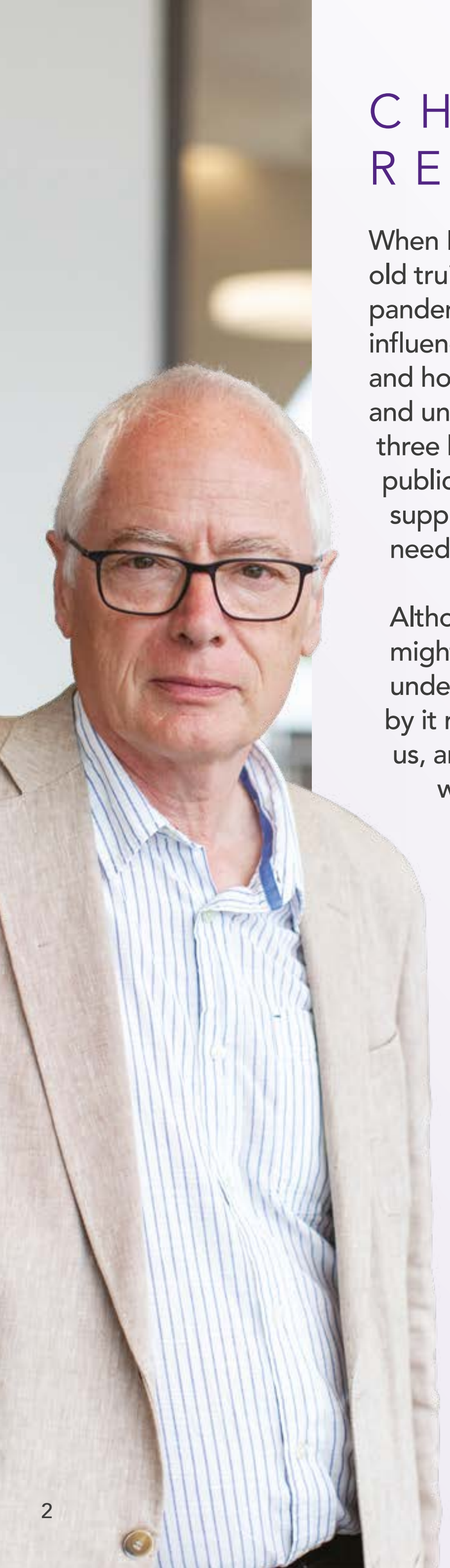
PLEASE SUPPORT US SO WE CAN CONTINUE TO MAKE AN IMPACT ON PEOPLE'S LIVES

www.psoriasis-association.org.uk

The Psoriasis Association Registered Charity Numbers 1180666 and SC049563

OUR ACHIEVEMENTS 2022



CHAIRMAN'S REPORT

When I look back over 2022 I'm reminded of the old truism, 'change is here to stay'. The COVID pandemic and its aftermath have continued to influence both what the Psoriasis Association does and how we do it, whilst new challenges, expected and unexpected, have arisen. Nevertheless, our three key aims - raising awareness, promoting and publicising the outcomes of research, and offering support, information and advice to all those who need it – remain unchanged.

Although awareness of psoriasis as a condition might be wider spread than in the past, understanding of its impact upon those affected by it remains poor. Improving this is a priority for us, and Psoriasis Awareness Week, held in October, was again a major focus. Webinars and a major relaunch of our website were accompanied by briefings to interested parliamentarians and a welcome return to public information stands. Throughout the year joint work with professional and government bodies on economic, health and healthcare matters was an important part of our senior staff's work and the re-emergence of face-to-face meetings and conferences offered an opportunity to re-establish and develop links with government and professional organisations.

The Priority Setting Partnership which we commissioned in 2016 provided us with a comprehensive view of research priorities which continues to guide our own programme. As in previous years we supported research through PhD and other grants, and we were able to provide extensions and some additional funding to researchers whose work had been delayed by the pandemic. Our five-year commitment to the BSTOP programme, first supported by the Psoriasis Association in 2011, has enabled it to go from strength to strength and it is now used as a resource by both national and international research projects. A fresh call for grants was launched in December, and the trustees look forward to the advice of our expert medical researchers and our lay advisory panel when they have considered the applications. I am grateful to them all for the time and care they give to this important work.

Perhaps the most significant change over the last year has been the steadily escalating role of electronic communications and social media. Virtual meetings and conferences, initially a hasty response to the imperatives of lockdown, have emerged as an established part of the world in which we live and work. Our first 'hybrid' annual conference last June offered an opportunity for a wider audience to hear and engage with our expert speakers and was much appreciated by both those who attended in person and on-line participants, whilst home-based working has brought both opportunities and challenges for our ever-willing and capable staff team. Social media, for some years a growing part of our engagement has continued to develop in range and scale, accounting for an increasing proportion of the information requests we receive. Telephone requests for help and advice continue, but (possibly for the first time) we received no written requests for help. The written word nonetheless remains the bedrock of much of our information provision, and we were proud to have the quality of our publications recognised through their reaccreditation by the Patient Information Forum Tick scheme. Our magazine, Pso, continues to form the basis of our communications with our membership.

As I have said before, all of this needs money. Recent years have seen a succession of financial shocks which have impacted on us and many other charities, but we nevertheless remain in good financial health. As ever I am grateful to my fellow trustees, our hard-working staff team and our professional advisers for their skilful management of our resources. Their expertise together with the continued support of our membership and the wider community mean that we are well prepared to continue our work. Thank you all.

Nick Evans
Chairman

WHO WE ARE

The Psoriasis Association has been improving the lives of people with psoriasis and psoriatic arthritis and their families for over 50 years. We were set up in 1968, to provide help, support and information to those that need it.

We are the leading national charity and membership organisation for people affected by psoriasis in the UK. We help people whose lives are affected by psoriasis and psoriatic arthritis by funding research, providing information and raising awareness.

Every year we help thousands of people with both conditions via our websites, helpline, publications and through our research programme. Since our foundation we have committed over £5.8m in grants and awards putting us at the forefront of psoriasis research injecting a significant amount of money both into funding the research and into disseminating the results of that research.

But we don't just fulfil a traditional grant funding role. We are investing in the future through patient advocacy and awareness raising to help all of those who are affected by psoriasis to live well with the condition.

In a perfect world there would be no need for The Psoriasis Association to exist, but while there is still significant need and the search for a cure is on-going, we are determined to ensure that people can live and do live well with psoriasis and psoriatic arthritis.

psoriasis
association

2022 HIGHLIGHTS

1. Redesigned and launched our **website** with new images and easy to use navigation.

2. Held our first **hybrid Annual Conference** and **AGM** where delegates could join us in the room or via zoom at home.

3. Continued our unwavering commitment to **high quality, relevant research** with our five-year research grant to BSTOP and by awarding one new PhD Studentship and one small grant.

4. Received **PIF Tick re-accreditation** ensuring our information resources remain high quality, accurate and relevant.

5. Launched our **Active Lives campaign** demonstrating how people can use their hobbies and interests to live well with psoriasis and PsA.

RAISING AWARENESS

Social Media

14,496	Twitter followers
14,281	Instagram followers
14,252	YouTube video content viewed
28	Stories shared during the year

Psoriasis Awareness Week 2022
29th October – 4th November

#PAW22 #PsoLiveWell

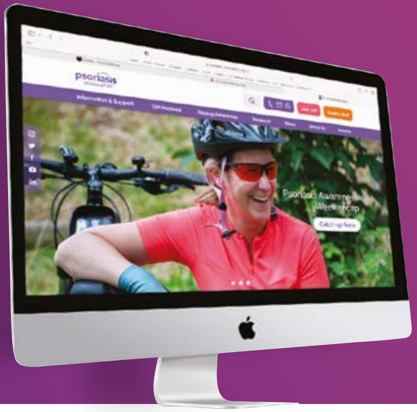
'Living well with psoriasis and psoriatic arthritis'.

The relaunch of our website, which was redesigned to incorporate the new set of photographs, taken during our Active Lives photo shoot in May, took centre stage during the week and was complemented by the release of shared stories from some of the primary participants.

Importance was placed on how people can use their hobbies and interests to live well with psoriasis and psoriatic arthritis which again drew inspiration from the number one research priority identified by the psoriasis Priority Setting Partnership (PSP) (do lifestyle factors such as diet, dietary supplements, alcohol, smoking, weight loss, and exercise play a part in treating psoriasis?).

Awareness Week Activites

- Main website redesigned and relaunched with new pictures from our Active Lifestyles photoshoot making it look fresher, brighter and easier to use
- A return to public information stands for the first time since the pandemic saw staff travel to Rushden and Derby to meet members of the public and offer advice and information



- A video tips montage of how people live well with psoriasis developed and released
- Third collaboration with the St John's Derm Academy to offer a free webinar on palmoplantar pustulosis featuring Professor Catherine Smith, Dr David Gleeson, Professor Francesca Capon, and Lucy Moorhead with 80 people attending.
- The **Shared Stories** section of our website was redesigned allowing us to share 4 more stories during Awareness Week.

Our continued involvement in key economic and political health issues, saw us work closely with:

Dermatology Council for Scotland

Dermatology Council for England

The National Institute for Health and Care Excellence (NICE)

British Association of Dermatologists

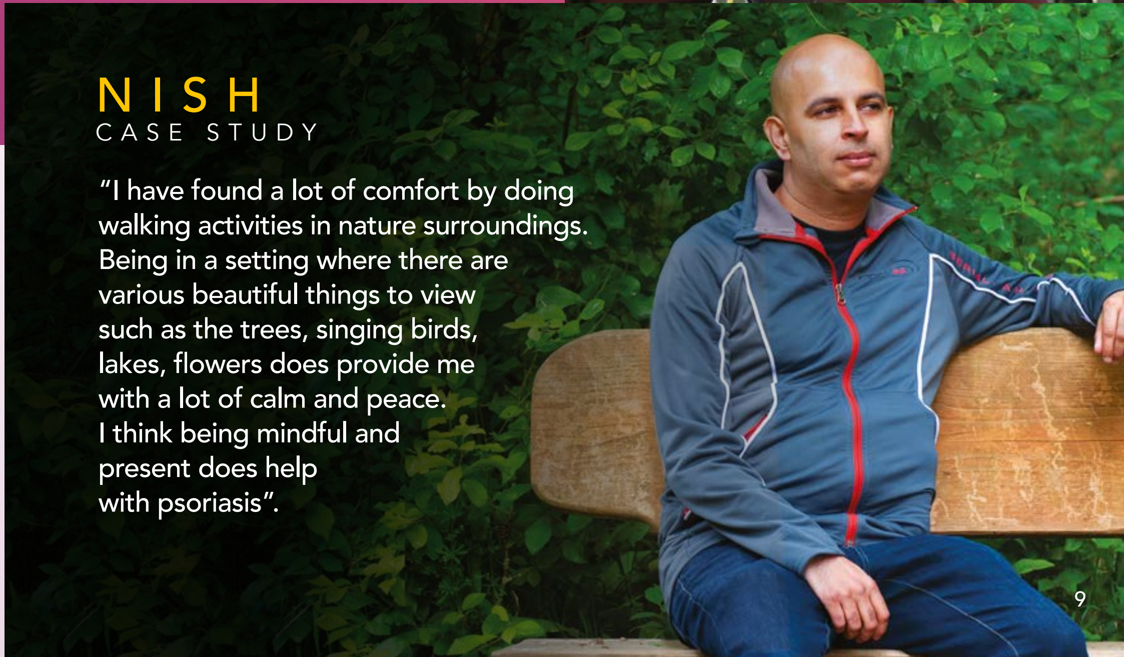
The advisory groups for NHS England and Improvement

NHS Outpatient Transformation projects in relation to teledermatology

ROSIE
CASE STUDY

"One of the lovely friends I made through sharing our psoriasis stories recommended that exercise could reduce my flare up. I have a bike at home and found that going on it every day really helped me mentally and it did seem to calm the patches a little.

During my last flare up I came to the conclusion that my psoriasis has made me the person who I am and I no longer feel as self-conscious as I did in previous years. To me the patches of psoriasis on my body are my beauty marks".



NISH
CASE STUDY

"I have found a lot of comfort by doing walking activities in nature surroundings. Being in a setting where there are various beautiful things to view such as the trees, singing birds, lakes, flowers does provide me with a lot of calm and peace. I think being mindful and present does help with psoriasis".

Conferences

We held information stands at:

- The British Association of Dermatologists (BAD) Conference in Glasgow
- The British Dermatological Nursing Group (BDNG) Annual Conference in Harrogate

Presentations

- Photonet (National Managed Clinical Network for Phototherapy in Scotland) Annual Meeting
- The Dermatology Clinical Research Network Meeting
- At the UCB sponsored Dermatology Nurse meeting regarding living well with psoriasis
- To MSc Clinical Dermatology students at the University of Hertfordshire
- Border Force staff
- MSK clinicians at the Rhem 101 Conference in Manchester

Government Affairs

More than Skin Deep Campaign

We were delighted to contribute to the Novartis sponsored 'More than Skin Deep' campaign this year and gave a presentation at the launch event for the final report at Westminster. This was designed to raise awareness of its findings and recommendations amongst Parliamentarians.

APPGS

We continue to work closely with and support the work of the All-Party Parliamentary Group on Skin (APPGS).

FUNDRAISING

London Marathon

Skydive

Charity stalls
- homemade cheese and cake stand sales
- homemade craft charity stall with raffle

Half marathons

Full marathons

10K

Triathlon

Half Ironman

Walking – 100 miles and 30 miles

5 mile run


Half and full marathons


Park runs


10K


Charity stalls


5 mile runs


Triathlon


London 10K

INFORMATION AND SUPPORT

592,912
visits to the main Psoriasis Association website in 2022

18,937
people registered to participate in our online forums

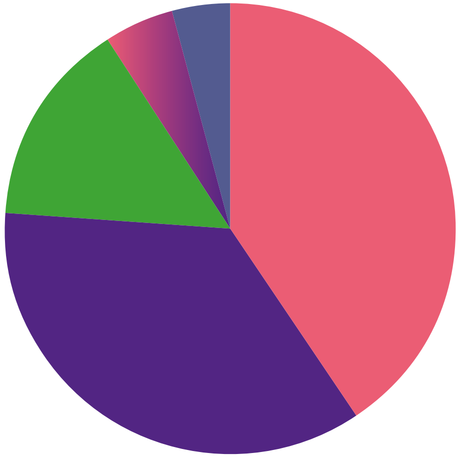
7,548
members of the private Facebook Group

1,593
followers on LinkedIn, an increase of almost 1/3 from last year.

There are so many ways you can contact us for help, support, information or a friendly listening ear.

801 helpline enquiries received in 2022:

41% by telephone
36% by email
15% by WhatsApp
5% by Instagram
4% by Facebook



Most common enquiries:

- 23% Scalp psoriasis
- 19% Plaque psoriasis
- 16% Psoriatic arthritis

729 leaflets and **2577** information sheets sent out

We offer over **50** information resources on all different types of psoriasis and treatments.

> Thank you so much for your detailed email. This is the most information and guidance I have ever been given with regard to my son and he is nearly fifteen.
>
> **N**

> Thank you so much for all the useful information. It is very much appreciated. And such a huge help. Also, thank you, once again for our chat on the phone. It felt encouraging to have a listening ear and to hear your advice and knowledge.
>
> **K**

Pso

Pso, our popular members magazine, is sent out seasonally 4 times a year and remains an important way of communicating with members.

PiF Tick

The Psoriasis Association has long prided itself on the quality, reliability, and relevance of the information it produces for those whose lives are affected by psoriasis and psoriatic arthritis. We were reaccredited with the PIF Tick for a second year in July 2022. Work has continued throughout the year to review all information resources and to ensure they all follow the PiF Tick production processes.

Trusted
Information
Creator
Patient Information Forum

ANNUAL CONFERENCE & AGM

A successful annual conference was held as a hybrid model for the first-time allowing people to join in person in Birmingham or at home via zoom. Both methods were very well received, and the conference continues to be an excellent vehicle for raising awareness and showcasing the research funded or supported by us.

Presentations by expert speakers including Psoriasis Association trustee, Dr Julia Schofield MBE on the NHS Outpatient Transformation Programme, Professor Laura Coates on the findings of the Psoriatic Arthritis PSP and Dr Satveer Mahil on COVID-19, vaccines and psoriasis complemented informative talks and tips on managing psoriasis and the results of Psoriasis Association funded research.

All presentations from the day are available on our YouTube channel as valuable resources of information and support.

RESEARCH

New research funded in 2022:

- The Cecil King Memorial Fund award was granted to **Dr Elaine Clarke** for her study "Self-compassion and supporting adherence to topical therapies in people living with psoriasis"
- Our PhD Studentship award was granted to **Dr Zenas Yiu** for his study Risk of Serious Infection associated with Interleukin 17 and 23 inhibitors compared with other biologics in people with psoriasis".

Grants Completed in 2022:

- **Dr Stephanie Shoop-Worrall** completed her Cecil King Memorial Fund grant "The impact of psoriasis on wellbeing and clinical outcomes in juvenile psoriatic arthritis".
- **Dr David Hill** completed his Psoriasis Association Small Grant award "Evaluating the effect of cannabinoid-induced inhibition of FABP5 for the treatment of psoriasis".
- **Dr Henning Holle** (grant holder) **Dr Sarah Etty** (student) completed the PhD studentship "An attentional bias approach to understanding and reducing the psychosocial burden of psoriasis".
- **Professor Nick Reynolds** (grant holder) and **Ashley Rider** (student) completed the PhD studentship "Investigating genetic control of the psoriasis transcriptome to define and validate drug and disease endotypes."

We also continued to support:

- A further 2 small grants
- 9 PhD Studentships
- The BSTOP 5-year extended funding project.

Dr Elaine Clarke

Dr Zenas Yiu

Dr Henning Holle

Dr Stephanie Shoop-Worrall

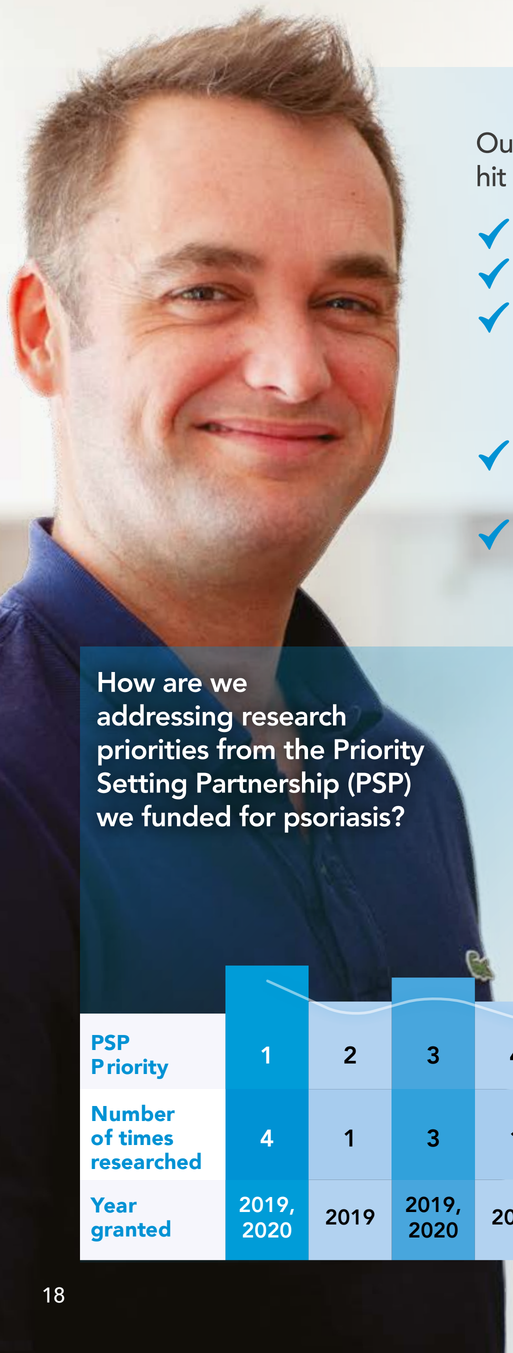
Dr Sarah Etty

Ashley Rider

Professor Nick Reynolds

RESEARCH IMPACT

BSTOP
Biomarkers and Stratification To Optimise outcomes in Psoriasis



Our £1m five-year investment into BSTOP hit key first year milestones in 2022:

- ✓ Key staff appointed.
- ✓ Governance procedures established.
- ✓ All relevant amendments to the BSTOP protocol, CRFs and management systems for ethics and regulatory approval submitted.
- ✓ 90% of clinical data stored on CAPTURE cleaned and quality controlled.
- ✓ 100% of BSTOP recall bioresourcing requests achieved to time and target.

How are we addressing research priorities from the Priority Setting Partnership (PSP) we funded for psoriasis?

Since 2019, all PhD applications have needed to demonstrate that they will be addressing at least one of the priorities identified by patients and clinicians in the PSP. Our funding of BSTOP is additionally seeking to address over half of these priorities. The Psoriasis Top 10 research priorities are detailed on our website.

PSP Priority	1	2	3	4	5	6	7	8	9	10
Number of times researched	4	1	3	1	0	0	1	2	1	1
Year granted	2019, 2020	2019	2019, 2020	2019			2020	2019	2021	2019

'Spotlight on'… Dr Stephanie Shoop-Worrall
Dr Shoop-Worrall presented the findings from her Cecil King Memorial Foundation funded study, granted and managed by the Psoriasis Association at our Annual Conference. She has since gone on to secure a £1million grant for a 5-year Career Development Award from the Medical Research Council to further research in this area.

Professor Nick Reynolds secured further funding from the study "Investigating genetic control of the psoriasis transcriptome to define and validate drug and disease endotypes" to act as the lead applicant for a 3-year study into "Personalised biologic treatment of psoriasis through biomarker integration and Artificial Intelligence-enabled mechanistic modelling of psoriatic plaque resolution." Student **Ashley Rider** is continuing research in this area as a research associate.

Articles authored by sponsored PhD Students were published in the Journal of Investigative Dermatology, Nutrition Bulletin, Clinical Science and ActaDV.

Professor Nick Reynolds and Dr Julia Schofield from our Medical and Research Committee hosted a virtual Hints and Tips Session for potential grant applicants in September. Promotion of this session and increased social media promotion of the grant call led to a significant rise in the number of PhD studentships received in December 2022 compared to December 2021.

'Spotlight on'…
Dr Stephanie Shoop-Worrall

FINANCIAL HIGHLIGHTS

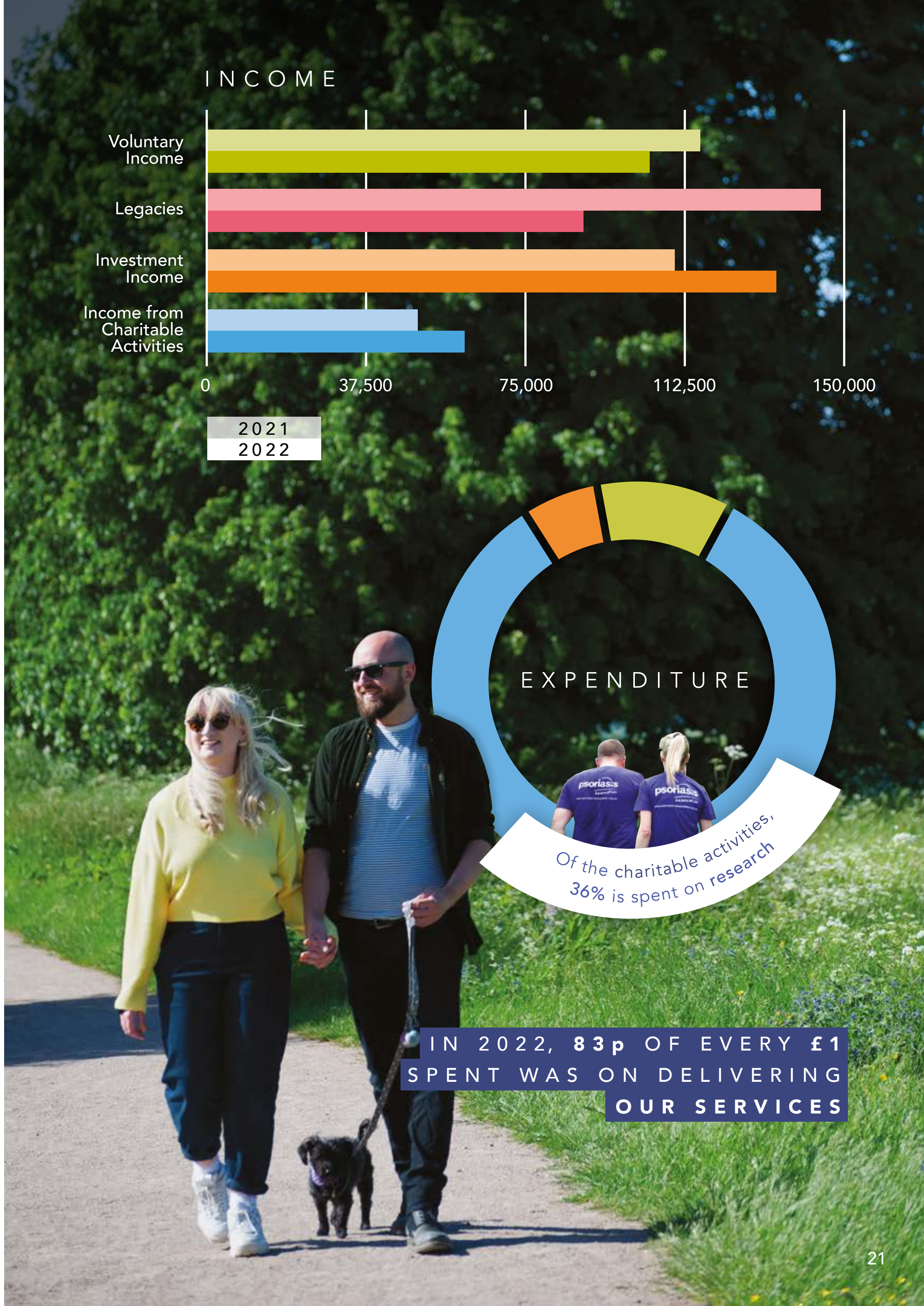
This information is a summary of the full accounts of the Psoriasis Association for the period 1 January 2022 to 31 December 2022. If you would like the full financial statements, Trustees annual report and Auditor's report please contact The Psoriasis Association or visit www.psoriasis-association.org.uk/who-we-are/funding

How we raised our money

Income	2022 (£)	2021 (£)
Voluntary Income (including, for example, membership subscriptions, fundraising by individuals, Gift Aid, donations in memoriam)	**103,358**	115,961
Legacies	**87,657**	143,412
Investment Income	**133,162**	110,031
Income from Charitable Activities (including, for example, corporate sponsorship, charitable trust donations, Pso advertising)	**60,302**	49,579
Total Income for the Year	**384,479**	418,983

How we spent our money

Expenditure	2022 (£)	2021 (£)
Raising Funds	**67,750**	62,672
Charitable Activities	**504,424**	934,626
Investment Management Costs	**33,048**	34,296
Total Expenditure for the Year	**605,222**	1,031,594



Of the charitable activities, 36% is spent on research

IN 2022, **83p** OF EVERY **£1** SPENT WAS ON DELIVERING **OUR SERVICES**

Total Net Assets	2022 (£)	2021 (£)
At 1st January	**7,265,057**	7,325,008
Add Incoming Resources	**384,479**	418,983
Deduct Net Resources Expended	**605,222**	1,031,594
(Losses)/Gains on Investment Assets	**(1,082,943)**	562,660
Gains on revaluation of Fixed Assets	**(5,000)**	(10,000)
At 31st December	**5,956,371**	7,265,057

The total assets are made up as follows	2022 (£)	2021 (£)
Endowment funds for research and educational work	**4,157,267**	5,004,890
Restricted funds for research	**360,880**	493,278
Restricted funds for Scotland	**53,865**	57,750
Unrestricted funds - General charitable work	**283,486**	418,296
Unrestricted funds - Designated funds	**620,873**	805,843
Unrestricted funds - Property fund (this reflects the value of the property purchased in 2007)	**480,000**	485,000
TOTAL	**5,956,371**	7,265,057
Change in assets	**(1,308,686)**	**(59,951)**

Where your money goes

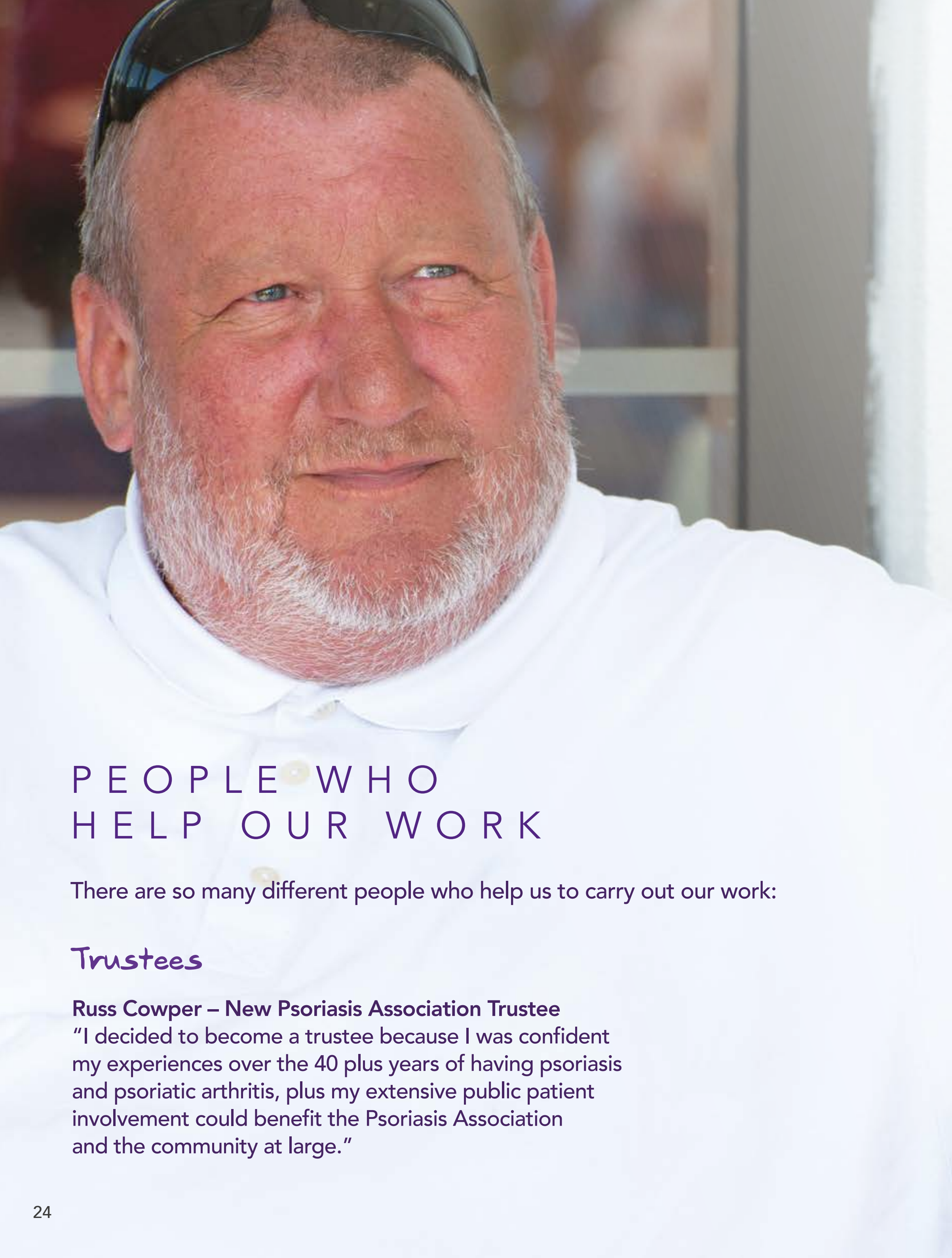
We have a policy to hold at least six months charitable expenditure in free reserves at any one time (estimated at £250,000), and the free reserves in 2022 was actually £283,485.

Funds and reserves

The total funds of the Psoriasis Association are broken down into three main categories:

- Not available to spend (endowments) ●
- Restricted funds (can only be spent in areas requested by donor) ●
- Unrestricted funds (available to spend) ● ● ●

Endowments – often as a result of legacies and other gifts.	£4,157,267
Restricted spend for example on research.	£414,745
Property – Head Office building of the Psoriasis Association.	£480,000
Designated spend – set aside for specific projects.	£620,873
Unrestricted funds – includes reserves.	**£283,486**



PEOPLE WHO HELP OUR WORK

There are so many different people who help us to carry out our work:

Trustees

Russ Cowper – New Psoriasis Association Trustee
“I decided to become a trustee because I was confident my experiences over the 40 plus years of having psoriasis and psoriatic arthritis, plus my extensive public patient involvement could benefit the Psoriasis Association and the community at large.”

Fundraisers

Vanessa Lawrence-French
“Psoriasis has been a part of my life for over 30 years now and thanks to the Psoriasis Association, I’ve always felt they’ve been a reliable team to turn to for up to date information and support.

I have enjoyed running the London 10k for the association a number of times and hope to represent them again over the coming years. Wearing the purple t-shirt and being cheered on by both members of the public and the association team, makes for a fun day and I feel great pride in supporting others with psoriasis”.

Medical and Research Committee

Professor Jonathan Barker – Chairman of the Medical and Research Committee
“Over a million people in the UK suffer from psoriasis. It can cause a lot of emotional distress not only for sufferers but also for their family and friends. Fortunately, driven by science much of which has been in UK, there have been significant advances in our understanding of this skin condition and how it impacts people. In turn this has led to new treatments and to a more holistic way of managing people with psoriasis. But there remains much to be done. The Psoriasis Association is playing a major role in funding UK research into psoriasis and in training the next generation of psoriasis researchers. I am very proud to help this effort through my involvement with the medical research committee.”

Researchers

Sylvia Zanesco

"We are proud to be working with the Psoriasis Association and its members to help answer one of the most important questions that people living with psoriasis have: do diet and lifestyle factors play a role? This was the top research priority in the James Lind Alliance Priority Setting Partnership, which included a survey of Psoriasis Association members. Our research project joins a multidisciplinary team of researchers including Nutritionists, Dietitians and Dermatologists to provide a unique perspective when exploring the role of nutrition, lifestyle, and psoriasis severity."

Lay information reviewers

Andy Taylor

"The Psoriasis Association regularly reviews its own information sheets to keep them up to date.

I help review these sheets because I want the Association to be its very best and so anyone contacting the organisation is able to access the most accurate information.

I want the Psoriasis Association to be recognised as an organisation that cares and can help. It is also a small way for me to give something back for all the help and support they have given me over the years as a member."

THANK YOU

for helping us to have a successful 2022...

All our members and supporters.

People who leave legacies to the Psoriasis Association.

Our Medical and Research Committee: Professor Jonathan Barker, Professor Anthony Bewley, Professor Christopher Griffiths OBE (until April 2022), Professor Eugene Healey, Dr Elise Kleyn, Professor Nick Reynolds, Dr Julia Schofield MBE, Susan Morgan, Helen McAteer.

External Peer Reviewers: Professor Francesca Capon, Dr Paola Di Meglio, Professor David Kelsell, Professor Richard Warren.

Trusts and Foundations who supported our work in 2022: Cecil King Memorial Foundation, Davis Rubens Charitable Trust, Marilyn Holzer Memorial Trust, Rick Mather David Scarse Foundation and the Lancashire Foundation.

People who donate towards our work with fundraising and gifts to mark special occasions.

Our Trustees: Nick Evans, Brian Murkin, Dr Julia Schofield MBE, Steven Astaire, Thomas Ball, Russ Cowper (from August 2022), Chris Dyer, Gill Hynes, Michael Israel, Karina Jackson, Susan Morgan, Matthew Swift.

Senior Staff: Helen McAteer, Laura Stevenson, Polly Matthews.

Life Vice Presidents: Professor Terence Ryan, Professor Christopher Griffiths OBE, John Ford MBE, Ray Jobling MBE, Jonathan Swift.

Companies who supported our work in 2022 via membership or unrestricted educational grants: Abbvie, Almirall, Amgen, Bristol Myers Squibb (BMS), Dermal Laboratories Ltd, Eli Lilly, Janssen, LEO Pharma , Novartis, T&R Derma and UCB.