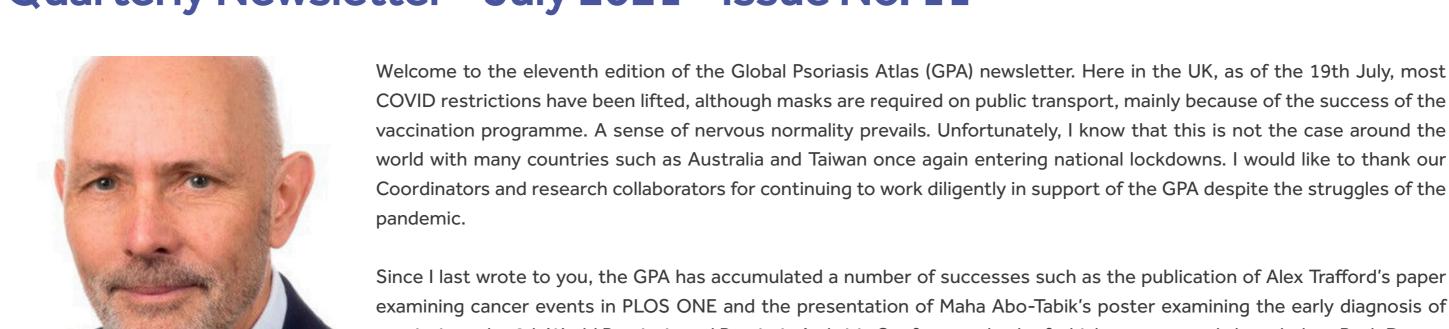
Quarterly Newsletter - July 2021 - Issue No. 11



Welcome to the eleventh edition of the Global Psoriasis Atlas (GPA) newsletter. Here in the UK, as of the 19th July, most COVID restrictions have been lifted, although masks are required on public transport, mainly because of the success of the vaccination programme. A sense of nervous normality prevails. Unfortunately, I know that this is not the case around the world with many countries such as Australia and Taiwan once again entering national lockdowns. I would like to thank our Coordinators and research collaborators for continuing to work diligently in support of the GPA despite the struggles of the

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examining cancer events in PLOS ONE and the presentation of Maha Abo-Tabik's poster examining the early diagnosis of psoriasis at the 6th World Psoriasis and Psoriatic Arthritis Conference, both of which you can read about below. Both Darren Ashcroft and I also lectured on the GPA at the Congress. Medical Coordinator, Tatjana Maul, has been working tirelessly on the GPA healthcare survey which will be ready for rollout once the final revisions have been made. The purpose of the GPA survey is to enable further mapping of psoriasis on a local and regional level and to help us gain a better understanding of common psoriasis characteristics. Research collaborations are progressing successfully with colleagues in Taiwan, Denmark, Greenland, Newfoundland and

Qatar. The GPA's plans to visit Myanmar have been postponed to 2022 due to the challenging situation in the country, however, in the interim, we are hoping to put together a series of educational webinars on psoriasis to support local colleagues. We are also currently working with digital agency, Swiss4ward, to develop the PsoWell resources into a web-app to enable access for psoriasis patients around the world. Meanwhile, may I wish you some relaxing time off over the summer and a return refreshed for what will be a dynamic and

exciting final quarter to 2021. With my best wishes,

Chris

Research Update



many challenges presented by the COVID-19 pandemic. Recently, the work led by Cristóbal Lecaros and Claudia De la Cruz to examine the incidence of psoriasis in Chile has been published in Clinical and Experimental Dermatology which you can view here: https://onlinelibrary.wiley.com/doi/10.1111/bjd.20096. Building on this, we are now finalising a new paper focussed on understanding the burden of co-morbidity in people with psoriasis in Chile. This is hugely important work and another major

I am very pleased to report that we have continued to make steady progress with our GPA research programme despite the

achievement for the GPA; and we look forward to sharing details of this paper once published. Several of our GPA Regional Coordinators have also published additional important papers focussed on the epidemiology of psoriasis in recent months too. April Armstrong has recently examined the prevalence of psoriasis among adults in the US using the 2003-2004 National Health and Nutrition Examination Survey (NHANES) data, reporting that psoriasis affects 3.0% of the US adult population, or more than 7.5 million adults: https://jamanetwork.com/journals/jamadermatology/articleabstract/2781378. Alexander Egeberg and colleagues have recently examined the test-retest accuracy of questionnaires on psoriasis and atopic dermatitis for measuring prevalence in an adult population. This study found that asking people about a history of psoriasis may be useful for assessing psoriasis prevalence, but a questionnaire does not appear to be a reliable

Finally, Alex Trafford, one of our GPA PhD students, has recently published a new study examining the concordance and timing of cancer recording between primary care, hospital and death registration data for people with psoriasis: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0254661. This study underpins our programme of work examining cancer incidence and mortality in people with psoriasis that we will report on later in the year involving cohort studies conducted in Denmark, Israel, Taiwan and the United Kingdom. We are very grateful for the valuable contributions made by all our international collaborators to make this work possible.

The IRASPEN-Registry is a global, prospective registry, investigating the genotype-phenotype correlation of pustular psoriasis (PP). IRASPEN comprises the prospective collection of data and biological material from multiple, global sites: https://www.iraspen.org/

Medical Coordinator Update



IRASPEN

The sub study IRASPEN-CS is a cross-sectional design comprising a one-time collection of data and photographs, based on the first visit of the IRASPEN main project. Objectives of the registry • To give insight on the natural course of disease in PP, namely reveal the burden of disease including frequency and

severity of flares • To reveal the need and efficacy of therapeutic interventions • To reveal further genetic causes of PP

• To describe transcriptional profiles, correlating with subtypes and severity of disease Primary and secondary endpoints

- Objective disease activity: • Number of flares in the last 2 years (baseline) / since the last visit
- PGA (depending on PP subtype, further specified as GPP PGA, PPP PGA) PP area and severity score, namely GPP ASI, PPP ASI
- Quality of Life Scores DLQI
- EQ-5D
- WPAI-GH
- PSS
- Patient reported outcomes: Disease activity VAS

method for assessing atopic dermatitis prevalence among

adults: https://jamanetwork.com/journals/jamadermatology/article-abstract/2781705

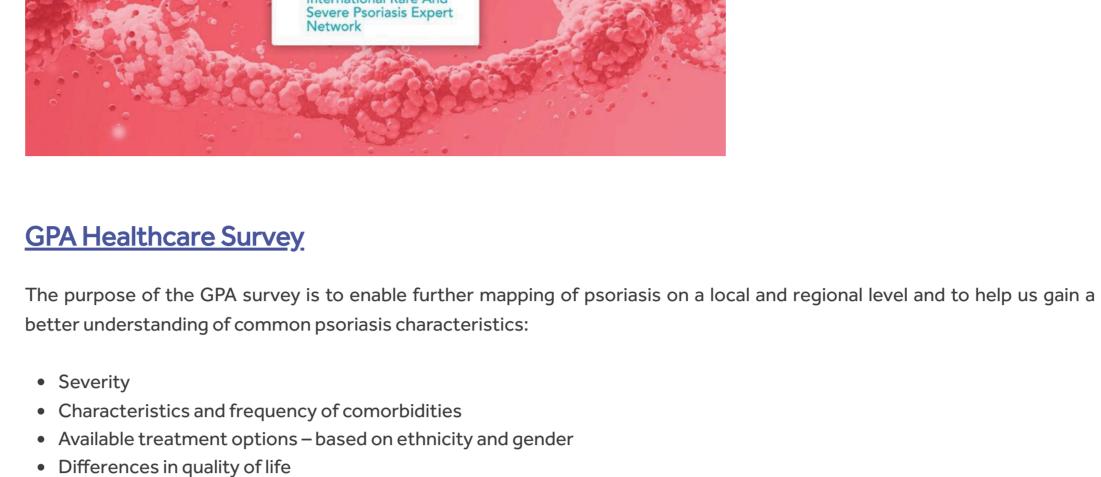
- Pain VAS The variable of primary interest (corresponding to an endpoint in a clinical trial) is the PGA / IGA severity grade, and as it is an

observational study, both the first as well as all other visits are relevant.

request. For further information, please contact: Julia-Tatjana. Maul@usz.ch

PD Dr Maul is keen for all GPA Regional Coordinators and dermatologists from around the world to contribute to the study.

The electronic case report form, information on ethical approval and reimbursement for the study can be provided on



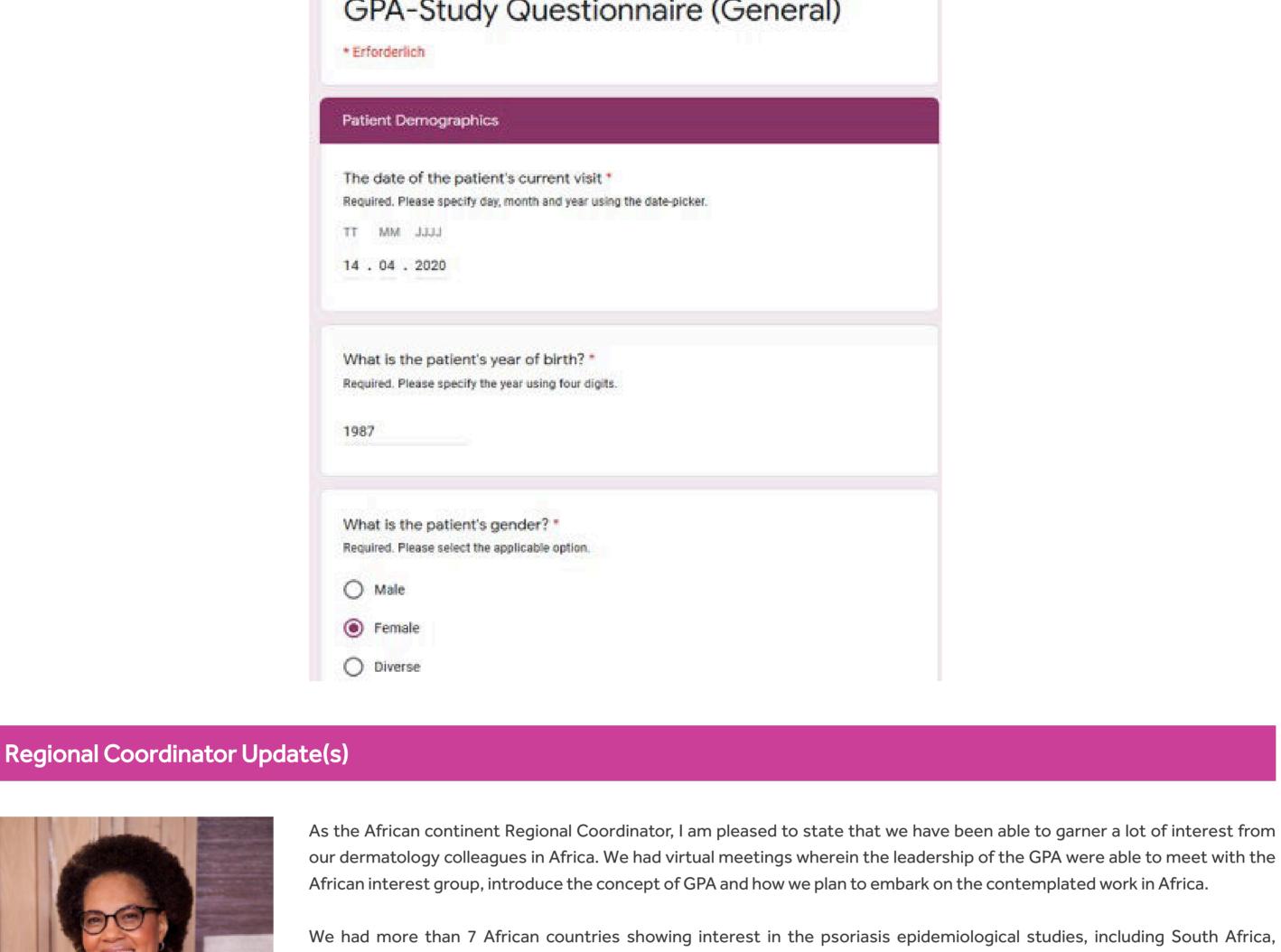
• Burden of disease • Influence of the level of education on the treatment response Over the past few months, PD Dr Maul and GPA Programme Manager, Rebekah Swan, have participated in individual calls with

many of our Regional and National Coordinators in order to provide guidance on the planned rollout of the GPA survey and to

collect feedback on the tool. During this important phase of work, we are asking our Regional Coordinators to work with us to

- identify National Coordinators in their regions who can assist with dissemination of the surveys, thus widening the GPA research network. We would like to thank you for your engagement with this process and for your hard work in identifying potential National Coordinators in your regions. This is a truly exciting phase of work and we are delighted by the response globally, especially in the African region. We would like to take this opportunity to thank Professor Ncoza Dlova for her efforts to identify colleagues with an interest in the work of the GPA.
- PD Dr Maul is in the process of providing information to our colleagues regarding the ethical approval process and we will be in contact again once PD Dr Maul has finished revising the tool based on the feedback received. If you require any further information, or would like to arrange a call please contact: Rebekah.swan@manchester.ac.uk

GPA-Study Questionnaire (General)



Ncoza Dlova



The 6th World Psoriasis and Psoriatic Arthritis Conference

Nigeria, Senegal, Madagascar and Tanzania. All the dermatologists found the GPA initiative to be an excellent project as it

creates opportunities for epidemiological data on psoriasis to be established in countries where there are limited resources

and funding for such research would otherwise be limited. This was also seen to generate opportunities for our residents and

young consultants to pursue their masters and doctoral studies using the same database that would be created.

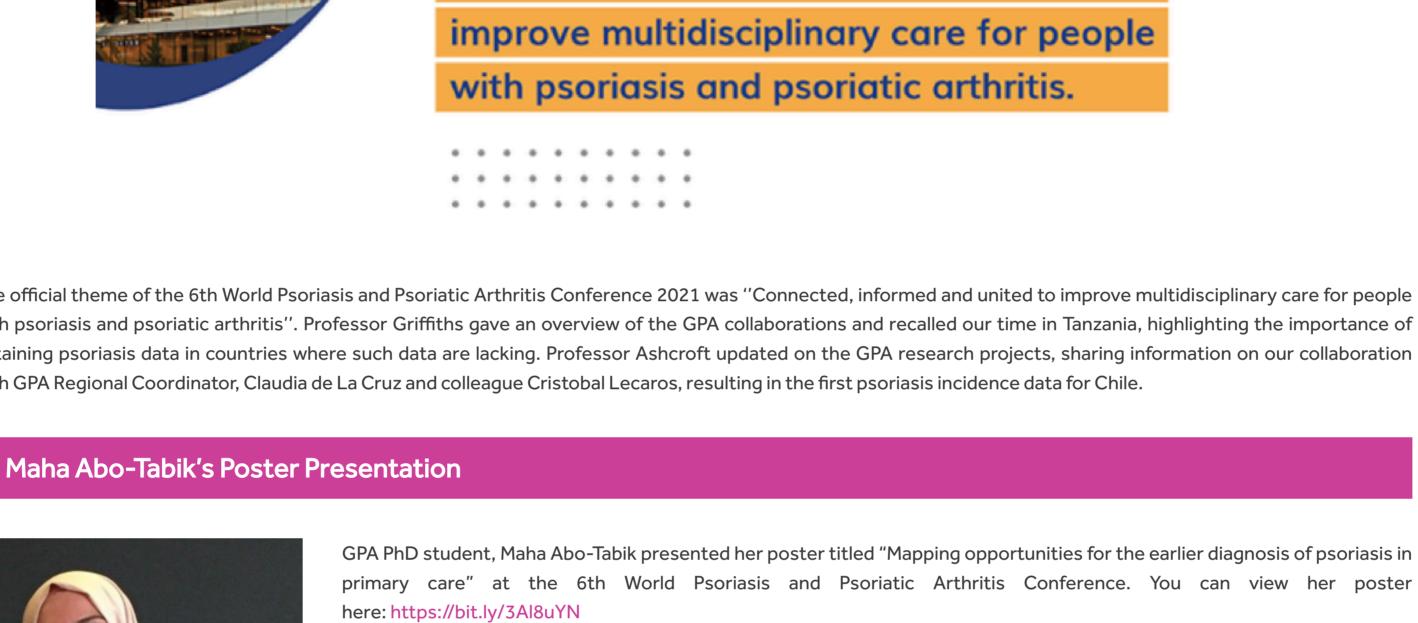
6th World Psoriasis & Psoriatic Arthritis Conference

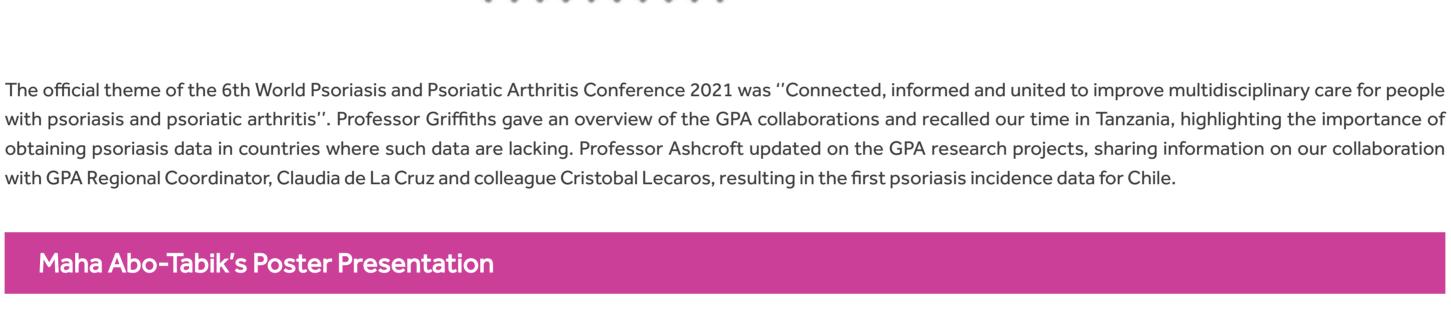
— June 30 - July 3, 2021 —

improve multidisciplinary care for people

Connected, informed and united to

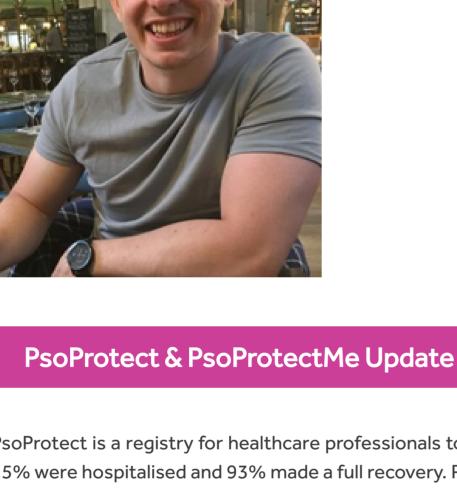
with psoriasis and psoriatic arthritis.





Congratulations to Alex Trafford for New Publication

Congratulations to GPA PhD student, Alex Trafford, for the publication of his paper "Concordance and timing in recording cancer events in primary care, hospital and mortality records for patients with and without psoriasis: A population-based cohort study" in the PLOS ONE. You can read the paper here: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0254661



PsoProtect is a registry for healthcare professionals to report cases of COVID-19 in psoriasis patients. So far, 1147 cases have been reported and, out of these cases, 15% were hospitalised and 93% made a full recovery. PsoProtect's publication in the British Journal of Dermatology found that greater risk-mitigating behaviour among people with immune-mediated inflammatory diseases receiving targeted therapies may contribute to the reported lower risk of adverse COVID-19 outcomes. Explore the data here: https://psoprotect.org/current-data/

PsoProtect

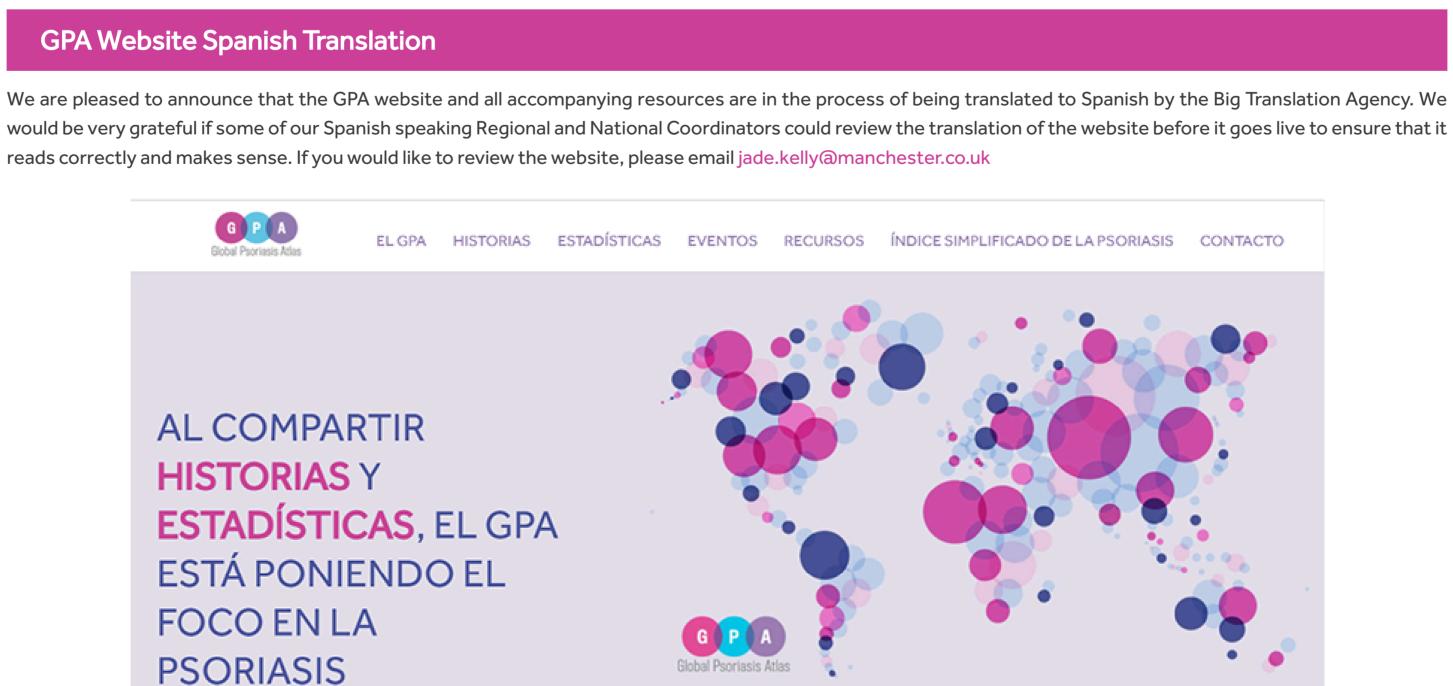
Ongoing Digital Developments We are currently working with software consultancy company, Swiss4ward, on two important projects. Firstly, in collaboration with Lis Cordingley, we are developing the PsoWell resources into a web app to enable access for psoriasis patients around the world. These resources include information on diagnosis, treatments, and lifestyles and behaviour changes.

PsoProtectMe is a registry for people with psoriasis to report how they have been affected by the pandemic, whether they've had COVID-19 or not. So far, 4501

participants have completed the survey and 11% of participants had been diagnosed with COVID-19. 1834 participants felt that their psoriasis had worsened during the

pandemic, 1680 felt that it had stayed the same and 312 felt that it had improved. Explore the data here: https://psoprotectme.org/current-data/

Pso**Protect**Me



Secondly, we are developing GPA PhD student, Maha Abo-Tabik's psoriasis training tool. The training tool aims to improve the diagnostic skills of primary care

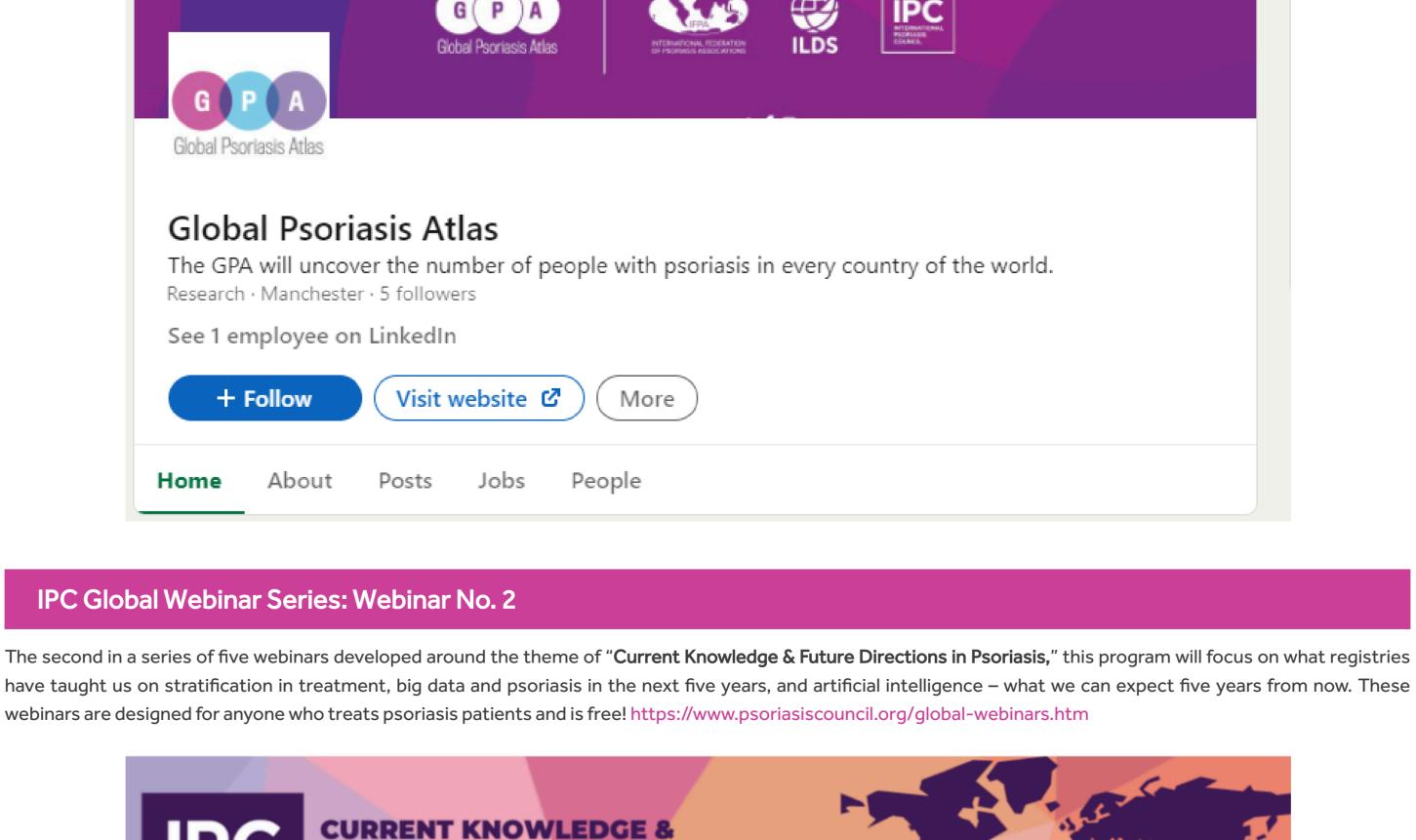
professionals for psoriasis. This educational resource will be based on the findings from our recent e-Delphi study. We aim to test the effectiveness of the newly

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developed training tool in an online study.

Working with Platform Worldwide Over the past few weeks, we have been working with social media agency, Platform Worldwide, to develop a social media strategy for the GPA, as well as new, branded content to post across all platforms. With the help of Platform, we have set up a LinkedIn account with the aim of connecting with more dermatologists around the world and sharing the important work of the GPA. If you have a LinkedIn account, or know anyone who would be interested in following the GPA, please do let us know as we would love to connect with as many dermatology specialists as possible.



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FUTURE DIRECTIONS IN PSORIASIS

A Global Webinar Series

Webinar No. 2 October 29, 2021 Personalized medicine with a focus on registries, big data and artificial intelligence **Upcoming Meetings** • Thursday 12th August – the GPA team will meet with the LEO Foundation to provide an update on project progress.

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Funders

FAQs

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Healthcare Data

Key Messages

PSORIASIS STORIES

THE GPA HOW CAN I SUPPORT GPA? EXPLORE THE DATA RESOURCES About the GPA Prevalence Heat Map What is Psoriasis

· Provide financial support Team Map **Annual Reports** Collaborate with us **EVENTS** Support the collection of data on the global burden of psoriasis **Posters CONTACT** Support our research **Publications** · Engage with us on social media Establishing a high quality GPA requires the SPI support of industry, organisations with **PRIVACY POLICY** regions and countries. **PSO WELL®**

relevant data sets and collaborations across Contact us

We always welcome new connections

and partnerships!

Here are some of the ways you can get involved:

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