands with our informative online resources and media activities. Alongside our dedicated support services, which include traditional print and telephone helplines as well as websites, social media and videos, we have funded and supported ground-breaking research and initiatives that have greatly enhanced the understanding and treatment of psoriasis. But there is still work to do. We continue to rely on your experiences and support to help us improve the lives of those affected by psoriasis.

Our story so far

A lot has happened since that first meeting in 1968. From our modest beginnings we have grown in to a national charity, supporting people with psoriasis and/or psoriatic arthritis across England, Wales, Scotland, and Northern Ireland.



THE PSORIASIS ASSOCIATION

1968

The Psoriasis Association was founded and membership cost 10 shillings per year!



1971

Our first research grant, of £115 for equipment, was awarded to Prof Terence Ryan



1989

By 1989 we had granted over £250,000 towards psoriasis research



1998

Our first website was launched [\(page 14\)](#)



2004

We contributed to the NICE Technology Appraisal for the first biologics to treat psoriasis



2008

We received Scottish Charity registration status and launched our first Facebook page



2011

Our two new identities and websites were launched and we were also awarded the Information Standard, showing that our information is accurate and reliable



2014

In 2014 we were funding 7 PhD Studentships



2018

We celebrated our 50th Anniversary with various projects such as our 50 for 50 campaign [\(page 28\)](#) and launching our WhatsApp service

1970

Our first members' magazine was published



1973

We moved to a new home with permanent staff, supporting over 40 branches across the UK



1993

Our first Psoriasis Awareness Week, which was so successful that we have continued to host the event annually [\(page 24\)](#)



1999

By 1999 we had funded over £1.5 million towards psoriasis research



2007

We awarded our first PhD Studentship and moved to new premises at Dick Coles House, Northampton



2009

We joined Twitter [\(page 18\)](#) and teamed up with the University of Manchester on the IMPACT project



2013

We gave valuable evidence to a parliamentary inquiry on the impact of skin disease



2016

We launched the psoriasis Priority Setting Partnership (PSP) [\(page 32\)](#)



2019

Our 50th anniversary celebrations culminated in our annual conference being held at the prestigious Royal Society. In addition, the psoriasis PSP Top 10 research priorities were published in the British Journal of Dermatology



Supporting people with psoriasis



An amazing network

"I was first diagnosed with psoriasis at 18 years old, and for the first 10 years I felt completely alone. Despite having very supportive friends and family, no one understood the mental and physical toll it was taking on me, especially through my twenties. It was difficult to explain in a way that they could understand that it was so much more than just a dry skin disorder.

My psoriasis experience started to change when I was introduced to the Psoriasis Association at an awareness talk about 5 years ago. Just finding the existence of the charity blew my mind. At first, I was wary of putting personal information and experiences on Facebook and stuck to the message boards on the website which offered some support. When I understood the privacy that came with a closed group and proper admin

I joined and my whole world changed. All of a sudden, I was enclosed in a supportive and knowledgeable community who understood exactly how I was feeling during my worst days and could celebrate my small but significant victories on my good days.

One aspect I love is the advice that is shared. I can post photos with no judgement, ask for advice and within a few hours I have loads of helpful suggestions and support. Equally if I find something that works well for me I can share that with the group in the hope that it will help someone else who is struggling. The Facebook group has become a community which I interact with on an almost daily basis and I can't imagine not having this amazing network of people in my life!"

Sonia M



Supporting... each other

The Psoriasis Association started out as a small support group in a front room, so we know how important it is for people with psoriasis and/or psoriatic arthritis to be able to connect with each other. Nowadays, these support networks are mostly online.

We host two different online support networks: our website forums and our closed Facebook group. These dedicated and highly popular safe spaces allow people with psoriasis and/or psoriatic arthritis to share their stories, experience, and expertise. In fact, they are so popular that our forums have been the most visited pages on the Psoriasis Association website over the last 10 years - **with over 4 million views.**

By the end of 2019 there were...

 **13,687**
Registered forum users

 **6,413**
Facebook group members

 **2,161**
Forum conversations happening

... offering advice and peer to peer support

"The website and the Facebook Group have been a lifeline. I have made some wonderful friends online – it makes such a difference to talk to people who are going through the same things or have people who will just listen. My son, Callum, has also found the Teen section very useful as going through puberty is a tricky time but psoriasis can make it just a little bit harder."

Karen Lowe - Guildford, Surrey



"The Facebook group is a great place to find non-judgemental help and support. It's like a big family where there is also humour- a microcosm reflecting the entire 'journey' of psoriasis."

Kevin Tudor - Kent

Why don't you dive in and take a look?

www.psoriasis-association.org.uk/forums

Supporting... you

Psoriasis is an individual condition and we believe that it's important to support people as individuals. Our helplines offer one to one support, tailored advice, or simply someone to talk to, for anyone affected by psoriasis and/or psoriatic arthritis.

Helping you when you need it

We have long offered confidential support over telephone, email, and by post, but did you know that since 2018 we have also had a confidential WhatsApp helpline?

Although open to everyone, our WhatsApp helpline was launched to help support young people after our survey found that 67% of young people with psoriasis felt isolated.



“*I found your WhatsApp helpline incredible. They gave me the confidence I needed to go back to the GP and demand to be taken seriously, which resulted in my guttate psoriasis disappearing. I can't thank you enough.*

Anonymous



12,292

Helpline conversations held over the last 10 years

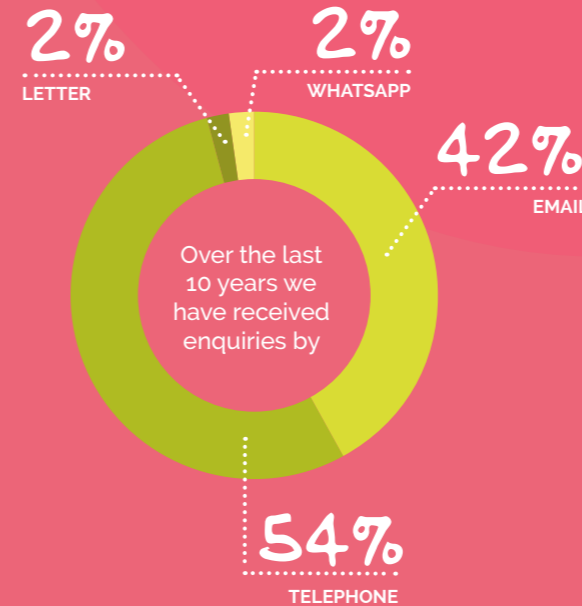


3,630

General information packs sent to individuals following these discussions

13,230

Leaflets and information sheets sent in the last 3 years alone



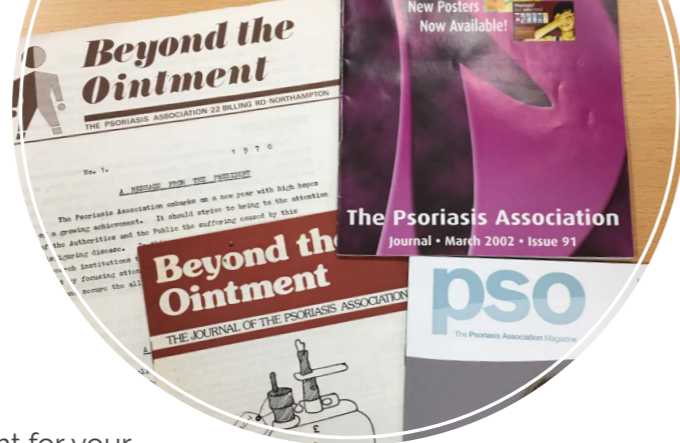
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"I believe it is important to recognise each enquirer's specific needs and help them to understand their psoriasis and the different types of treatment pathways available. In doing so, we can empower individuals to feel more confident and to proactively communicate with their healthcare professionals in a positive way."

Laura Bell, Helpline Administrator –
Psoriasis Association

Pso informed

First launched as 'Beyond the ointment' in 1970, our quarterly members magazine 'Pso' is brimming with interesting content such as cutting edge research, real life stories, and the latest news.



Fighting for your treatment choices

Did you know that we also work behind the scenes to fight for your right to treatment choice?

New treatments have to be assessed on their effectiveness and value before they can become available on the NHS. These assessments look at evidence from the pharmaceutical company, healthcare professionals, and patient representative groups such as ours.

Since the assessment of the first biologics to treat psoriasis began in 2004, we have consulted on every relevant biologic and systemic medicine assessed by NICE (National Institute for Health and Care Excellence) and the SMC (Scottish Medicines Consortium) to ensure that the patients' perspective is always taken into consideration.

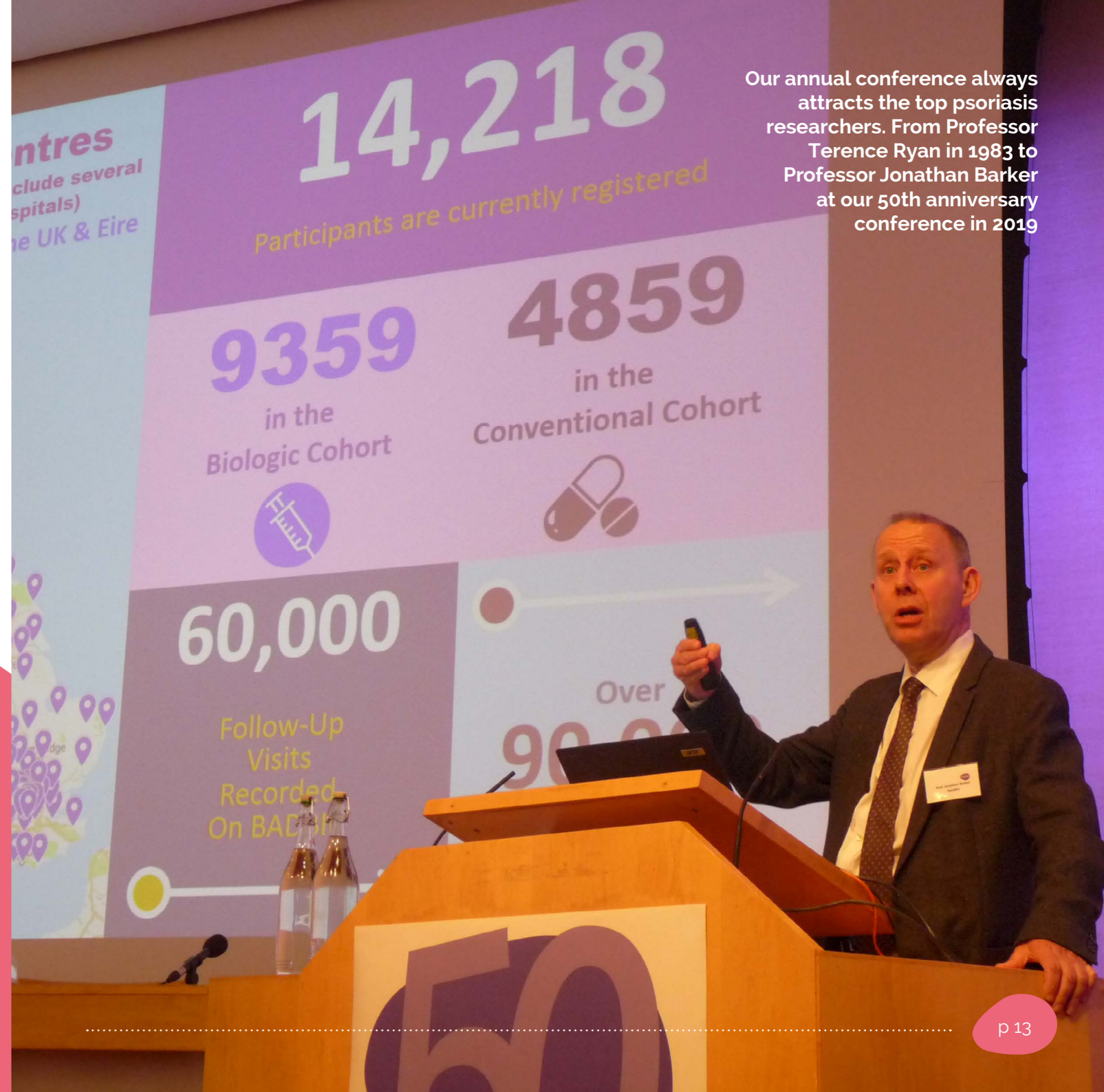


Watch our conference talks on YouTube



Getting together

Our annual conference and AGM brings together Psoriasis Association Trustees, members, supporters and staff in a one-day event packed full of talks and presentations. To ensure that no-one misses out we have filmed these fascinating talks since 2016. So far our talks have covered topics ranging from new campaigns, to people's experiences of living with psoriasis, to our cutting edge research projects.



Our annual conference always attracts the top psoriasis researchers. From Professor Terence Ryan in 1983 to Professor Jonathan Barker at our 50th anniversary conference in 2019

Supporting... the community

The internet is full of information and when you are looking for answers it can sometimes be tricky to know where to turn. Our websites and social media feeds provide a host of factual, up-to-date information to keep everyone affected by psoriasis and/or psoriatic arthritis in the know.

Information you can trust

Our first website was launched way back in 1998. It's had a few re-designs since then and in 2011 was joined by PsoTeen, which is aimed at teenagers and young people living with psoriasis. While the designs may have changed, the content has always remained a trusted source of information for people affected by psoriasis and/or psoriatic arthritis around the world.

Our first ever website!



Psoriasis Association Website

4,881,635 Website visits
3 million Visitors
10 million Page views in the last 10 years

PsoTeen Website

133,667 Website visits
114,327 Visitors
300,000+ Page views since PsoTeen was launched in 2011

Our personal cheerleaders



"I was diagnosed with plaque psoriasis before the internet was a thing. After being diagnosed with guttate psoriasis during a strep induced flare six years ago I quickly found myself frustrated trying to find answers online that I trusted. What makes the Psoriasis Association stand out for me is the fact they fund research - and not only that, their research is answering questions I have been asking for a long time. Another important thing for me is that they are not influenced by pharmaceutical companies. This makes decision making much less exhausting, knowing I have a reliable and unbiased source of information.

*I mostly access information about psoriasis via the Psoriasis Association website, however I have also used their social media channels. My favourite thing that the Psoriasis Association does on social media is act as a cheerleader. I love this so much. If I post about my psoriasis, **there is always a human behind the logo** cheering me on and supporting me. Sometimes that fist bump is all I need to get out there and be more than my skin."*

Gemma Boak - York

Starting the conversation

Our social media channels allow us to get the word out about the latest treatment updates, campaigns, research, charity news and much more. However, it's your likes, comments and shares that spread the word and ensures that up-to-date, accurate information about psoriasis is shared across the globe.

Since the start of 2016 our channels have generated:



14,724 Retweets

2,702 Replies

23,632 Likes



59,003 Likes

3,571 Comments



34,729 Reactions

7,978 Shares

9,110 Comments



"Through the Psoriasis Association Instagram I have gained so many new contacts and friends who also have psoriasis who I can now offer support and share tips with. The account has been fantastic for boosting my confidence while informing me more about my condition."

Anonymous



"My name is Damini and I have had psoriasis since I was 6 years old. Throughout the years, the Psoriasis Association has actively helped me throughout my journey with the condition, and has been my go-to place for psoriasis updates and information. It's a great place to discuss or get any advice, as they offer a great community and network. Information is so readily available with all the social media channels. I find the Instagram and Twitter pages to be particularly helpful and the team have always offered quick and assertive responses whenever I have had a question or a query. I like to get actively involved in awareness projects for psoriasis and the Association has been a great help in aiding and involving me with various projects."

Damini Mistry - Leicester



Raising awareness



Changing minds, changing lives

"The Psoriasis Association provides an invaluable platform for those of us who are willing and able to communicate our experiences. This can never be underestimated because so many find hope and succour in shared experience. Personally I have been able to share my experience and knowledge through the 50 for 50 initiative, I have spoken at the Annual Conference and been involved with the Association's sponsored psoriasis Priority Setting Partnership. I am currently on the Steering Committee for the psoriatic arthritis Priority Setting Partnership again with Psoriasis Association involvement.

Raising awareness makes our lives easier. Those awkward explanations, the long sleeves, the covered legs, the long hair and the feelings of disgust with ourselves are diminished by educating people about what it is that afflicts us. To be treated like everyone else is the goal, raising awareness can achieve that and enhance life for us all."

Russ Cowper - Manchester

Raising awareness ... in politics

Often, big changes start at the top. As active members of the All-Party Parliamentary Group on Skin, Cross Party Group on Psoriasis and Psoriatic Arthritis, and Cross Party Group on Skin, we make sure that the voices of people with psoriasis and psoriatic arthritis are heard not only in Westminster, but also in the Scottish Parliament and the National Assembly for Wales.

Answering your politics FAQs

What are the All-Party Parliamentary Group on Skin (APPGS), Cross Party Group on Psoriasis and Psoriatic Arthritis, and Cross Party Group on Skin?

The All-Party Parliamentary Group (APPG) on Skin, which was founded in 1994, consists of a group of cross-party MPs (Members of Parliament) and Peers (members of the House of Lords) who work closely with health professionals, patient groups like ours and pharmaceutical companies to increase understanding about skin care issues in Parliament. It meets 3 times a year and benefits from input from its Advisory Group which is chaired by Psoriasis Association Chairman Nick Evans.

The Cross Party Group on Skin seeks to highlight similar issues on the causes, prevention and treatment of skin disease in the devolved Welsh Parliament while the Cross Party Group on Psoriasis and Psoriatic Arthritis aims to improve services for those with the conditions in Scotland.

Why do we attend these groups?

These groups have an important role to play in raising awareness of the issues affecting those with psoriasis and psoriatic arthritis in Parliament and we regularly attend their meetings to increase understanding among politicians of the issues that people face as a result of their condition(s).

The groups examine issues of policy, compile reports and act as a forum for partners in skin care to engage with politicians with an interest in the issue. In 2020, we have contributed to a major new report focusing on 'Mental Health and Skin Disease' which expects to make a number of recommendations to policymakers on psychodermatology coverage, service design, healthcare professional training and research priorities.

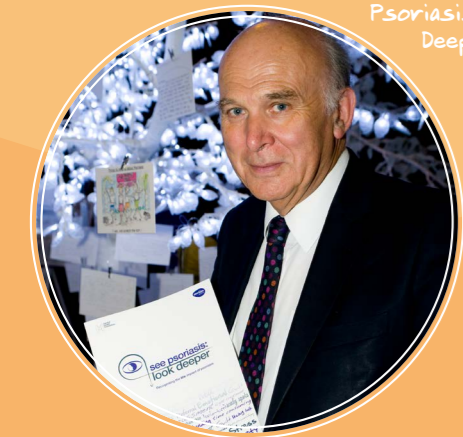




Helen McAteer presenting at the APPGS Inflammatory Skin Conditions event, July 2019



Sir Vince Cable at the Westminster launch of See Psoriasis: Look Deeper



Helen McAteer speaking at Westminster during the launch of See Psoriasis: Look Deeper



How do these groups make a difference?

These groups make a difference in a huge number of ways. Our collaboration with pharmaceutical company Janssen on the Psoriasis: Act. Stop Ignoring Campaign in 2011 actively encouraged those with psoriasis to proactively seek better psoriasis management. We presented the results of our 'Know Your PASI' survey during an APPGS meeting in Westminster and requested their endorsement of the PASI in standard clinical practice. The issue was widely publicised by the media and our call for a PASI assessment to be included in the NICE clinical guideline for psoriasis management was successful in 2012.

In 2018, The British Association of Dermatologists' Specials Working Group alerted the APPGS to the systemic overcharging of 'special' prescriptions to the NHS. The APPGS subsequently raised these concerns in Westminster making the front page of The Times and leading to several Parliamentary questions being tabled for debate.

How else does the Psoriasis Association raise awareness in politics?

In addition to APPG and CPG meetings, we regularly attend roundtable discussions with politicians, give presentations, and consult on new guidelines and government papers. In 2013 we provided information to Rosie Cooper, MP for West Lancashire, about psoriasis, which she used in the dermatology debate in Parliament and in 2019 helped table an Early Day Motion recognising Psoriasis Awareness Week and calling for the government to improve access to healthcare professionals for people with psoriasis who are planning for a family. We also launched our long running campaign 'See Psoriasis: Look Deeper' at Westminster, allowing us to speak directly to politicians, including Sir Vince Cable, about the impact that psoriasis has on people's lives.

Laura Stevenson, Deputy CEO - Psoriasis Association



Raising awareness... with the public



The visibility of psoriasis means that people are exposed to the reactions of everyone around them and unfortunately there are still many misconceptions surrounding the condition. We are working to raise awareness and educate the general public about psoriasis and psoriatic arthritis to fight these misconceptions and help to improve the day to day lives of people with psoriasis and/or psoriatic arthritis.

Launched in 2015, our YouTube channel contains factual, informative videos. These cover a wide range of topics including what it's like to live with psoriasis, experiences of treating psoriasis and starting a family, talks from our researchers about their pioneering work, and the Itch Challenge - can you resist the urge to scratch?



14,977 Video views



25 Videos



Speaking Out

"The reaction I have received when raising awareness of the condition has been extremely positive. Being in the public eye provides me with a platform to speak up about psoriasis which is something that I don't think many people have done before. It's vital that people understand that they are not alone with the condition and hopefully I can continue to work with the Psoriasis Association to normalise it. Psoriasis is a life-long skin disorder and it can be extremely hard to accept that it might not go away. I want people to understand that there is a support network available and there are people available to help. The Psoriasis Association are doing a brilliant job and I look forward to continuing to support them in the future."

Malin Andersson

Working with the media

We work with the media to inform the public about psoriasis and counter the common misconceptions that many people have. Over the years we have been featured in all types of media, including radio, online, print and TV. This has ranged from local newspapers such as the Dorking and Leatherhead Advertiser, to national coverage on ITV's This Morning.



Helen McAteer being interviewed during Psoriasis Awareness Week 2019

“

Knowing that you're not alone

"During a particularly bad flare up of psoriasis I discovered the Psoriasis Association and their 50 for 50 project. I began reading everyone's various stories and found it comforting to know that it wasn't "just me". I decided to put my story down on paper and found it quite therapeutic. After sharing what I'd done with a friend I decided to send the Association my story. I hoped that reading it would help someone - just like everyone else's stories had helped me. More recently I've shared my experience on BBC Radio Wales and BBC Wales News. At times it was overwhelming and frightening, but the thought of helping even one person listening or watching made it worthwhile. Psoriasis can be isolating and lonely, and knowing that there is a community out there who understand what you're going through and who are ready to listen and help is invaluable."



175,392

Leaflets, posters, information cards and flyers have been sent out over the last 10 years



1000+

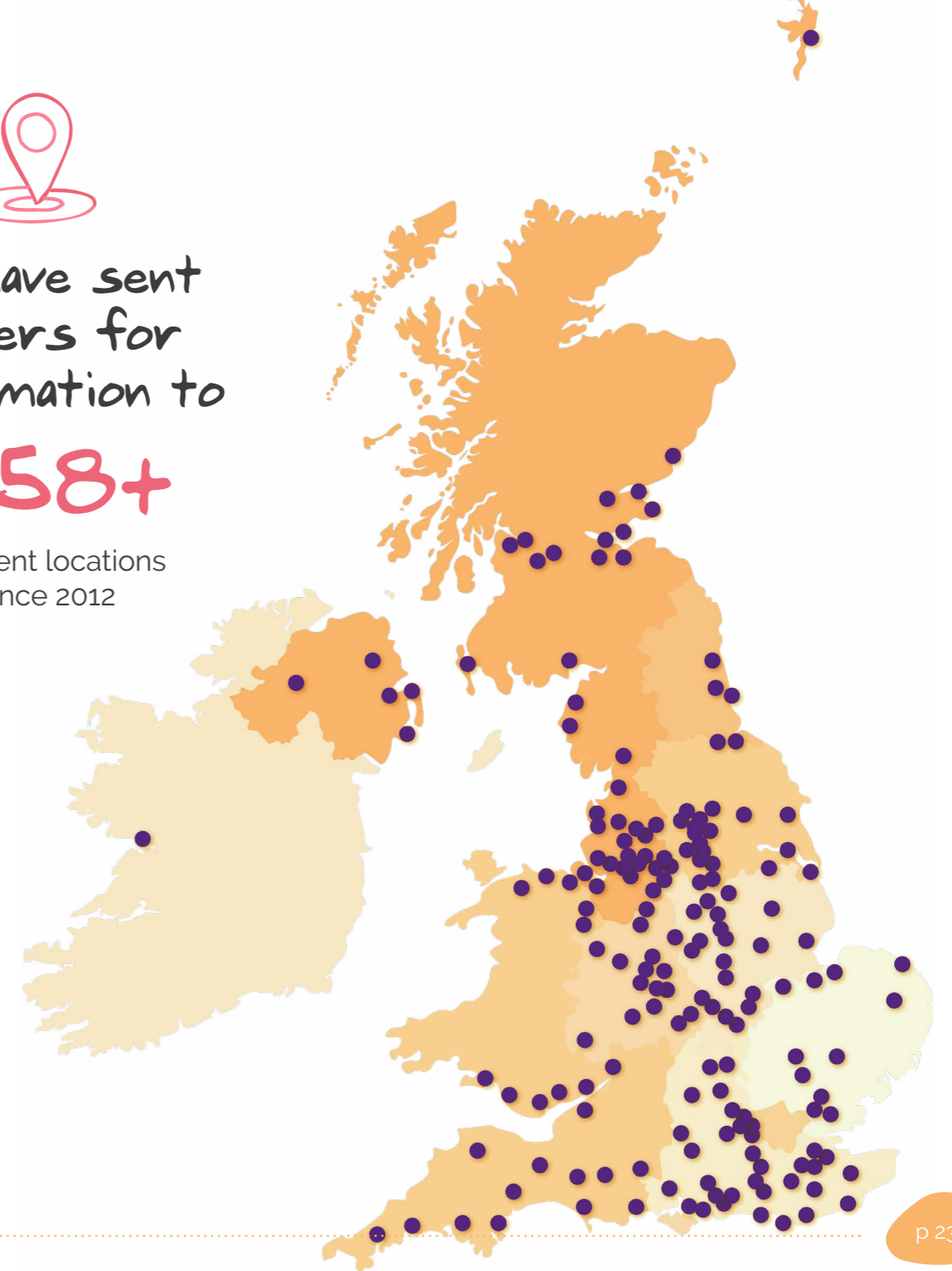
We have received over 1000 orders for information in the last 10 years



We have sent orders for information to

258+

different locations since 2012



Ffion Rees - Swansea

Waiting room reading

Every year we send thousands of leaflets and posters to GP surgeries, pharmacies, rheumatology and dermatology centres across the UK. Placed in waiting rooms for everyone to read, or given to people with psoriasis to provide extra information about a new treatment, our leaflets raise national awareness in a local setting.

Annual Psoriasis Awareness Week

Over the last few years we have used our awareness week to raise awareness of a number of different aspects of living with psoriasis and/or psoriatic arthritis:

2011 PsoTeen

Did you know that over a third of people with psoriasis develop the condition before they are 16? In 2011 we highlighted the prevalence of psoriasis in young people and launched our new website PsoTeen. Alongside promotion through our poster and radio campaign, PsoTeen was also featured on the BBC News website and in the Daily Mirror.

2012 See Psoriasis: Look Deeper

The Psoriasis Association and the Mental Health Foundation came together to raise awareness of the impact that psoriasis can have on a person's quality of life and mental and emotional wellbeing. We received over 100 postcards from our supporters describing how psoriasis made them feel or had impacted their lives. The See Psoriasis: Look Deeper report was then launched at a special event at the Houses of Parliament in front of Health Select Committee members, MPs, and healthcare professionals. This collaboration, funded by AbbVie, continued for many years and gave invaluable insight into how people's lives are affected by psoriasis. It was also behind the 'Ps.Arthritis' and 'Small Steps' campaigns in 2015 and 2017.

2013

I wish someone had told me...

In 2013 we launched 'I wish someone had told me...', a booklet where members and supporters shared their hints and tips about living with psoriasis. We ran a successful media campaign with the help of an unrestricted educational grant from LEO Pharma - many of the booklet contributors and our staff were interviewed for radio, press, or television.

2014

New information leaflets launched

The leaflets covered a wide range of topics, from 'What is psoriasis?' to 'Biologics for psoriasis and psoriatic arthritis'. The See Psoriasis: Look Deeper collaboration also launched 'Psoriasis, You Won't Stop Me!', a new series of support booklets to help people with psoriasis manage emotions and behaviours frequently associated with the condition.



2015 Ps.Arthritis

In 2015 we launched 'Ps.Arthritis'. This campaign, which was funded by AbbVie, included videos and infographics to help people with psoriasis be aware of the signs and symptoms of psoriatic arthritis.



2017 Small Steps

Our Small Steps campaign encouraged small, positive lifestyle changes that could help improve psoriasis symptoms. With a grant from AbbVie, we launched a postcard booklet containing eight lifestyle tips (and a summary of the evidence behind them) and also a short animation.



2019 Treating psoriasis before, during and after childbirth

During Psoriasis Awareness Week 2019 we launched four new videos about pregnancy, childbirth and psoriasis, from a mother, father and clinician's point of view. In addition, we created a psoriasis and pregnancy resource containing the 'top tips' from parents who are living with psoriasis.



2016 PsoriasisIS...

Our PsoriasisIS... campaign invited people with experience of psoriasis to share what the condition means to them. We also launched the original film, 'Psoriasis - The Skin I'm In', which tells the real life stories of people living with psoriasis. The film was made in association with See Psoriasis: Look Deeper.



2018 Young people with psoriasis

Following the results of our young people's survey earlier in the year, we promoted our recently launched WhatsApp service. This was designed to support teenagers and young adults affected by psoriasis - 67% of whom had said in our survey that they felt isolated by their condition. We also shared real life stories from young people living with psoriasis, which helped raise awareness of how psoriasis affects their daily lives and hopefully showed other young people that they aren't alone.



Seeing beyond the skin

"In 2012 we teamed up with the Mental Health Foundation, Dr Sandy McBride and Professor Chris Bundy to run **See Psoriasis: Look Deeper (SPLD)**, a campaign (funded by Abbvie) to raise awareness of the impact of psoriasis and which called for improved holistic care – considering both the individual's physical symptoms and psychological wellbeing.

We asked our supporters to complete a postcard entitled "Dear Psoriasis..." describing how their psoriasis makes them feel and impacts their life. We received over 100 completed postcards. From the humorous to emotive, but all incredibly honest, they gave an invaluable insight into the real impact that psoriasis has on daily life and mental wellbeing. In fact, the postcards were so insightful that they were written up as a publication in the prestigious *British Journal of Dermatology*, and the publication has since been cited 19 times.

The postcards were also included within the SPLD report, which brought together psoriasis research, real life experiences, and calls for policy makers to enact changes to ensure holistic care for people with psoriasis. The report was launched at a special event in Westminster attended by some of the postcard authors, MPs, healthcare professionals and Health Select Committee members. With talks from the SPLD team, the report and postcards on display, these influential attendees could see for themselves why the changes we were calling for were so important.

The NICE clinical guideline on psoriasis has since included recommendations to assess the effect the condition has on an individual's psychological wellbeing and quality of life while the Quality Standard for psoriasis now contains clear advice on the needs and methods to assess the impact of psoriasis. The NHS Commissioning Guidance has also recommended that GPs be supported to improve their ability to assess the psychological and social impact of psoriasis as well as the physical."

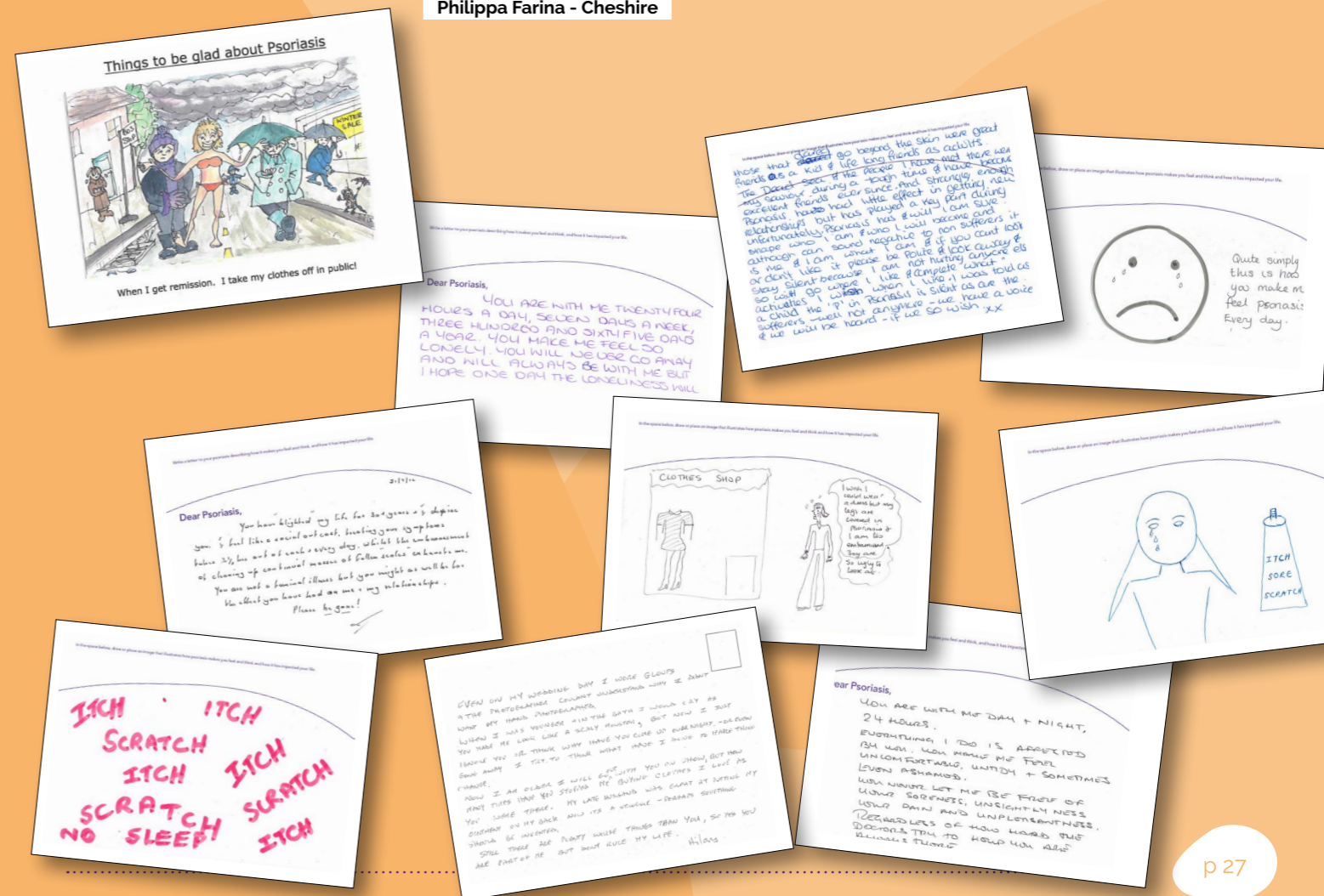
Helen McAteer, CEO - Psoriasis Association



"I drew a series of cartoon postcards for the See Psoriasis Look Deeper Campaign. I was determined to find the "positives" about having psoriasis. I managed 10 different ones. They were all true: I have made some great friends at the Dermatology Unit in Manchester and kept the staff in long term employment! I still pursue the sun and quiet places and although hoovering (for Britain!) isn't my favourite pastime; I am very, very good at it! The rest, I'm working on!

So the impact after 10 years? The cartoons gave me 10 good reasons to be cheerful about psoriasis and I carry them with me always."

Philippa Farina - Cheshire



Key Campaigns

In addition to Psoriasis Awareness Week, we also run campaigns throughout the year. Over the last decade, these have ranged from celebratory awareness events to protest campaigns to fight for people's right to share their psoriasis experiences online.

Life's an Itch **ITCH**

We collaborated with Celgene (who funded the project) and the British Dermatological Nursing Group to raise awareness among healthcare professionals of the impact of psoriasis itch on people's lives. We commissioned a collection of thought-provoking artwork based on our supporters' descriptions of psoriasis itch. This helped kick start the discussion among healthcare workers about this under recognised symptom. The campaign also saw the development of an Itch Discussion Tool and the 'itch challenge' which helped improve the conversation around itch and raise public awareness.

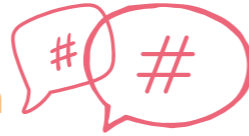
50 for 50



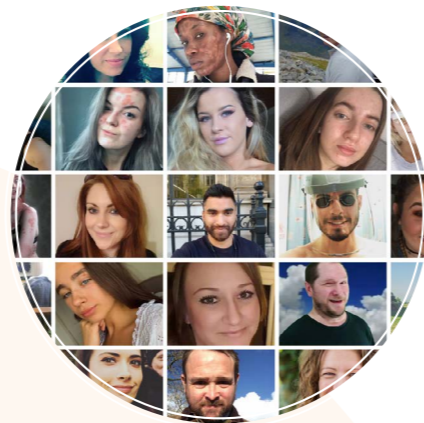
For our 50th anniversary year (2018-2019) we featured 50 real life stories from people living with psoriasis and/or psoriatic arthritis through our website and social media channels. The response to the campaign was overwhelmingly positive, with people from all over the world getting in touch to share how their condition has impacted their lives. We received so many stories that we decided to continue sharing them - head on over to our website to take a look!

Some of our 50 for 50 contributors

Hashtag campaign



In 2018, prominent psoriasis community hashtags including **#psoriasisawareness** **#psoriasisucks** **#psoriasiswarrior** and **#getyourskinout** were blocked on Instagram and psoriasis content was being removed from Facebook. We started a petition calling for the re-instatement of the blocked hashtags and content, which received over 3,000 signatures and national media coverage. The hashtags were subsequently re-instated. When this happened again in 2019 we took action by calling for clarity from Instagram and requesting that the issue be fixed as soon as possible.



Raising awareness... in healthcare

Individuals with psoriasis or psoriatic arthritis will meet and work with many different healthcare professionals over their lifetime. It is therefore vital that we raise awareness of psoriasis and the patient experience of psoriasis among as many professionals as possible. We do this by:



Attending conferences

Every year we attend multiple academic and professional conferences where we discuss psoriasis and the patient experience of healthcare with attendees.



Carla Renton at the British Association of Dermatologists conference 2011



Dominic Urmston at the Royal College of General Practitioners conference 2016



Giving talks to healthcare professionals

These talks allow us to explain how healthcare can be made better for people with psoriasis and/or psoriatic arthritis.



Helen McAteer at the British Association of Dermatologists conference 2019



Helen McAteer presenting at the Immune Mediated Inflammatory Diseases Summit in 2012



Writing articles for medical journals

These articles allow us to reach healthcare providers around the globe - one of the journals that we have published in, the British Journal of Dermatology, has 80,000 page views per month!



Two of our articles in the British Dermatological Nursing Group Journal

Promoting the patient perspective

"The MSc programme in Clinical Dermatology at the University of Hertfordshire is one of the world-leading postgraduate programmes for clinicians in dermatology.

The Psoriasis Association contributes to this programme by delivering a session annually in the Therapeutics for Skin Conditions module. This talk covers the patient's experience of treatments and the resources available to support them. Since 2006, more than 350 students from all over the world have participated in this learning experience, resulting in a significant global reach.

The talk presents the powerful patient perspective on the burden and cost of skin treatments and the challenge of referral to specialist settings, illustrated with direct quotations from patients.

The presentation from the Psoriasis Association contributes to a grounded view of the central role of the patient and the impact that psoriasis has on their lives.

Many overseas students choose to incorporate aspects of patient education and psychological support into their final project. This is ground-breaking for their areas of practice, and is often inspired by this presentation from the Psoriasis Association."

Kathy Radley, Senior Lecturer and Module Lead for Therapeutics for Skin Conditions - University of Hertfordshire

66

Kathy Radley
Senior Lecturer
& Module Lead

Madeleine Flanagan
Programme Lead MSc
Clinical Dermatology



As well as reaching individual healthcare professionals, we also work collaboratively with organisations such as NICE, the Dermatology Council for England and NHS England to effect change for people with psoriasis.

- 2011** (Star in ribbon icon): We had input into the Quality Standards for Dermatology and the Quality Standards for Teledermatology.
- 2013** (Speech bubble icon): We participated in a scoping workshop for the NICE Quality Standard on Psoriasis.
- 2013** (Person lying down icon): We gave advice regarding the provision of phototherapy treatment.
- 2013** (Checkmark icon): We endorsed the NICE Quality Standard on Psoriasis.
- 2014** (Document icon): We were involved in development of a guideline on Seronegative Spondyloarthropathies.
- 2014** (Group of stars icon): 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 EU.
- 2018** (Cross icon): We were involved in the Best Value Biologic Programme with NHS England.
- 2018** (Clipboard icon): We were part of the British Association of Dermatologists' Specials Working Group that raised awareness of the NHS being overcharged for 'special' prescriptions.
- 2019** (Bottle of cream icon): As part of the Dermatology Council for England, we campaigned for NHS England to change their guidance to stop the rationing of emollients for people with psoriasis.

Researching psoriasis



Finding the best questions

"Between 2017 and 2018 we conducted a Psoriasis Priority Setting Partnership (PsPSP). We invited those with lived experience of psoriasis and the health-care professionals who care for them to: i) identify key unmet needs; and ii) prioritise the order in which these should be addressed by research.

Our study resulted in a "Top 10" list of research priorities, which will ensure that future research is relevant for the needs of people with psoriasis and those who manage the condition.

But we didn't stop there. Having noticed that we were receiving a large number of questions on "Health Care Delivery", and recognising that managing the complex needs of individuals with psoriasis is not well catered for, we analysed this theme separately. This enabled us to create a blueprint for psoriasis care – designed by patients and health-care professionals. We also

identified questions submitted to the PSP that had already been addressed by research. These questions are now informing awareness raising exercises and education programmes for patients and clinicians. The Psoriasis Association were central to the success of the PsPSP. They had the vision to propose a PSP for psoriasis and to develop a funding stream. They had representation on the PsPSP Steering Group and were "hands-on" and "sleeves rolled up" throughout all stages. In summary, the PsPSP has been an exemplar of team working and partnership, in which the Psoriasis Association has had a pivotal role. Our outputs will inform future research, communications, education and health service delivery for psoriasis across the UK."

Dr Helen Young, Lead for the UK Psoriasis Priority Setting Partnership – University of Manchester



Meet the team that decided the final 'Psoriasis Top 10' research priorities

Research results in ... change

Change is the ultimate goal for research. Research leading to a change in policy, a change in healthcare practice, or a new treatment could make a real impact on the lives of people with psoriasis and psoriatic arthritis. However, change often takes many years of research and a lot of funding. It is therefore especially exciting when some of the projects that we have supported go on to have an impact in the real world.

Projects that we have funded so far have:



Created a new therapeutic exercise programme, which is now being trialled in a clinical study.



Helped to inform the development of the Psoriasis Rapid Access Clinic, which is currently being trialled in Salford.



Informed daily clinical practice as part of the NICE Clinical Knowledge Summaries for Psoriasis. These summaries are a vital resource for primary healthcare professionals and have a direct effect on how people with psoriasis are treated.



Raised awareness amongst clinicians of the importance of well-being services for people with psoriasis and provided detailed accounts of the support available and how to access this.



Trained dermatology staff to help people manage their psoriasis through lifestyle behaviour change, with the aim of rolling this practice out across the UK and beyond.



Discovered a way to predict future effectiveness of adalimumab (Humira) and ustekinumab (Stelara) after just four weeks of treatment. This has now been included in clinical guidelines and is being integrated into standard practice.

Modifying psoriasis management

"PsoWell™ (Psoriasis and Wellbeing) is a novel one-day training programme that improves clinicians' knowledge, skills and confidence to empower people with psoriasis to effectively manage their condition through lifestyle behaviour change. The training was developed through the IMPACT (Identification and Management of Psoriasis Associated Comorbidity) programme of research at the University of Manchester. IMPACT showed that clinicians felt unprepared to address psychological and lifestyle factors in dermatology consultations for those patients who needed it. To address this, we developed PsoWell™.

As part of their 50th birthday celebrations, the Psoriasis Association funded Professor Chris Bundy (Cardiff University) to implement PsoWell™ training in dermatology centres across the UK and evaluate the dermatology specialist staffs' views of the approach. Training days were held in Cardiff, Harrogate, Derby, Manchester, Belfast, London, Bristol and Dundee, with 119 dermatology staff attending.

Our initial analyses suggest that clinicians value the training. They say it encourages reflection on their current practice style and develops their Motivational Interviewing skills to empower their patients to manage their psoriasis in a structured and personalised way. As well as changing their own practice, the PsoWell™ trained clinicians now need to make the business case for this support in dermatology clinics across the UK. This approach would provide integrated and dedicated psychological support for behaviour change in those people with psoriasis who need it. In time, we hope to take this approach to clinical practice beyond the UK."

Professor Chris Bundy and Rachael Hewitt
- Cardiff University

PsoWell training led by Professor Chris Bundy



Professor Chris Bundy & Rachael Hewitt



Research results in... new knowledge

Each research project that we promote or fund helps us to build a bigger, better picture of psoriasis and psoriatic arthritis. This cutting edge knowledge is then shared with people around the world through journal publications, conference presentations, and public engagement activities.

Building the psoriasis picture over the last 10 years



The Psoriasis Association has funded **35 research projects**



£2,062,776 awarded in research grants



Our researchers have increased global knowledge of psoriasis with **47 publications**



Psoriasis Association funded research has led to the development of **new research tools, methods, datasets and databases**. Some of these new materials have already been used by other researchers to conduct new, exciting research projects!

“ Creating tools enables new research

"I have developed an application for the exploration of our biological sequencing data, including results from our computer analyses (bioinformatics). The user-friendly nature of this application means that in-depth bioinformatic knowledge isn't required to extract value from it. This will allow other members of the research community to explore our data and aid them in addressing their own research questions."

Ashley Rider, Psoriasis Association PhD student
- Newcastle University

Interested in research?

Join our Research Network! Members of the Network are sent opportunities to participate in, or to help shape, psoriasis research. You can get involved with as many opportunities as you like and there is no minimum involvement required. Previous opportunities have ranged from becoming a Patient Associate Editor for the British Journal of Dermatology, to testing an online support programme, to taking part in cutting edge research.

Contact us to find out more! [See page 46.](#)



Making personalised medicine a reality

"In 2011, the Psoriasis Association provided critical early funding to set up the Biomarkers of Systemic Treatment Outcomes in Psoriasis (BSTOP) study and since then, we have collectively attracted nearly £10 million in further funding. Our aim is to identify markers that will enable us to give the right medicine to the right patient at the right time. We are doing this by collecting blood and other biological samples as well as looking at how drugs are handled in the body, with over 7,000 patients recruited so far and more than 29,000 samples collected. Once discovered, doctors will be able to use the genetic and biological blueprint of each patient to identify which treatments are most likely to work (and be the safest or least likely to cause side effects). At the same time, we are developing a sample and data resource that could be used by other researchers to study any aspect of psoriasis.

Through BSTOP, major steps forward have already been accomplished, as we have identified markers of response and also how to improve outcomes to biologic treatments by monitoring therapeutic drug levels, making personalised medicine a reality. The future plans include expanding our study to all types and severities of psoriasis and exploring the influence of environmental factors on the development and progression of psoriasis."

Professor Catherine Smith
- St John's Institute of Dermatology

BSTOP Team

BSTOP
Biomarkers of Systemic Treatment
Outcomes in Psoriasis



Professor Catherine Smith



Sharing our science with the world

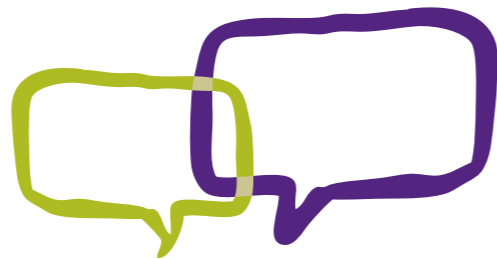


"During my PhD I presented my work at various national and international meetings. Some of these were scientific but my favourite ones were to a broader audience. Public engagement and raising awareness of science is so important. I was delighted to win the Peoples Prize at a Three Minute Thesis competition where I realised how much my work resonated with the public audience. Upon completion of my work I also prepared a leaflet for the patients who had kindly donated tissue biopsies for my studies to allow them to see how their donations had helped to progress psoriasis research. Science communication is close to my heart and sharing information of the biology behind psoriasis to families and patients gave a deeper sense of purpose to my studies"

Dr Erin Michele O'Shaughnessy, Psoriasis Association funded PhD Student – Glasgow Caledonian University



Dr Erin Michele O'Shaughnessy



Spreading the word

Just as researchers give presentations at conferences to share their results and raise awareness of the work in the scientific community, our researchers also take part in public engagement activities to raise awareness of their findings and of psoriasis research amongst the general public. These range from face to face events, school visits and science workshops, to online activities and the Psoriasis Association's 'Meet the Researcher' videos.



Watch some of our current PhD students explain their work in our Meet the Researcher videos!



Noeline Nadarajah University of Southampton

Shamarke Esse University of Manchester



Thanos Niaouris King's College London

Research results in... more research

Our research strategy is to invest in the future of psoriasis and psoriatic arthritis research. By funding early stage projects and PhD students, we have supported the careers of numerous new researchers and provided the start-up funding for many exciting projects.



Driving discoveries

"My lab is interested in identifying the genes that predispose people to common and rare forms of psoriasis. We also want to establish what happens in the skin and immune system, when these psoriasis genes start to malfunction. We believe these are important questions, as a proper understanding of disease mechanisms is crucial to the development of efficient treatment.

The Psoriasis Association has been supporting my research for many years. In fact, I was awarded their first PhD studentship back in 2006! Since then the Association has funded three more PhD students in my lab, with a fourth due to start in the autumn. These have been, with no exception, bright and motivated individuals who have brought new skills and energy to the group. One student, for example, had a background in programming and was able to apply new computational methods to the study of skin inflammation.

The support of the Psoriasis Association has enabled my group to make some key discoveries. For instance, it has allowed us to show that a protein called IL-36 is abnormally active in the skin and blood of individuals with severe psoriasis. These results have important implications, given that drugs blocking IL-36 are currently being developed. Thus, there is no question in my mind that the Psoriasis Association PhD programme is enabling important research advances, while also helping to train a new generation of scientists, who are committed to the study of inflammatory diseases."

Dr Francesca Capon – King's College London

Dr Francesca Capon and her lab group



£8 million

Because we funded their early stage work, our researchers have been able to secure over £8 million in additional funding to support and continue their vital work.

18

This further funding has supported 18 new projects or fellowships.

21

We have helped to develop the next generation of talented researchers by funding 21 PhD studentships.

£3.61

Every £1 spent on research allowed our researchers to win, on average, a further £3.61 to carry on their cutting-edge research.



"Our researchers have made many exciting discoveries across all aspects of psoriasis. We will carry on this legacy by continuing to fund early career psoriasis researchers – building both our knowledge of psoriasis and the capacity to carry out cutting-edge projects. We'll ensure that these discoveries are of the utmost importance to people with psoriasis by promoting their involvement in the projects and using the psoriasis PSP results to guide our research strategy."

Dr Sarah Hartwell

Research Engagement Officer – Psoriasis Association

Working together to accelerate psoriasis research

In addition to funding research, the Psoriasis Association also collaborates on research projects. We bring the patient voice to these research projects, ensuring that the outcomes will have the biggest possible positive impact for people with psoriasis and psoriatic arthritis.

Some of our recent collaborations include:



IMPACT

Identification and Management of Psoriasis Associated Comorbidity

This collaboration created the PsoWell training programme for healthcare practitioners, which enables them to empower their patients to effectively manage their psoriasis through lifestyle changes.



PSORT

Psoriasis Stratification to Optimise Relevant Therapy

This consortium aims to develop an algorithm to predict which biologic therapy would work best for each patient, removing the current 'trial and error'.



BSTOP

Biomarkers of Systemic Treatment Outcomes in Psoriasis

B-STOP aims to identify biomarkers that can predict which systemic treatments are most likely to work for each patient.



BADBIR

British Association of Dermatologists Biologic and Immunomodulators Register

This observational study is looking at the long-term safety of biologic treatments for psoriasis compared to systemic treatments.



APRICOT

Anakinra for Pustular psoriasis: Response in a Controlled Trial

The interleukin (IL)-1 family of proteins are important in palmo-plantar pustulosis (PPP). This clinical trial is therefore testing whether the IL-1 blocking drug anakinra can treat PPP.



PLUM

Pustular psoriasis, eLucidating Underlying Mechanisms

This study is researching the genetic causes of pustular psoriasis and investigating why it is different to other forms of psoriasis.



Psoriasis PSP

Psoriasis Priority Setting Partnership

This study identified the 10 research priorities that are the most important to people affected by psoriasis.

Thank you to our supporters

We couldn't have done this without you!

A lot has changed since we were founded in 1968 but what hasn't changed is how much we need and appreciate your support. None of our achievements would have been possible without you so we wanted to say thank you. Thank you to the fundraisers, the members, the individuals who left legacies, and all of our supporters.

Over the last 10 years our incredibly inventive fundraisers have ...



run marathons



held boxing matches



hosted big band evenings



skydived



had flower growing competitions



run fantasy football leagues



shaved their heads

...to name but a few.

Along with Gift Aid, the generosity of our members, individual donors, fundraisers, and legacy donations provided almost three quarters of our income. Without this incredible kindness we would not have been able to continue our vital work supporting people with psoriasis and psoriatic arthritis.

389 Fundraising events

17,489+ miles

have been covered by sponsored runs, walks, swims, cycles, and banger rally races.



Our work is not done yet...

This report is a celebration of our successes so far. However, there is much left to do. We need your help to continue to support people with psoriasis and/or psoriatic arthritis, raise awareness, and research the causes, nature and care of these conditions. There are many ways that you can support the Psoriasis Association, from helping to distribute leaflets, to fundraising, sharing your psoriasis or psoriatic arthritis story, or becoming a member.

Get in touch to find out more about supporting the Psoriasis Association – see page 46.



Volunteer for us by:

☆ Becoming a media contact

We often receive requests from journalists or media production staff looking for case studies. Sometimes we also contact the media ourselves to raise awareness of Psoriasis Association events and achievements. Our media contacts share their experiences of psoriasis or psoriatic arthritis and help us raise awareness through the media.

☆ Reviewing our information

At the Psoriasis Association we are committed to producing good quality information and upholding the principles of the Information Standard. This could include giving your feedback and opinions on our information sheets, leaflets, or web content.

☆ Being an event speaker

Occasionally we need people with psoriasis or psoriatic arthritis to share their experiences at an event such as a conference, lecture, support group or meeting.

☆ Being on the consultation panel

Members of our consultation panel can be contacted to offer their opinion, or comment, on anything from our own services and literature to taking part in industry or academic initiatives.

☆ Helping with leaflet or poster distribution

Help raise awareness of psoriasis and the Psoriasis Association by taking our literature into your local GP surgery or Dermatology clinic.

☆ Being part of the research network

Members of the Network receive emails with opportunities to take part in, or to help shape, psoriasis research. Please note, these opportunities may come from third parties e.g. academic researchers as well as from the Psoriasis Association.

Support us by:



Giving a donation

Whether it's a one off gift or a regular donation, every single one helps us to continue our work in supporting people affected by psoriasis, raising awareness of the condition and funding research projects



Becoming a member

Become a member to show your support for our work and receive our quarterly journal with hints and tips on managing your psoriasis and/or psoriatic arthritis.



Leaving a legacy

Leaving us a gift in your will can help us to carry on our important work with people whose lives are affected by psoriasis and/or psoriatic arthritis.



Shopping online

Shopping through Amazon Smile or Easy Fundraising is an easy way to raise money for the Psoriasis Association at no extra cost to you. Select the Psoriasis Association as your chosen charity and we will receive a donation from the retailer when you shop with them.

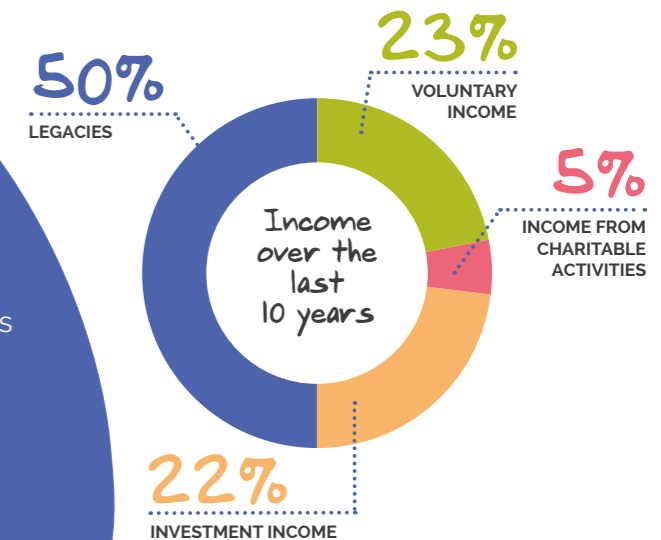


Fundraising for us

All those who generously give up their time to support the Psoriasis Association by fundraising and raising awareness play a vital role in helping us to continue with our work. Whatever the event, we can provide you with promotional materials, sponsorship forms if required and a t-shirt or running vest.



Did you know that you can also help us raise funds by setting up a Facebook fundraiser? Every pound makes a difference and helps the Psoriasis Association support people with psoriasis, their families and carers.



How can we help you?

Contact our confidential helpline:



Call

01604 251 620

Available Monday - Friday
09.00 - 14.30



Email

mail@psoriasis-association.org.uk

Available Monday - Friday
09.00 - 14.30



Message on WhatsApp

07387 716 439

Available Monday - Thursday,
09.00 - 17.00, and
Friday 09.00 - 16.30



To find us &
send snail mail

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Northampton
NN4 7BF



Websites

www.psoriasis-association.org.uk
www.psoteen.org.uk



Twitter

[@PsoriasisUK](https://twitter.com/PsoriasisUK)



Instagram

[@Psoriasisuk](https://www.instagram.com/Psoriasisuk)



Facebook Page

[@PsoriasisUK](https://www.facebook.com/PsoriasisUK)



Closed Facebook Group

facebook.com/groups/PsoriasisUK



YouTube

youtube.com/c/psoriasisassociation1



LinkedIn

linkedin.com/company/psoriasis-association

Acknowledgements

We also wanted to say a huge thank you to everyone who has contributed to the Psoriasis Association over the last 10 years. Without their hard work, we wouldn't be where we are today.

Thank you to everyone that has contributed over the last 10 years as:

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and all of our clinical reviewers, lay reviewers,
and volunteers!



psoriasis-association.org.uk
psoteen.org.uk

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