

Thank you  
for helping  
us to have a  
successful  
2018...

**Our members and supporters**

People who fundraise on our behalf

People who leave legacies to  
the Psoriasis Association

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Steven Astaire, Thomas Ball, Steve Churton,  
Chris Dyer, Gill Hynes, Michael Israel,  
Karina Jackson, Susan Morgan,  
Dr Julia Schofield MBE, Matthew Swift

**Our Medical and Research Committee**

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

**External Peer Reviewers**

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Dr Elise Kleyn, and Professor Nick Reynolds.  
With additional support from Professor Charlotte  
Proby and Professor Edel O'Toole

**Our Staff**

Helen McAteer, Polly Matthews, Carla Renton,  
Dominic Urmston, Sarah Hartwell, Laura Bell  
and Diane Botterill

**Trusts and Foundations who  
supported our work in 2018**

Cecil King Memorial Foundation Trust,  
Davis Rubens Charitable Trust and  
the Morton Charitable Trust

**Companies who supported our work in 2018 via  
membership or unrestricted educational grants**

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



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**OUR ACHIEVEMENTS 2018**

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JOIN US IN CELEBRATING OUR  
50TH ANNIVERSARY YEAR...



## CHAIRMAN'S REPORT

Fifty years ago the consultant dermatologist Dr Dick Coles made a note – “May 1968: Psoriasis Association Steering Committee formed.” Since then the Association has grown to become the UK's leading national charity and membership organisation for people affected by psoriasis - patients, families, carers and health professionals. We have commissioned research totalling over four million pounds to date, and have become a major source of information and help for those affected by psoriasis.

The AGM and Conference in May marked the beginning of our 'birthday year', and since then we have taken forward several initiatives intended to mark the event in ways that reflect our aims. Additional research funding has given support to post-doctoral researchers, our new 'WhatsApp' service has been launched as part of our ever-growing engagement with social media, and November saw a major academic conference on psoriasis held jointly with the British Association of Dermatologists' Dowling Club at the Royal College of Physicians. The 'fifty for fifty' project in which fifty people share their stories of psoriasis and psoriatic arthritis is a reminder if one is needed of the conditions continuing impact upon people's everyday lives.

Alongside all of this our indefatigable staff team have continued to deliver 'business as usual'. A successful research funding round saw three further PhD studentships commissioned, and the Priority Setting Partnership funded by the Association two years ago published its conclusions during Psoriasis Awareness Week in November. The results of this major project will inform research priorities for the Association and others in years to come. Our websites saw over 800,000 visits, and we have nearly 16,000 followers on social media. 12,000 people are registered to engage with our on line forums, creating lively and sometimes challenging debates on a range of topics. Our telephone lines remain busy, with nearly 500 calls during the year. Changing the Association's legal status to that of a charitable incorporated organisation has been successfully progressed during this year and took effect on 31st December 2018, implementing the decision taken by last year's AGM. The business of running the business – managing our office, our finances, our publications and other communications – remains a largely invisible but essential part of what our staff team do and I am grateful to them for their continued diligence.

Engaging with the wider world remains a priority. The Association had a presence at major professional annual conferences including the Royal College of General Practitioners, the British Dermatological Nursing Group, and the British Association of Dermatologists. Our staff continue to be involved in key economic and political issues, working with the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC), and the All Party Parliamentary Group on Skin. There was also key involvement with NHS England on the Best Value Biologic programme.

The fiftieth anniversary has offered an opportunity to look back and celebrate past achievements, but we must also look forward. Psoriasis remains a relatively common long-term condition for many people and is well recognised as having a significant social and psychological impact on people's lives. Our aims – supporting research into the causes and treatment of psoriasis, the provision of information, advice and support for those affected by the condition, and raising awareness of its impact – remain relevant for the future. As ever the support the Association receives from its members and others has been amazing. Looking back over the year I have seen people cycle, golf, slim, bake cakes, hold parties and give up drink, all to raise funds for us. Others have shaved their heads, walked, and run any number and type of marathons. All have been ambassadors for the psoriasis community, raising not just funds but awareness.

*'Thank you for your continued commitment and support.'*

**Nick Evans**  
Chairman,  
Psoriasis Association

# INTRODUCTION

The Psoriasis Association in 2018 followed the same objectives as those from when it was formed in 1968:

- To promote and fund research into psoriasis
- To raise awareness of psoriasis
- To provide information, advice and support to those whose lives are affected by psoriasis

Whilst much has changed in 50 years in the treatment of psoriasis and psoriatic arthritis, there is still work to do in increasing the understanding amongst healthcare professionals and the general public. In notes from a psoriasis group session in 1968, our founder, Dr Dick Coles, wrote...

*“value of knowing other people with same disease, most psoriatics feel isolated by their disease and think that they are also isolated cases of the disease.”*

In 2018 we surveyed 250 young people with psoriasis, sadly, 67% of respondents reported feeling isolated. In order to give young people an alternative method of contacting us, which would be convenient to them, in May 2018 we launched a WhatsApp messaging service.



In notes from the first psoriasis group session held by Dr Dick Coles in 1963, the issue of itching was discussed. The results of our Psoriasis Priority Setting Partnership research project in 2018, posed the question for research “What is the best way to treat the symptoms of psoriasis: itching, burning, redness, scaling and flaking?”. We also launched an “itch challenge” video during Psoriasis Awareness Week 2018 to highlight the very real impact of this often ignored symptom of psoriasis.

In Dr Coles’ notes made just before the formation of the Psoriasis Association, he observed that “older members stressed the importance of learning to live with psoriasis – newer members still looked for a cure”. In 2018, research funded by the Psoriasis Association spanned genetics to the psychosocial burden of the condition – and much in between.

And so, from a meeting in a front room in Northampton, in 1968.....lights, camera, action to a national charity, and the work in 2018.

# 50TH ANNIVERSARY YEAR

## HIGHLIGHTS

The Psoriasis Association has funded over £4 million of research into many aspects of the condition. A celebratory symposium, with the Dowling Club was held at the Royal College of Physicians in November 2018. The eminent speakers at the symposium had all received funding at various points in their careers from the Psoriasis Association, and the delegates consisted of PhD Students, Nurses, Consultants, Academics and Researchers. The meeting concluded with a guest oration from Professor Chris Griffiths OBE – Psoriasis research in the UK: past, present and future.



The 50th Anniversary year is running from the 49th AGM in May 2018 to the 50th AGM in May 2019.

## CAMERA

A celebratory animated film highlighting the major achievements of the Psoriasis Association in the context of corresponding world events was launched at the Annual Conference and AGM in May 2018. The animation could be viewed via the Psoriasis Association website and was shown at the British Association of Dermatologists Annual Conference in July 2018. It was also shown at the 50th Anniversary Symposium at the Royal College of Physicians in November 2018.

The 50 for 50 project was launched at the Annual Conference and AGM in May 2018. This project is giving the real life patient stories of 50 people living with various forms and severities of psoriasis, with one story released each week on the Psoriasis Association website and Instagram account. Many of the stories are accompanied by photos, giving our followers and supporters a unique insight into other people's lives. By releasing the stories on our social media channels in addition to our traditional membership magazine and website, it is hoped to ease some of the isolation reported by people with psoriasis.



## ACTION

In our survey of 250 young people with psoriasis in March 2018, 69% of respondents felt that their Healthcare Professional doesn't understand how psoriasis makes them feel. In order to improve the consultations patients are having regarding their psoriasis, the Psoriasis Association is delighted to have been able to make the Pso Well training course available for up to 100 healthcare practitioners to attend and supply future evaluation. The central aim of the Pso Well training course is to provide healthcare practitioners with cutting edge knowledge about psoriasis and its co-morbidities, and to equip practitioners with consultation skills that best support patients to change health-related behaviours which are known to influence psoriasis and psoriasis-related co-morbidities, and to self-manage their condition more effectively.

Our young people's survey found 42% of respondents feeling too embarrassed to seek help. In May 2018, we launched a WhatsApp messaging service in order to offer confidential advice in a way young people feel confident using.

Research remains an important area of our work, and we were delighted to support the Psoriasis Optimisation of Relevant Therapies (PSORT) programme into its' fifth year, as part of our 50th Anniversary commemorations.

# FUNDRAISING

A cyclist rode from Edinburgh to Istanbul, another London to Paris and a team of 9 teenage cyclists cycled 30 miles together.



3275  
miles cycled  
in 2018

1400  
miles  
walked

Dry  
January

SpecSavers held  
Friday Awareness days  
for 4 months



swam  
50k



Head  
Shaves

260  
miles  
ran



One Lord of the Rings Fan walked on a treadmill for 1350 miles following the footsteps of Frodo and Sam from Bag End (The Shire) to Mount Doom (Modor) this is the equivalent of Los Angeles to Austin, Texas! Our fundraiser completed it in 10 months, it took Frodo and Sam around 6 months!

5

Number of countries marathons were run to raise funds /awareness of the Psoriasis Association (France, Spain, England, Scotland and Wales)



total number of  
fundraisers

58

Cake sales



77

t-shirts and vests sent  
out in 2018

# SUPPORT

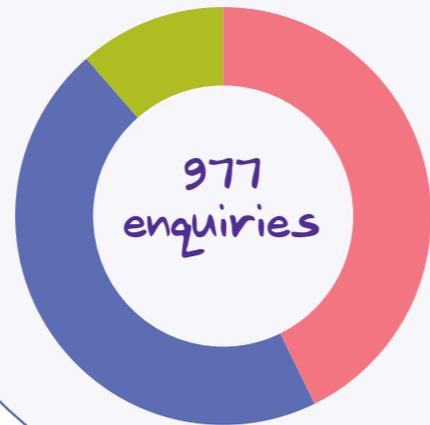
In our survey of young people with psoriasis, two-thirds of respondents reported feeling isolated owing to their psoriasis, with 42% feeling too embarrassed to seek help. In order to offer a means of contacting the Psoriasis Association to help combat isolation, but also to boost confidence in order for people to seek help, the Psoriasis Association launched a WhatsApp messaging service. The WhatsApp service offers enquirers a confidential and convenient method of communication in which they can receive information, advice and support from our helpline team. Following the launch in May 2018, we received 115 enquiries using this service.

WhatsApp  
07387 716439





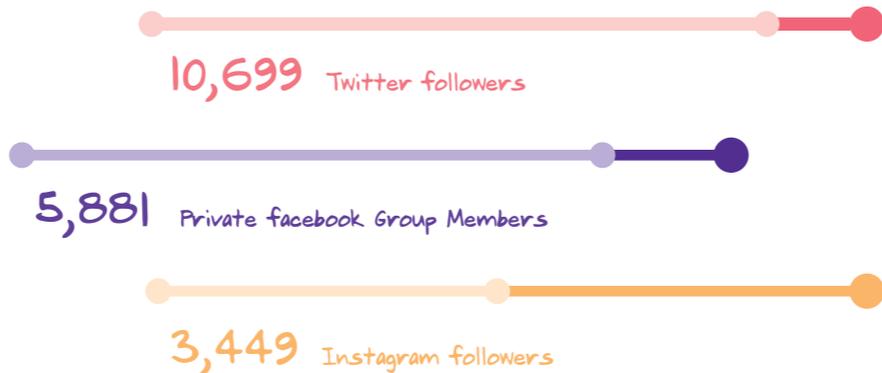

@psoriasisUK



416  
email enquiries received

446  
telephone enquiries received

115  
WhatsApp enquiries received



Sometimes it is the Psoriasis Association giving the support. Other times it is the Psoriasis Association benefitting from support. An area in which we are very committed is facilitating peer-to-peer support. Thousands of people regularly post on our website forums and Facebook group offering their own experiences to others. With feelings of isolation often being reported amongst people with psoriasis, participating in online forums can offer genuine support, knowing there are others going through similar experiences.

Your support and input in 2018 allowed us to:

In 2018 we received exceptional support from the Psoriasis Community:

World leading clinicians and academics speaking at our meetings

Over 3,100 people signing our change.org petition when our popular psoriasis hashtags were blocked on Instagram and Facebook

Clinicians, academics and patients contributing their time and expertise freely to our Psoriasis Priority Setting Partnership research and our own research grants programme

psoriasis association

Make valuable contributions to 7 NICE Technology Appraisals and 5 SMC Assessments for treatments for psoriasis or psoriatic arthritis

Represent the needs of people with psoriasis/psoriatic arthritis on the NHS England Best Value Biological Medicines programme

Present examples of both good and poor practice to Members of Parliament, Members of the Welsh Assembly and the Dermatology Council for England

## GOVERNANCE

On 2nd December 1968, the Psoriasis Association became a registered charity, with charity number 257414.

There were six Trustees at the formation of the Psoriasis Association.

On 13th November 2018, the Psoriasis Association was registered as a Charitable Incorporated Organisation, with charity number 1180666.

There are currently 13 Trustees of the new Psoriasis Association.

When marking five years of the Psoriasis Association, the then Chairman, David Wood, referred back to its' foundation -

*"The Association set out to achieve an atmosphere of optimism"*

The Psoriasis Association in 2018 continues to work on this principle. Whilst we do not wish to shy away from the reality of living with psoriasis or psoriatic arthritis, we wish to empower people in how to live well with the principal condition and all other supplementary conditions associated with it.

## SPOTLIGHT ON Psoriasis Priority Setting Partnership

During 2018, the "Top Ten Research Priorities for psoriasis" were finalised and revealed to be...

1 Do lifestyle factors such as diet, dietary supplements, alcohol, smoking, weight loss and exercise play a part in treating psoriasis?



2 Does treating psoriasis early (or proactively) reduce the severity of the disease, make it more likely to go into remission, or stop other health conditions developing?

3 What factors predict how well psoriasis will respond to a treatment?



6 Does treating psoriasis help improve other health conditions, such as psoriatic arthritis, cardiovascular disease, metabolic syndrome and stress?

9 Is a person with psoriasis more likely to develop other health conditions? If so, which ones?

4 What is the best way to treat the symptoms of psoriasis: itching, burning, redness, scaling and flaking?

7 Why do psoriasis treatments stop working well against psoriasis and when they stop working well, what's the best way to regain control of the disease?

10 What's the best way to treat sudden flare ups of psoriasis?



5 How well do psychological and educational interventions work for adults and children with psoriasis?



8 To what extent is psoriasis caused by a person's genes or other factors, such as stress, gut health, water quality, change in the weather or temperature?

This was the culmination of two years work, funded by the Psoriasis Association, undertaken by Dr Helen Young and the University of Manchester, with support from the James Lind Alliance.

The research priorities will be considered when the Psoriasis Association funds future grants, in addition to the National Institute of Health Research (NIHR).

# RESEARCH

## Meet the Researchers

In 2018, we launched three new videos, presented by Psoriasis Association funded PhD Students. The videos enabled us to learn more about the research the PhD Students were undertaking – and were viewed 1,700 times following their launch in August 2018.

The students and projects highlighted were...



**Shamarke Esse**

(Principal Investigator - Dr Richard Warren) at the University of Manchester, The risk of cancer in psoriasis patients treated with biologic therapies compared with conventional systemic therapies: results from BADBIR



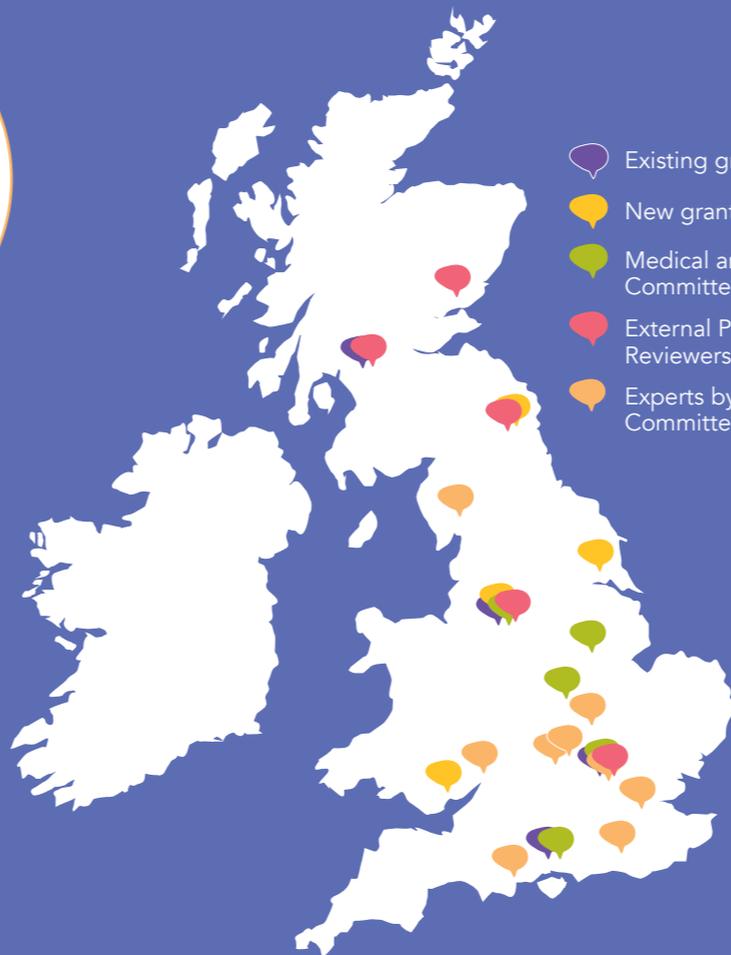
**Noeline Nadarajah**

(Principal Investigator - Professor Eugene Healy) at the University of Southampton, Mutation burden of narrowband UVB



**Thanos Niaouris**

(Principal Investigator - Dr Francesca Capon) at Guys Hospital, The role of IL-1 and IL-36 in Palmar Plantar Pustulosis (PPP)



In November 1971, the Psoriasis Association awarded its' first research grant. The grant was for £115 and was awarded to Dr Terence Ryan for a centrifuge for the biochemical analysis of blood specifically for research into psoriasis, along with a thermostatic water bath. Fast forward to 2018, and the Psoriasis Association awarded three new PhD Studentships:



**Professor Nick Reynolds** at Newcastle University, Investigating genetic control of the psoriasis transcriptome to define and validate drug and disease endotypes.



**Dr Henning Holle** at the University of Hull, An attentional bias approach to understanding and reducing the psychosocial burden of psoriasis.



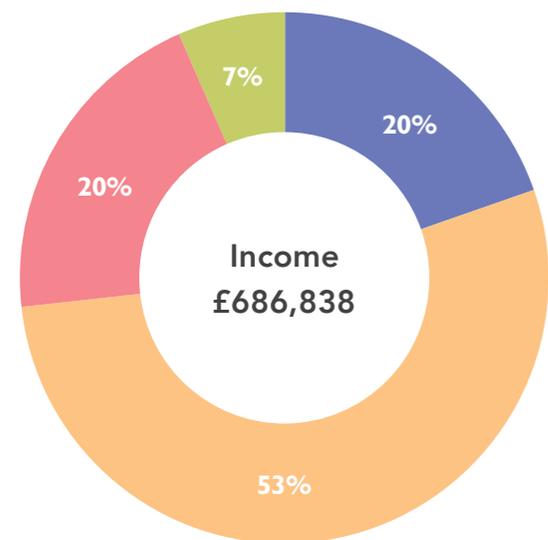
**Dr Helen Young** at the University of Manchester, Investigating the therapeutic benefits of exercise in patients with psoriasis.

An "Experts by Experience Committee" (EXEC) was established in 2018 in order to assess the research grant applications by people with psoriasis. This is to ensure our research is pertinent to the people who fund it. The Medical and Research Committee and External Peer Reviewers assess all applications to ensure they are scientifically sound, relevant, achievable and likely to benefit people with psoriasis. We are extremely grateful for the time given so generously by the Medical and Research Committee, External Peer Reviewers and the EXEC.

We recognise that the impact of the research the Psoriasis Association funds extends beyond our current monitoring ability, and so during 2018 teamed up with Researchfish in order for our researchers to keep us updated years after the grant has been completed.

# FINANCIAL HIGHLIGHTS

This information is a summary of the full accounts of the Psoriasis Association for the year ended 31st December 2018. If you would like the full financial statements, Trustees annual report and Auditor's report please contact the Psoriasis Association or visit [www.psoriasis-association.org.uk/who-we-are/funding](http://www.psoriasis-association.org.uk/who-we-are/funding)



"We are incredibly grateful to those who remember the Psoriasis Association and our work in their will. The commitment of individuals and families to ensure that our work can continue into the future is most generous. A legacy can help the Psoriasis Association to improve the way people with psoriasis or psoriatic arthritis are treated and could help us to better understand the condition. A legacy can help the Psoriasis Association to raise awareness amongst the general public, healthcare professionals, industry, academics, researchers and parliamentarians. A legacy can also help us to be innovative in our methods of providing reliable information, whilst also respecting the traditional methods."

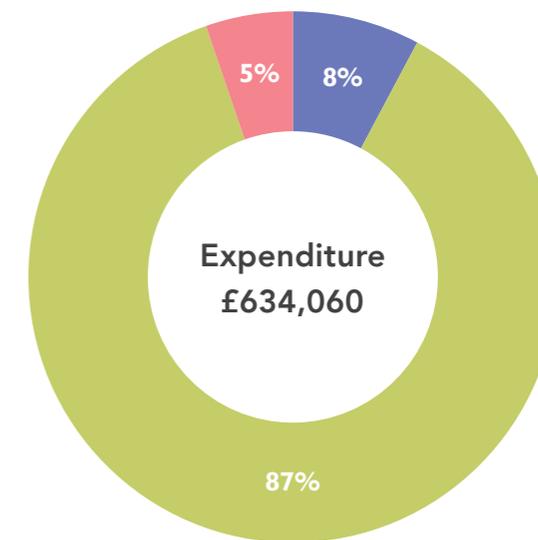
*If you would like to leave a gift to the Psoriasis Association in order to help future generations, or would like more information about leaving a legacy, please contact the office.*

Income	2018 (£)	2017 (£)
Voluntary Income (including, for example, membership subscriptions, fundraising by individuals, Gift Aid, donations in memoriam)	135,111	102,961
Legacies	367,557	373,383
Investment Income	138,850	147,860
Income from Charitable Activities (including, for example, corporate sponsorship, charitable trust donations, Pso advertising)	45,320	23,261
<b>Total Income for the Year</b>	<b>686,838</b>	<b>647,465</b>

Expenditure	2018 (£)	2017 (£)
Raising Funds	50,017	57,181
Charitable Activities	550,391	385,302
Investment Management Costs	33,652	32,272
<b>Total Expenditure for the Year</b>	<b>634,060</b>	<b>474,755</b>

The accounts are demonstrated at year end prior to the charity's net assets and operations being transferred into the new Charitable Incorporated Organisation on 31st December 2018.

The total assets are made up as follows	2018 (£)	2017 (£)
Endowment funds for research and educational work	3,477,126	3,824,540
Restricted funds for research	607,795	473,813
Restricted funds for Scotland	69,900	74,837
Unrestricted funds - General charitable work	302,632	269,281
Unrestricted funds - Designated funds	961,180	1,092,892
Unrestricted funds - Property fund (this reflects the value of the property purchased in 2007)	500,000	490,000
<b>TOTAL</b>	<b>5,918,633</b>	<b>6,225,363</b>
<b>Change in assets</b>	<b>(306,730)</b>	<b>476,925</b>



Total Net Assets	2018 (£)	2017 (£)
At 1st January	6,225,363	5,748,438
Add Incoming Resources	686,838	647,465
Deduct Net Resources Expended	(634,060)	(474,755)
(Losses)/Gains on Investment Assets	(369,508)	304,215
Gains on revaluation of Fixed Assets	10,000	-
<b>At 31st December</b>	<b>5,918,633</b>	<b>6,225,363</b>