# Global Psoriasis Atlas

### **Annual Report**

Year 3: April 2019 - March 2020







### Contents

	P-3-
Foreword	3
Mission	4
Vision	4
The Launch of the Atlas	6
Psoriasis: Building the Global Picture	8
The GPA and the World Health Organization	9
The GPA: A Strong Organisation Built to Collaborate	10
Our Team	11
Structure and Governance	12
Governance and Lea <mark>dership</mark>	13
Global Network, Regional Approach	14
Regional Coordinator Spotlight	16
Research Work Stream Progress	20
Work Stream 1 Progress	20
Work Stream 2 Progress	24
PhD Progress	27
Introducing Our Medical Coordinator	30
Global Collaboration: Tanzania	32
Success Factors for the GPA Programme	34
GPA: Phase II 2020-2023	35
Highlights 2017-2020	36
Outreach	37
News 2019-2020	38
Social Growth	40
Engagement	41
Publications, Abstracts and Presentations	42

# Foreword

### It has been quite a year one way or another.

As I write this from Manchester in late March, the full global significance of the COVID-19 pandemic is starting to sink in. Many cities are in lockdown; health services around the world are struggling to cope with the influx of ill and very ill patients; universities are closed or closing; research has stopped and educational and scientific meetings continue only via video-conferencing. Despite all of this, it is only right that we have something to celebrate namely the outstanding year of success enjoyed by the Global Psoriasis Atlas and its team of dedicated international enthusiasts led by Rebekah Swan. As you will read in the report, we undertook our first GPA fieldtrip. In July 2019, a group of us went to Tanzania where we learnt a huge amount about how psoriasis is both diagnosed and managed in East Africa. Dr Tatjana Maul reconnected with Chile and Brazil to learn more about psoriasis care in those countries and Professors Ashcroft and Augustin and their teams continued to add to our knowledge about psoriasis worldwide and presented this at conferences and in scientific journals. Probably the standout success of the past year was the launch of the GPA Website, fittingly on World Psoriasis Day, 29 October 2019. Please take the time visit the site - we are interested in your thoughts. We have now finished Phase I (2017-20) of the GPA and the other piece of excellent news is the procurement of funding to cover most of our planned work for Phase II (2020-23) from our Lead Supporter the LEO Foundation.

At this juncture I would also like to thank two of our Board of Governors, who stepped down in the past year, for their unswerving support of the GPA. Dr Harvey Lui, the first Chair of the Board in his role as President of the ILDS and Lars Ettarp, whose drive and vision as President of IFPA laid the foundations of what was to become the GPA.

A year of success but also one of uncertainty. May I wish all of you and your families good health and fortitude in the coming months.

**Professor Chris Griffiths OBE** Director, Global Psoriasis Atlas







# Mission

The mission of the GPA is to ensure that people with psoriasis, wherever they live in the world, have access to the best available care.

# Vision

The GPA will become the leading epidemiological resource globally on psoriasis providing the common benchmark on the burden of psoriasis in all countries and regions throughout the world. The Atlas will seek to: drive continuous improvement in understanding the natural history of psoriasis; uncover how it affects the individual and society; understand how healthcare can be improved for those living with the disease. Professor Griffiths with a patient and local dermatology specialist who is acting as Maasai interpreter. Tanzania, July 2019



# **The Launch** of the Atlas

We launched the Global Psoriasis Atlas website on the 29th October 2019, to coincide with World Psoriasis Day.

This important milestone means that, for the first time, experts and those living with psoriasis can gain a greater understanding of the complex skin condition endured by so many people.

This landmark achievement has been accomplished by the International Federation of Psoriasis Associations (IFPA), the International League of Dermatological Societies (ILDS) and the International Psoriasis Council (IPC). The culmination of the research work conducted at The University of

Manchester and the University Medical Center Hamburg-Eppendorf, will help construct a global picture of psoriasis.

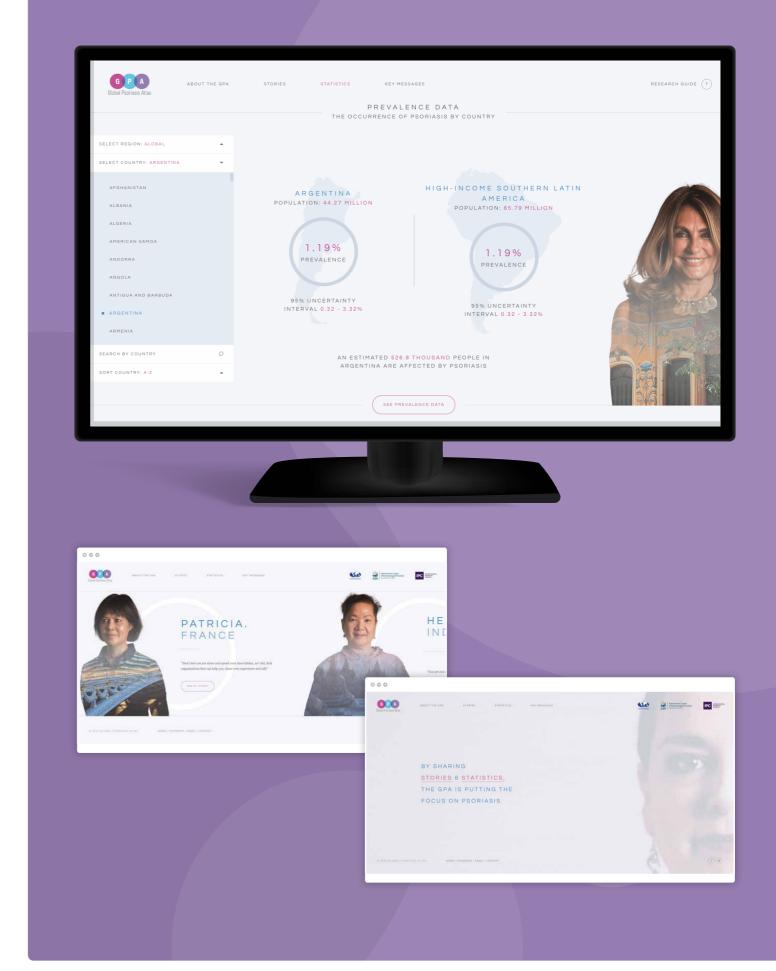
Bringing together both the latest data and compelling insights, it serves as a valuable source of information not only for researchers, policy makers and healthcare providers across the world but the many people who live with psoriasis.

As well as serving as a transformational, educational and open access scientific tool, the Global Psoriasis Atlas also presents the human face of psoriasis, sharing first-hand experiences. Working with IFPA we were fortunate to be able to film the personal stories of people from around the world with psoriasis. These powerful accounts

We are grateful to the people who shared their story with us. Rebekah Swan, Programme Manager

highlight many of the impacts that are experienced when living with this potentially life changing skin disease.

Our understanding of the epidemiology of this chronic condition is limited in many countries but the Global Psoriasis Atlas is poised to radically transform this in the future. It will uncover the true burden of the disease, ensuring those people living with psoriasis have access to the best available care, wherever they live in the world.





## Psoriasis: Building the **Global Picture**

# million people

with psoriasis globally

Our systematic review identified that

of countries

have epidemiological data

on psoriasis

### The prevalence

of psoriasis appears to vary depending on genetic background and geographic location. For example, our data indicates a prevalence estimate of

> 0.06% in Taiwan compared to a prevalence estimate of

1.91% in Denmark

# The GPA and the **World Health** Organization

The resolution passed by the World Health Assembly in 2014 highlighted that psoriasis should be viewed as a serious non-communicable disease and the subsequent WHO report on psoriasis<sup>1</sup>, published in 2016, paved the way for the development of the GPA. The resolution was aided by the 2012 systematic review from the University of Manchester reporting on the global epidemiology of psoriasis<sup>2</sup>. This highlighted marked variations in the reported prevalence and incidence of psoriasis, both within and between countries. Importantly it identified knowledge gaps in our understanding of the natural history and burden of psoriasis globally. Specifically:

- Few studies focused on the incidence (new cases) of psoriasis over time:
- Most studies contributing data on disease prevalence were conducted in Europe and the USA, with far fewer identified from Asia, Africa and South America.
- No studies simultaneously compared trends in incidence, prevalence and mortality longitudinally in patients with psoriasis to determine: (i) whether the prevalence of psoriasis is increasing over time; and (ii) if so, whether this is driven by increasing trends in incidence and/or whether patients are nowadays living much longer with psoriasis due to reductions in early mortality

These data, coupled with the identification in 2012 by the International League of Dermatological Societies (ILDS) that psoriasis was one of its "Grand Challenges in Global Skin Health", catalysed the tripartite partnership between the International Federation of Psoriasis Associations (IFPA). the ILDS, and the International Psoriasis Council (IPC) to take forward a GPA.

<sup>1.</sup> World Health Organization. (2016). Global report on psoriasis. World Health Organization. https://apps.who.int/iris/handle/10665/204417 <sup>2</sup>. Parisi R, Symmons DPM, Griffiths CEM, Ashcroft DM. Global Epidemiology of Psoriasis: A Systematic Review of Incidence and Prevalence. J Invest Dermatol 2013;133:377-85.





Global report on **PSORIASIS** World Health

Good epidemiological data are essential for disease control and appropriate healthcare planning...and dermatology remains one of the most neglected fields of epidemiological study. There is a need for better quality data on incidence and prevalence of psoriasis to understand better the size and distribution of the problem. World Health Organization, 2016

# The GPA: **A Strong Organisation Built to Collaborate**

The GPA is a collaboration between three leading international organisations in world dermatology: International Federation of Psoriasis Associations (IFPA); International League of Dermatological Societies (ILDS): and International Psoriasis Council (IPC) and The University of Manchester (UoM) as the lead academic institution.

Everything we achieve is thanks to our collaborating organisations, partners and passionate supporters. This global community is growing every year. Rebekah Swan, Programme Manager



The collaborating organisations are the joint project owners of the GPA. Project success can be attributed to the integrated and synergistic interactions between the academic institution and the three

partner international organisations. These organisations, between them, represent psoriasis associations around the world, international dermatology societies and the education and empowerment of global key opinion leaders in psoriasis.

The International Federation of **Psoriasis Associations** is a non-profit organisation comprising psoriasis associations from around the world. Together, they campaign for improved medical care, greater public

understanding and increased research to improve the lives of people who live with psoriasis and psoriatic arthritis.

The International League of Dermatological Societies has been promoting skin health around the world for over 80 years. The ILDS represents dermatology at the highest level with 190 Member Societies from more than 80 countries they represent over 200,000 dermatologists.

Finally, the International Psoriasis Council is a dermatology-led, voluntary, global, nonprofit organization with a network of more than 100 psoriasis experts, thought leaders, and professionals, dedicated to improving patient care around the globe.

# Our **Team**



Director Professor Chris Griffiths



Rebekah Swan



Professor Darren Ashcroft



Work Stream 2 Lead Professor Matthias Augustin



Dr Julia-Tatjana Maul



Research Associates Ireny Iskandar



Nirohshah Trialonis-Suthakharan

PhD Students Alex Trafford



Maha Abo-Tabik



Peslie Ng'ambi



Administrator Jade Kelly











IPC INTERNATIONAL PSORIASIS COLINICI

We believe that it is possible to understand the epidemiology of psoriasis in every country of the world. To help us achieve this, we work with a wide-ranging team of experts. We have a smart, passionate and caring team hard at work around the world.



Caroline Bach



ILDS Executive Director Joanna Groves



IFPA Executive Director Patrik Vuorio



IFPA Scientific Officer Sicily Mburu



Christy Langan



GPA Associates, Collaborators and Enthusiasts

Dermatologist, Manchester, UK Sidra Khan



Tina Tian



Director, Regional Dermatology Daudi Mavura

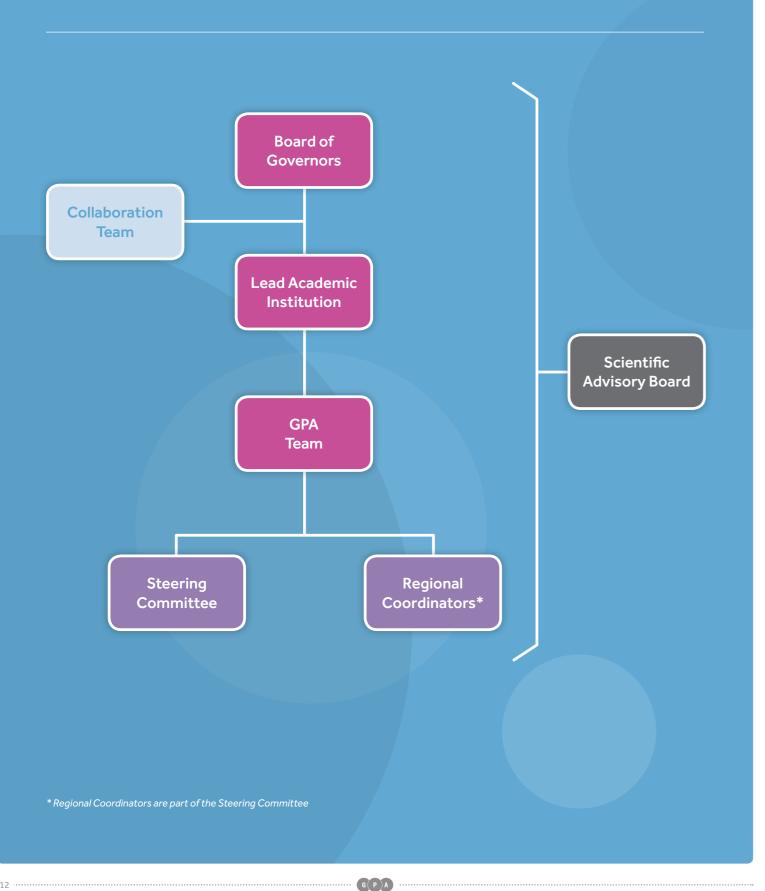


Dermatologist, Chile, Daniela Armiio



Doctor and Researcher, Chile, South America Cristóbal Lecaros

## Structure and Governance



## Governance and Leadership

**GPA Board of Governors** membership includes: the Presidents of the three Collaborating Organisations and other non-voting members. The Board of Governors is chaired by the ILDS President and is the project's highest decision making authority and has overall governance responsibility for the GPA project, including reviewing

and agreeing the annual GPA budget.

The Governors ensure that the GPA is kept abreast of emerging opportunities and overseeing risk mitigation protocols developed by the Steering Committee. In addition to biannual meetings, in Phase II quarterly teleconferences will also be held for the Board. The ILDS is responsible for the organisation of the Board meetings.

#### Scientific Advisory Board (SAB) will

be established in Phase II to provide international and independent scientific oversight of the work of the GPA and its Collaborating Organisations. The SAB will consist of up to five individuals, including the Chair. Expertise would include epidemiology; dermatology; health economics; global health and patient expertise. The GPA Programme Director, Research Director, Programme Manager and the Presidents of the Collaborating Organisations will conduct an annual video conference with the SAB.

Lead Academic Institution reports directly to the Board and provides updates on project progress to the Steering Committee at the time of the annual European Academy of Dermatology and Venereology Congress in the autumn and the annual meeting of the American Academy of Dermatology held in the spring.

#### **GPA Steering Committee** is

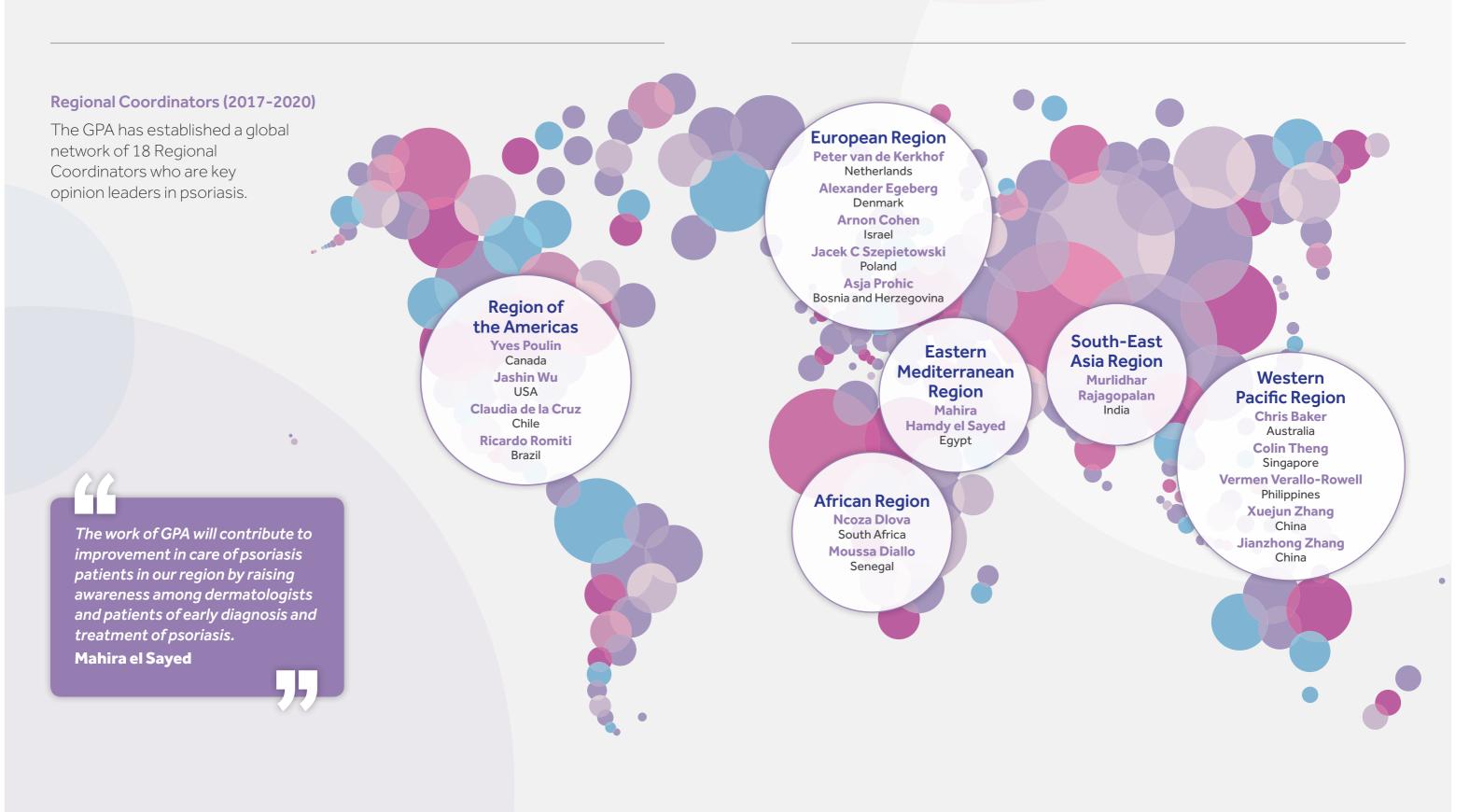
chaired by the GPA Director and is composed of a lead from each of the Collaborating Organisations along with the Project Executive Team comprising the GPA Research Director and GPA Programme Manager. The GPA Medical Coordinator and our 18 Regional Coordinators also sit on this group. The committee are responsible for oversight of significant decisions, emerging opportunities and risk mitigation. The GPA Programme Manager monitors progress and provides written reports generated by the research team to the committee. The Steering Committee reports to the Board of Governors. Meetings take place on two occasions each year: at the time of the annual European Academy of Dermatology and Venereology Congress in the autumn and the annual meeting of the American Academy of Dermatology held in the spring.

**GPA Team** provides overall project progress updates to the Steering Committee including, finance, communications and marketing and achievement of milestones. The team hold a monthly teleconference with collaborators outside The University of Manchester. team as well as internal face to face monthly meetings for the GPA staff and PhD students based at The University of Manchester.

**Collaboration Team** provides assistance to the Board of Governors through oversight of the GPA project progress. Members include executives and lead GPA staff from the Collaborating Organisations and the GPA Programme Manager. Weekly teleconferences are held to review the progress of the GPA and review partnerships, budget setting and support with marketing and communications.

Regional Coordinators are part of the Steering Committee and provide updates to the committee on work ongoing in their regions. They also communicate ideas and guestions to the Research Director and GPA team during the meeting. In addition, they are invited to provide updates in the GPA quarterly newsletter and to work with collaborators in their region to market and promote the GPA.

# Global Network, **Regional Approach**



GPA

# Regional Coordinator Spotlight

on the incidence of co-morbidities in

psoriasis will encourage governments

to recognise psoriasis as a disabling

What inspires you the most in your

The thing that inspires me most is

the patients and their stories. The

new era of biologic therapy has given

hope to many patients and being able

return them back to their normal life is

to clear the patients of disease and

disease worthy of allocating more

resources.

field of work?

beyond inspiring.

### **Mahira el Sayed**

#### What made you want to specialise in the field of psoriasis?

Psoriasis is a very common disease in Egypt affecting a wide range of patients of different ages and genders. It is an extremely debilitating disease and the ideal treatment is not always available so I took special interest in the disease over 15 years ago. I was lucky to join the International Psoriasis Council which motivated me even more to work with my patients.

#### How did you get involved in the **Global Psoriasis Atlas?**

I got involved with the Global Psoriasis Atlas through the International Psoriasis Council, which is a partner of the GPA, of which I have been a councillor and now proudly a board member.

#### How does your work contribute to the Global Psoriasis Atlas?

Working closely with psoriasis patients on a daily basis and recognising the burden they carry due to their disease will make me able to further contribute to the work of the GPA.

#### What are the challenges of psoriasis management in your country/region?

There are a lot of challenges facing us in the region in terms of the management of psoriasis patients, due to socio-economic and political factors. As a result, patients with moderate to severe psoriasis are undertreated and have significant disease burden. Patients are stigmatized which prevents them from seeking early treatment for fear of judgement. Lack of awareness among dermatologists and limited governmental funding contributes to the problem.

#### How will the work of the Global Psoriasis Atlas contribute to improvements in care for people with psoriasis in your country/region?

The work of the GPA will contribute to improvement in the care of psoriasis patients in our region by raising awareness among dermatologists and patients of early diagnosis and treatment of psoriasis. Also, focusing

**ESTIMATED** THOUSAND

### **Xuejun Zhang**

#### What made you want to specialise in the field of psoriasis?

As we all know, psoriasis is a serious global problem endangering human health. Currently, there are at least 60 million people with psoriasis in the world, and more than 2 million in China. Due to wrong diagnosis, untimely diagnosis, inappropriate treatment, inadequate medical care and social bias, many psoriasis patients suffer unnecessary pain. To promote the development of psoriasis prevention, treatment and improve the life quality of psoriasis patients in China, my work is focused in the field of psoriasis.

#### How did you get involved in the Global Psoriasis Atlas?

As a Regional Coordinator, I have publicised the campaign for the Global Psoriasis Atlas in China. I set up the Chinese Committee of the GPA. Then, I conducted the Psoriasis Healthcare Survey among dermatologists and patients. Now, I am organising the education program for patients and building an online questionnaire system.

#### How does your work contribute to the Global Psoriasis Atlas?

Until now, our group have finished the Psoriasis Healthcare Survey questionnaire among 1345 dermatologists and 460 psoriasis

patients in China. We have established the Chinese Committee of the GPA during Chinese Psoriasis Committee and selected 100 hospital dermatology clinics as GPA monitoring points. The online questionnaire system is under the debug phase.

#### What are the challenges of psoriasis management in your country/region?

Due to the COVID-19 pandemic, China is facing a number of challenges at present and as a result, our education programme for psoriasis has been affected. However, we have plans in place to change from a face to face educational model to an online model.

#### How will the work of the Global Psoriasis Atlas contribute to improvements in care for people with psoriasis in your country/region?

For psoriasis patients: this project helps me to gather Chinese dermatologists together and learn more about caring for psoriasis patients. It will teach them about psoriasis, make them understand how to relieve their patients' uncomfortable condition, reduce the recurrence rate of psoriasis, lighten the burden of medical expenses, improve their life quality and rebuild their self-confidence.



For dermatologists: they will get the latest epidemiological knowledge of psoriasis and treatment guidelines.

#### What inspires you the most in your field of work?

Public education is really important. It can significantly reduce the recurrence rate of psoriasis, improve their life quality and rebuild their self-confidence. Now, the short-term outcome of biologics is good for psoriasis, but the recurrence of the disease can be high. I plan to explore the mechanism of recurrence after using biologics.



### Regional Coordinator Spotlight



### Claudia de la Cruz

#### What made you want to specialise in the field of psoriasis?

My interest in psoriasis began at a very young age during my residency program when I saw a lot of children affected by the disease. I completed my thesis on this subject in order to get my degree in dermatology and took a special interest in the epidemiology of psoriasis for this age group. Psoriasis was my very first area of interest in dermatology and the focus of my attention at that time, as it is now. The treatment that patients receive often does not satisfy their needs and they see their whole life affected by the disease. The chance of relieving them of the burden caused by this disease was my primary reason to take interest in this area and to consider the new discoveries regarding their treatment. It was very exciting for me to investigate what was affecting their life quality using the available new information in medicine.

#### How did you get involved in the **Global Psoriasis Atlas?**

As a board member for the International Psoriasis Council. was working in research on access to therapy for psoriasis around the word and I had a lot of information to contribute, especially in my region. So, when I heard about the GPA project, I saw an opportunity to collaborate. This work will not only help Chile (which is the country I represent) but also the whole Latin American continent, encouraging better health policies based on the information discovered. During the process of coordinating for the region I have also worked with professor Ricardo Romiti from São Paulo, Brazil, trying to get as much information available to develop the Atlas.

#### How does your work contribute to the Global Psoriasis Atlas?

There is a lot of work ongoing in Latin America and, as there has been a lack of data available to conduct research. most countries do not have official numbers on the epidemiology of psoriasis. My work has mostly been based on creating this information in the field by recording patients' experiences in hospitals and also private health facilities. The major contribution to this work has been Dr Cristobal Lecaros, with whom we have recruited analysed data from about 9000 patients. Along with this, we have been supported by Dr Tatjana Maul from Switzerland and together we have created and applied a prospective questionnaire which by now has been completed by over 800 patients from Chile and Brazil and we expect to publish results by the end of the year.

#### What are the challenges of psoriasis management in your country/region?

Definitely the most relevant challenges for my country and region are to improve the access of patients to treatment in two ways: Firstly by educating general physicians, family physicians and dermatology physicians on psoriasis as a disease and also on its impact on life quality for the patients, as much as how it should be treated. Secondly, we need to improve the access to the treatments available for this disease. This is very difficult to achieve patients in Chile and the rest of South America, especially when it comes to systemic therapy which is not usually given by their doctors or financed by the health system.

#### How will the work of the Global Psoriasis Atlas contribute to improvements in care for people with psoriasis in your country/region?

I am confident that this work will improve the management of psoriasis in my country. We have always thought that the incidence was between 3-5%, but with this work we have discovered that is near to 1.7% of the population affected by this disease. This lowers the expected costs associated with systemic therapy in patients who need it, and health authorities may take action on this to improve access to treatment.

#### What inspires you the most in your field of work?

It is particularly rewarding for me to see the happiness of my patients and their families after they recieve appropriate treatment for this disease. Living with psoriasis should not lower a person's chances of achieving a good quality of life, and I am proud to contribute to ensuring that people with psoriasis receive the best possible treatment for their disease

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## **Research** Work Stream Progress

### **Work Stream 1 Progress**

I am pleased to report that we have completed all our milestones for Work Stream 1, and subsequently initiated new work to further extend our international research programme.

Two extensive systematic reviews have been completed: the first, the largest ever review examining the international data on the incidence and prevalence of psoriasis from population-based studies; and the second detailed systemic review examining the risks of developing or dying from cancer among people with psoriasis. These are important data resources that underpin the development of the Global Psoriasis Atlas which we also launched on World Psoriasis Day (29 October 2019).

We have continued to work closely with our GPA Regional Advisors to identify electronic health record data sources, and taken forward new studies examining the epidemiology of psoriasis. In November, we published new work reporting on time trends in the incidence and prevalence of psoriasis in Israel, in collaboration with Prof Arnon Cohen. We have initiated new studies in Chile and Taiwan too, and will be reporting on these new population-based study findings later this year.

Planning for further new research studies in other countries is well underway too. We have worked closely in partnership with the ILDS and received additional funding support from the UK Global Research Challenge that allowed us to spend time at the Regional Dermatology Training Centre in Moshi, Tanzania in July 2019 to better understand the healthcare systems and data collection methods throughout Sub-Saharan Africa. Building on this, we are now seeking additional support to take forward new research studies in Sub-Saharan Africa.

We are very grateful to all our international dermatology colleagues who completed our Delphi survey that we launched to establish consensus on clinical examination-based diagnostic criteria for psoriasis in adults. We reached consensus on 9 diagnostic criteria among the international panel, and are looking forward to reporting on all these new insights, and further developing the diagnostic criteria in validation studies with our international collaborators.

#### Professor Darren Ashcroft

The link between psoriasis and cancer

Beyond the high societal burden that psoriasis creates through its relatively high prevalence, the condition also enacts a significant burden on the individuals that it affects. Pain and discomfort may arise from plaque sites, whilst societal stigmatisation can often lead to mental and emotional detriment. These issues are often compounded by further comorbidities that have been shown to be associated with psoriasis. An increased risk of cardiovascular disease in people with psoriasis has been suggested in a number of studies, with a recent meta-analysis of 75 studies finding a 40% increased risk in people with psoriasis compared to those without the condition<sup>1</sup>. The association between psoriasis and metabolic syndrome, an overarching health state representing diabetes, hypertension and obesity, has similarly been explored through a meta-analysis, with a 226% increased risk reported<sup>2</sup>. Additional evidence has also suggested an association with psoriatic arthritis<sup>3</sup>, depression and anxiety<sup>4</sup>.

Cancer has similarly been explored as a potential comorbidity in psoriasis. However, the link remains unclear. Despite this lack of clarity, there are a number of plausible mechanisms for an association between psoriasis and cancer. Chronic inflammation plays a key role in the pathogenesis of psoriasis and has been suggested as potentially causing an increased cancer risk. Supporting evidence for this mechanism is provided through the increased cancer risk seen in other conditions involving chronic inflammation, such as Crohn's disease and Barrett's oesophagus<sup>5</sup>. Beyond chronic inflammation, it has also been posited that factors associated with psoriasis may lead to an increased risk of cancer. Indeed, smoking, alcohol consumption and obesity are all associated with psoriasis<sup>6</sup>. Given the independent association between these factors and cancer.

their increased prevalence in people with psoriasis may go some way to explaining an increase in risk. Finally, a number of studies have considered the role that certain therapies used in psoriasis treatment, particularly phototherapies and immunosuppressants, may play in any change in cancer risk. Understanding the risk of cancer in psoriasis, and especially the role that these potential mechanisms may play, remains complex and challenging.

#### Summary of results from a systematic review of psoriasis and cancer risk

As the Global Psoriasis Atlas progresses, one of the important aims is to understand the complex picture of comorbidities surrounding the condition. A key step in understanding the place that cancer holds in this picture is consolidating the information that is already available in the literature. This important step was achieved through the completion of systematic review and meta-analysis<sup>7</sup>, which not only identified all relevant studies on the topic, but also pooled estimates of cancer risk from these studies together in order to provide greater precision.

For the initial systematic review, six electronic databases (MEDLINE, Embase, MEDLINE in Process, Cochrane Central Register, Web of Science, and LILACS [Literatura Latino-Americana e do Caribe em Ciências da Saúde]) were searched from database inception to November 2017. In order to be considered eligible, studies were required to meet the following eligibility criteria: prospective or retrospective case-control or cohort study design; at least one study group of psoriasis patients; one comparison group consisting of non-psoriasis patients or the general population; and cancer incidence or mortality as an outcome. There were no restrictions by geography or language. The risk of bias and study quality was assessed using the Newcastle Ottawa Scale<sup>8</sup>.

Through database searching, 2830 records were identified. This number fell to 2302 once duplicates were removed. Articles were then screened through two stages: (1) title and abstract screening (2) full-text screening. A total of 2206 records were excluded through initial title and abstract screening, with common reasons for exclusion including randomised control trial study design, lack of an appropriate comparison group and case report study design. Of the 96 studies screened by full-text, 40 were excluded, with common reasons including: drug study with selected population; lack of direct comparison measure; and mortality study with no cancer-specific estimates. An additional 2 records were identified through hand-searching of reference lists. Following this screening process, a total of 58 studies were included in the systematic review, of which 50 considered cancer incidence and 15 considered cancer mortality.

Studies of cancer incidence were mostly conducted in North America (36%) or Europe (54%), with the remaining studies conducted in Taiwan (10%). Study setting was split between hospital (56%) and population (44%). There was variation in the ascertainment of covariates between studies, with 70% of studies not reporting smoking status, alcohol consumption or obesity. The quality of cancer incidence studies was mostly fair (58%), with high quality (26%) and low quality (16%) studies less numerous.

Studies of cancer mortality were similarly conducted across North America (20%), Europe (73%) and Taiwan (7%). Study setting was also split between hospital (67%) and population (33%). However, the proportion of studies not reporting smoking status, alcohol consumption and obesity (53%), was lower than was found in cancer incidence studies. Study quality was also different in studies of cancer mortality, with 53% of studies being high quality, 33% fair and only 14% low.

### **Work Stream 1 Progress**

#### **Risk of developing** or dying of cancer: A Meta-analysis

Using the studies identified through the systematic review, it was possible to conduct a meta-analysis by pooling estimates of cancer incidence and mortality risk in psoriasis. This pooling was achieved through a Der-Simonian-Laird random-effects model<sup>9</sup>, with effect estimates combined through the generic inverse variance approach. In order to provide a more nuanced understanding of cancer risk, studies were pooled according to the severity of psoriasis that was considered in their study population.

#### Cancer incidence

The risk of all cancer incidence was found to be elevated in studies that considered all psoriasis severities (18% increased risk) and studies that only considered severe psoriasis (22% increased risk). Although the risk was

slightly higher in studies of severe psoriasis, it was not significantly so. A number of site-specific cancers were also found to be associated with psoriasis, regardless of whether the study considered all psoriasis severities or just severe psoriasis, including: colorectal; kidney; laryngeal; liver; lymphoma; Non-Hodgkin lymphoma; keratinocyte cancers; oesophageal; oral cavity; and pancreatic cancer.

#### **Cancer mortality**

In contrast to cancer incidence, the risk of all cancer mortality was only found to be increased in studies of severe psoriasis (22% increased risk). Furthermore, due to the limited number of mortality studies, there was no opportunity to consider sitespecific cancer mortality in studies of all psoriasis severities. There were sufficient studies to consider a limited number of site-specific cancers in severe psoriasis, with an increased risk found for oesophageal, liver and pancreatic cancer.

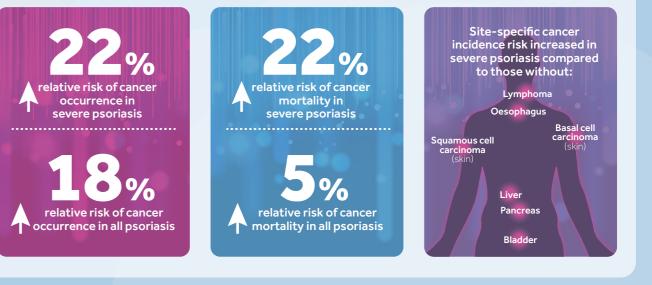
#### Further findings

Beyond the main findings of the meta-analysis, there are several other important considerations. Primarily, for a number of the pooled estimates of cancer incidence and mortality risk, there was high heterogeneity, potentially reflecting the lack of clarity in the association. Finally, additional stratification according to the covariates considered in the study, suggested that the risk of all cancer incidence was lower in studies that took smoking, alcohol consumption and obesity into account.

### Association of Psoriasis With the Risk of **Developing or Dying of Cancer:** A Systematic Review and Meta-analysis



#### Compared to those without psoriasis



- <sup>1.</sup> Miller IM, Ellervik C, Yazdanyar S, Jemec GB. Meta-analysis of psoriasis, cardiovascular disease, and associated risk factors. J Am Acad Dermatol, 2013;69(6):1014-24.
- <sup>2.</sup> Armstrong AW, Harskamp CT, Armstrong EJ. Psoriasis and metabolic syndrome: A systematic review and meta-analysis of observational studies. J Am Acad Dermatol. 2013.68(4).654-62
- <sup>3.</sup> Gelfand JM, Gladman DD, Mease PJ, Smith N, Margolis DJ, Nijsten T, et al. Epidemiology of psoriatic arthritis in the population of the United States. J Am Acad Dermatol. 2005;53(4):573.e1-.e13.
- <sup>4.</sup> Olivier C, Robert P, Daihung D, et al. The risk of depression, anxiety, and suicidality in patients with psoriasis: A populationbased cohort study. Arch Dermatol. 2010:146(8):891-5
- <sup>5.</sup> Coussens LM, Werb Z. Inflammation and cancer. Nature. 2002;420(6917):860-7.
- <sup>6.</sup> Guenther L, Gulliver W. Psoriasis comorbidities. J Cutan Med Surg. 2009;13(SUPPL. 2):S77-S87. <sup>7.</sup> Trafford AM, Parisi R, Kontopantelis E,
- Griffiths CEM, Ashcroft DM. Association of Psoriasis With the Risk of Developing or Dying of Cancer: A Systematic Review and Meta-analysis. JAMA Dermatology. 2019:155(12):1390-403.
- <sup>8.</sup> Wells G, Shea B, O'Connell J, Robertson J, et al. The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomised studies in meta-analysis. 2011. Available from: URL: http://www.ohri.ca/programs/ clinical\_epidemiology/oxford.asp.
- 9. Chapter 9: analysing data and undertaking meta-analyses. In: Deeks JJ, Higgins JPT, Altman DG; Cochrane Statistical Methods Group, eds. Cochrane Handbook for Systematic Reviews of Interventions. https:// handbook-5-1.cochrane.org/chapter\_9/9\_ analysing\_data\_and\_undertaking\_meta\_ analyses.htm. Published 2011. Accessed January 25, 2018.

### Work Stream 2 Progress

#### We are pleased to present the Work Stream 2 progress this year for the Global Psoriasis Atlas.

Work Stream 2 made great progress in completing the Latin American field study on psoriasis healthcare.

We have completed the field research on healthcare data and drug access for psoriasis in 18 Latin American countries: Dominican Republic, Venezuela, Mexico, Peru, Panama, Bolivia, Argentina, Brazil, Chile, Nicaragua, Colombia, Honduras, El Salvador, Costa Rica, Ecuador, Guatemala, Uruguay and Paraguay.

We are currently drafting the first version of the 'Psoriasis Healthcare and Facts in Latin America' booklet. The booklet summarises facts on healthcare, clinical facets, disease burden and drug use amongst others in Latin America. We would like to show our gratitude to Dr Julia-Tatjana Maul, Dr Maria Jose Valencia Lopez, GPA Regional Coordinator Dr Claudia de la Cruz (Chile) and Dr Ricardo Romiti (Brazil) and all the Latin American dermatologists' participants in the survey for their support and knowledge. We encourage dermatologists around the world to participate in the healthcare survey in order to gain a full understanding of psoriasis healthcare.

We are also updating our desk research on potential epidemiological data sources on psoriasis on the web. Potential data sources are updated from health ministries, national registries, NGO's, statistical/ public health and research institutes and claims data. In the next step, the data owners of each source will be individually contacted. Data sources will be reviewed for accessibility, methodologies and data quality. In parallel, a methodology is going to be developed to test whether data linkage between different data sets can be carried out on the basis of statistical modelling under the leadership of a statistician from the Hamburg team.

Work Stream 2 is currently developing a sampling strategy and submitted the ethical application to conduct the global explorative GPA PsoHealth survey on psoriasis treatment. The first steps of cooperation agreements with regional coordinators and dermatologists from GPA and internal institute networks are going to be initiated.

Professor Matthias Augustin

#### **Psoriasis treatment** in Latin America – **Drug availability**

We are pleased to report that, in addition to the exploratory healthcare study on psoriasis, we have also collected data on the availability of approved treatments for psoriasis and psoriatic arthritis. This survey was conducted from June to August 2019 using an online guestionnaire in 18 Latin American countries. To confirm the survey findings, we also examined publicly available data from pharmaceutical companies. In each country, a minimum of 4 and a maximum of 10 dermatology experts were recruited to report on the approved traditional systemic treatments, biologicals and biosimilars for psoriasis and psoriatic arthritis. Data on psoriasis and psoriatic arthritis for the following 13 countries are presented in this annual report: Argentina, Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Honduras, Guatemala, Mexico, Nicaragua, Peru and Paraguay.

#### Table 1. Non-biological drug approval in Latin America for psoriasis

	Acitretin	Cyclosporine	Fumaric acid esters	Leflunomid	Methotrexat	Tofacitinib	Others
Argentina	$\checkmark$	✓		✓	$\checkmark$		
Brazil	$\checkmark$	✓			$\checkmark$		
Chile		✓			1		
Colombia	1	1			1		
Costa Rica	1	✓		1	1	$\checkmark$	
Ecuador	1	✓			$\checkmark$		
El Salvador		1			1		
Honduras		✓		1	1	1	
Guatemala		✓		1	1		
Mexico		✓		1	1		
Nicaragua		$\checkmark$			$\checkmark$		
Peru	$\checkmark$	$\checkmark$			$\checkmark$		
Paraguay		1		✓	$\checkmark$		

#### Table 2. Non-biological drug approval in Latin America for psoriatic arthritis

	Acitretin	Cyclosporine	Leflunomid	Methotrexat	Tofacitinib	Others
Argentina		✓	1	1		
Brazil		$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
Chile		$\checkmark$		$\checkmark$		
Colombia			$\checkmark$			
Costa Rica	1	$\checkmark$	1	1	$\checkmark$	
Ecuador						
El Salvador		$\checkmark$		1		
Honduras		$\checkmark$	$\checkmark$	1	✓	
Guatemala		$\checkmark$	$\checkmark$	1	1	
Mexico				1	$\checkmark$	
Nicaragua		$\checkmark$		$\checkmark$		
Peru						
Paraguay			1	1		

One of the key findings of the guestionnaire is that Methotrexate and ciclosporin are licensed among the non-biological drugs for psoriasis and psoriatic arthritis in almost every surveyed country, while Fumaric acid esters and Dimethylfumarate are not approved in Latin America (table 1

and 2). Furthermore, 'Apremilast' is rarely available in Latin America except for Argentina, Mexico, and Costa Rica. A difference is observed in the accessibility of Acitretin for psoriasis and psoriatic arthritis. According to the findings, the drug is approved for psoriasis in six countries but not for

psoriatic arthritis, except in Costa Rica. Specifically, the facts must be considered that psoriatic arthritis is treated by rheumatologists as well, and possibly rheumatologists have access to this particular drug (M Abdulghani et al.).

### Work Stream 2 Progress

#### Table 3. Biological drug approval in Latin America for psoriasis

	Adalimumab	Certolizumab	Etanercept	Guselkumab	Infliximab	lxekizumab	Risankizumab	Secukinumab	Tildrakizumab	Ustekinumab	Others
Argentina	1	1	1	∕*	1	1		1		1	
Brazil	1		1		1			1		1	
Chile	1		1		1			1		1	
Colombia	1	1	1		1	1		1		1	
Costa Rica	1	1	1	~	1	1		1		1	
Ecuador	1							<i>✓</i>		1	
El Salvador	1							<i>✓</i>		1	
Honduras	1		✓		1			✓		1	
Guatemala	1		1		1			✓		1	
Mexico	1		$\checkmark$	✓	1	1		✓		1	
Nicaragua			1							1	
Peru	1		✓		1			✓		1	
Paraguay	1		1		1						

\*Guselkumab is recently approved in Argentina

Table 4. Biological drug approval in Latin America for psoriatic arthritis

	Adalimumab	Certolizumab	Etanercept	Infliximab	lxekizumab	Risankizumab	Secukinumab	Tildrakizumab	Ustekinumab	Others
Argentina	1	<i>√</i>	✓	<i>√</i>	<i>√</i>		<i>√</i>		<i>√</i>	
Brazil	1		1	$\checkmark$			$\checkmark$		~	
Chile	1		1	1			1		<ul> <li>✓</li> </ul>	
Colombia	1	✓	1	$\checkmark$	1		1		✓	
Costa Rica	1	<i>✓</i>	1	1	1		1		1	
Ecuador										
El Salvador	1						1		1	
Honduras	1		1	1			1		1	
Guatemala	1		1	1			1		1	
Mexico			1		1		✓			
Nicaragua			1						~	
Peru										
Paraguay	1		$\checkmark$	✓						

Biological drugs are available and licensed for both psoriasis and psoriatic arthritis and follow more or less the same trend of availability (table 3 and 4). The most commonly licensed drugs are Adalimumab, Etanercept, Infliximab, Secumkinumab, and Ustekinumab. However, Abatacept, Brodalumab and Tildrakizumab are not approved in the surveyed countries. Guselkumab was recently approved in Argentina

(February, 2020). Furthermore, Costa Rica's report showed that most biologics for psoriasis are authorised including Certolizumab, Golimumab, Guselkumab and, Ixekizumab.

# PhD Progress

### Maha Abo-Tabik

The aim of my work has been to develop a clinical examination-based diagnostic tool for chronic plaque psoriasis in adults (age 18 years and above).

The development of this tool provided the basis for my PhD project entitled "Examining the epidemiology of psoriasis".

A three-step international electronic Delphi (e-Delphi) consensus method was used to establish the diagnostic tool. The consensus process took place between January 2019 and August 2019. The research methodology and initial results were presented at the University of Manchester postgraduate summer showcase, 2019.

The expert agreed diagnostic criteria for chronic plaque psoriasis would be valuable to standardise practice, to assist non-dermatologists in making a correct diagnosis and to regulate case definition in future epidemiological studies into psoriasis.

The final results of the e-Delphi exercise have been accepted for a poster presentation at the 100th Annual Meeting of the British Association of Dermatologists in July 2020.

The first challenge I faced with my work was the scarcity of highguality published research related to the clinical diagnosis of psoriasis. Previously, there have been many attempts to build diagnostic tools for psoriasis including genetic and molecular tests, histopathology, skin imaging (using dermoscopy

or video-dermoscopy), computer or questionnaire-based tests and traditional Chinese medicine diagnostic criteria. However, the diagnostic accuracy of these criteria varied widely across different categories, and most of the proposed diagnostic approaches did not undergo proper validation.

We tackled this problem in two ways; firstly, by conducting a detailed review of literature targeting all studies with a primary aim to make a clinical diagnosis of psoriasis. From this literature, we identified all possible diagnostic items that could serve as proposed clinical criteria for our diagnostic tool.

Secondly, by using the Delphi technique as the study methodology. The Delphi method has been widely used to answer a research question that required experts input from the clinical community as these data were not available in the existing literature.

Another challenge was the international involvement of experts in the study. However, the geographic limitation has been overcome again by our research methodology using an electronic approach (e-Delphi technique).

Fifty expert dermatologists from 27 countries took part in this consensus exercise and this covered six regions of the world, giving the study a fair global involvement.

We targeted expert dermatologist with specialist clinical and research experience in the diagnosis and management of psoriasis. The study participants were members of the International Psoriasis Council (IPC) and the Global Psoriasis Atlas (GPA), which adds further credibility to the research output.





Upon completion of the ongoing projects, we will hopefully have a validated, standardised approach for the clinical diagnosis of chronic plaque psoriasis in adults and a better understanding of the factors associated with earlier diagnosis of psoriasis in the healthcare setting.

I am currently working on two projects in parallel. The first one is a case-control study to identify missed opportunities for earlier diagnosis of psoriasis in primary healthcare settings using the Clinical Practice Research Datalink (CPRD). In this study we will look retrospectively into patients' records to identify possible health care events such as misdiagnosis, treatment, referrals and hospital admissions that could serve as an indicator for a missed opportunity for earlier diagnosis of psoriasis.

The second project is a validation study for the results of the e-Delphi exercise. We aim to conduct an international. multicentre, diagnostic accuracy study during the upcoming year.

Upon completion of the ongoing projects, we will hopefully have a validated, standardised approach for the clinical diagnosis of chronic plaque psoriasis in adults and a better understanding of the factors associated with earlier diagnosis of psoriasis in the healthcare setting.

#### PhD Progress



### **Alex Trafford**

In the last year, the main focus of my PhD has been completing my first piece of empirical work, a systematic review and meta-analysis, and publishing these findings.

In order to complete this work, I first spent several weeks searching through scientific literature for previous papers looking at the association between psoriasis and cancer. Once I had identified all the relevant studies. I then combined their estimates in order to summarize our current understanding of cancer risk in psoriasis. Studies that provided estimates of cancer risk according to psoriasis severity were combined separately so that we were able to better understand how differing psoriasis severity may alter risk. Preliminary results of cancer incidence in psoriasis were presented as a poster at the 2019 British Association of Dermatologists Annual Meeting in Liverpool. Following this, in October, the full results of this work were published in JAMA Dermatology, with following media interest from publications including the New York Times and Newsweek.

With the completion and publication of the meta-analysis, I then moved on to a primary analysis of cancer risk in psoriasis using UK primary care (GP), secondary care (Hospital) and mortality data. This work is multifaceted and ongoing. The first step has been to assess how cancer cases are recorded across our databases to ensure that our results are accurate. Following this, the number of cancer occurrences in people with psoriasis

has been compared to the number of cancer occurrences in people without psoriasis, in order to understand if there is any difference in risk. In ongoing work, the role of other factors, such as psoriasis severity, smoking, alcohol consumption and obesity, in any difference in risk will also be explored. A combination of results from the meta-analysis and the first stage of this their potential role in the link between ongoing work was presented as part of a poster at the Division of Pharmacy and Optometry Showcase at the University of Manchester and won the third-place prize.

The most considerable challenge in my work remains the difficulty in establishing the true nature of the relationship between psoriasis and cancer. Although our meta-analysis reported an increased risk of cancer in people with psoriasis, there was also notable variation in estimates of cancer risk from different studies. This variation reduces the strength of our understanding. Furthermore, there is still a lack of clarity surrounding the mechanisms by which psoriasis influences cancer risk. Whilst stratification according to whether studies took factors such as smoking and obesity into account in our metaanalysis suggested that these factors may play a role in increased cancer risk, they did not appear to explain all of the increase in risk. Understanding the complex mechanisms underlying the link between psoriasis and cancer therefore remains a significant and important challenge.

There are a number of ways in which these challenges have been addressed and continue to be addressed. In the meta-analysis of cancer risk in psoriasis, studies were grouped according to the severity of psoriasis

that they considered in order to understand whether this factor played a role in any difference in risk. Additionally, studies were analysed according to whether they took smoking status, alcohol consumption and obesity into account. Stratifying analysis according to these factors has helped to give an initial insight into psoriasis and cancer. In our ongoing primary analysis, we are focussing on ascertaining smoking status, alcohol consumption and obesity levels in order to provide further understanding into the roles of these factors.

The completion of these works will hopefully improve our understanding of the association between psoriasis and cancer, and pave the way for improved patient care.

In the next 12 months I hope to finalise our current work on cancer recording and cancer risk in people with psoriasis using UK databases. The completion of these works will hopefully improve our understanding of the association between psoriasis and cancer, and pave the way for improved patient care. I also hope to synthesize the work completed over the last three years and complete my PhD.

### Peslie Ng'ambi

During 2019 and 2020, my main focus was to understand the current evidence and identify the gaps in the published literature on the economic impact of psoriasis.

My first meta-review was conducted with the aim of understanding the current scale and scope of the evidence base reporting estimates of the economic impact of psoriasis. Methods used to generate the economic impact of psoriasis were also scrutinised. The meta-review was conducted in order to understand how my PhD could contribute to the existing body of knowledge. All the systematic reviews reiterated the considerable economic impact that psoriasis exerts on the individual and society. The economic impact of psoriasis has been noted to be similar or higher than other noncommunicable diseases such as pancreatic cancer, melanoma, prostate cancer and asthma. However, there was a high degree of heterogeneity in the studies reporting the economic impact of psoriasis. The identified heterogeneity motivated my second review aimed at identifying, and if necessary, developing a descriptive framework defining a nomenclature system for the relevant components and methods when identifying and quantifying the economic impact of disease. This was because the current existing reviews showed a limited scale and scope. Furthermore, there was no systematic way of understanding the existing published estimates of the economic impact.

All the systematic reviews reiterated the considerable economic impact that psoriasis exerts on the individual and society.

This review produced a framework to enable the design and reporting of studies that identify, measure and value the economic impact of disease. This was the first necessary step towards improving consistency and coherence in understanding published estimates of cost of illness and burden of disease. The developed framework was shared with academic experts in health experts for their expert opinion and validation. This then led to the own going systematic review on the cost of illness and burden of disease of psoriasis with the aim of identifying and critically appraising published studies that report values for the economic impact of psoriasis.

Findings from these reviews have been presented at a number of conferences, the most recent being an abstract at the ISPOR Europe 2019, Copenhagen. This conference was attended by 5500 people from 90 countries. ISPOR is the largest professional society for health economics and outcomes research.

During the past year, I have attended a number of useful courses which included Alternative Economic Assessment for Expressing Healthcare Value and Informing Resource Allocation Decisions. This course offered knowledge of alternative methodological frameworks for economic assessment and examined fiscal health modelling (FHM) which reflects the government perspective on population health and investments in medical technologies. This is important in establishing the economic impact of disease. I also attended a course on Budget Impact Analysis (BIA) which described the methods used to estimate the budget impact of a new health care technology and presented six basic steps for estimating budget



impact: 1) estimating the target population; 2) selecting a time horizon; 3) identifying current and projected treatment mix; 4) estimating current and future drug costs; 5) estimating change in disease-related costs; and 6) estimating and presenting changes in annual budget impact and health outcomes.

Following the breakdown of economic impact into two groups (Cost of Illness and Burden of Disease), future work will be centred on cost of illness. This research study will focus on the adult population (18 years and above) with plaque psoriasis. In addition, the empirical research will be restricted to selected case countries which will include the UK. For the UK, we are currently exploring using the Hospital Episode Statistics (HES) database. The HES is a database containing details of all admissions, A and E attendances and outpatient appointments at NHS hospitals in England. Therefore, the project will focus on people with psoriasis being treated in hospital and hence likely to have more severe psoriasis. There is also the potential of linking the HES dataset to the Patient-Reported Outcome Measures (PROMS) dataset. The PROMS dataset is only available in people who have had specific interventions but contains EQ5D data, so may allow some calculation of burden of disease albeit in a limited sample of people with psoriasis. The final country selection will be in liaison with the GPA Regional Coordinators and will take into consideration the feasibility and all other relevant practical issues.

## Introducing Our **Medical Coordinator**

### **Dr Julia-Tatjana Maul**

Dr Julia-Tatjana Maul, a board-qualified dermatologist and senior physician from the University Hospital of Zürich, Switzerland, was appointed as the Medical Coordinator of the Global Psoriasis Atlas (GPA).

She was invited to take up the position by Professor Griffiths at the GPA Steering Committee meeting held at the European Academy of Dermatology and Venereology in October 2019. Dr Maul was awarded an International Psoriasis Council (IPC) fellowship for the year 2020 which allowed her to continue her work on epidemiological data collection that she began in Latin America in 2018 on behalf of the GPA. Furthermore, part of her role as Medical Coordinator is to coordinate and connect the GPA Regional Coordinators around the world and thereby foster psoriasis research on an international scale.

On behalf of the GPA, the goal of her research trip to Latin America was to further map psoriasis on a local and regional level and to gain a better understanding of the common psoriasis characteristics, its severity, frequency of comorbidities and available treatment options. Furthermore, her research focuses on the differences between quality of life and influence of the level of education on the treatment response and also takes account of gender and ethnicity.

As epidemiological data and treatment registries are limited or non-existent in most of the Latin American countries. Dr Maul generated her own questionnaire with the aim of collecting prospective and retrospective data. Together with the collaborating sites in Chile and Brazil, she conducted the survey to address the limited data available. This led to an extension of the collaborative work conducted in 2018.

The survey is based on the Swiss Dermatology Network for Targeted Therapies (SDNTT) and other European registers (such as BADBIR and PsoBest) in order to allow a comparison of Latin America with Europe. The goal of the survey was to compare the data across regions and countries with data from previously conducted studies. The project aims to enable psoriasis patients to access the best available treatment and to better understand the true disease burden of psoriasis and will contribute to the further development of the Global Psoriasis Atlas.

Dr Maul was inspired to start the project following her first research field trip to Latin America in 2018 when she ascertained that people with psoriasis in the region lack access to systemic and biologic therapies.

During January and February 2020, Dr Maul visited more than 35 hospitals, clinics and private practices in Chile and Brazil. Together with Professor Griffiths, the Director of the GPA, Dr Maul started the Latin American research project in Santiago de Chile, Chile, and visited Dr Claudia de la Cruz, GPA Regional Coordinator for Latin America. Professor Griffiths and Dr Maul consulted together with Dr Claudia de la Cruz and Dr Daniela Armijo in multiple clinics and hospitals around central Chile. Furthermore, Dr Maul continued to investigate and research psoriasis by collecting reallife data with all of these centres.

Dr Maul continued her research in São Paulo, where she worked closely with Professor Ricardo Romiti, GPA Regional Coordinator. During her trip,







Dr Maul gave lectures to present her research, the GPA, and widely promoted the work of the GPA in the region. Dr Maul is very grateful for the engagement and assistance received by the GPA Regional Coordinators,

I am really happy to be a part of this second Latin American GPA project which would not have been possible nor successful without the great help of the GPA team, especially Professor Griffiths, Rebekah Swan, Dr Claudia de la Cruz, Professor Ricardo Romiti and the open arms and the warm welcome of the Latin American colleagues helping to conduct this study. With this humanistic project and the extended collaboration with so many sites, we build the foundation to improve psoriasis care in Latin America. For me, this is an excellent basis for future projects. I am really looking forward to returning soon. Dr Julia-Tatjana Maul

Dr Claudia de la Cruz and Dr Ricardo Romiti, and dermatology specialists throughout Latin America. Without their support, this research work would not have been possible. Furthermore, Dr. Maul is also thankful for the involvement of Dr Valenzuela. Professor Cabrera, Dr Riveros, Dr Hevia, Professor Vera Nuevo, Dr Amijo and Dr Pizarro from Chile and Dr Cavalho, Dr Rocha, Dr Galvão, Dr Barboza da Silva, Dr Bortoletto, Dr Keiko and Dr Follador from Brazil who included a lot of patients. By the end of February 2020, more than 800

#### Dr Maul would like to the thank the following hospitals and clinics for their kind collaboration:

- University Hospital of Chile
- Clínica Alemana and the private practice
- Clinica Dermacross in Santiago de Chile
- Hospital San Juan de Dios
- Hospital San Esteban in Los Andes
- Hospital Clinico Fuerza Aerea de Chile The Military Hospital
- The Catholic University Hospital Centro International de Estudios Clinicos
- Clinica Las Condes

- Hospital Dr. Sótero Del Río The DermaMed practice in Santiago de Chile
  - University Hospital of Osorno
  - Clínica Alemana in Osorno
  - University Hospital Valparaíso
  - Medical SkinCenter in Valparaíso

São Paulo

Private Practice

- Hospital Curacavi
  - Universitario Saude ABC in São Bernardo do Campo • Hospital da Clinicas University of

GPA

patients had been included in the surveys in Chile and Brazil which is a significant achievement.

Dr Maul's research suggests that there are regional differences in the availability of psoriatic treatment and burden of disease in Latin America. To validate this, all datasets need to be analysed after the data cutoff (end of March 2020). Further research is required to increase our understanding of psoriasis in Latin America and, ultimately, to improve the life of psoriasis patients on a global scale.

- Institute of Bahia. Centro
- Hospital Conde de Lara
- Hospital AME Maurice Pate,

- University of Unicamp in Campinas Hospital Universitario Polydoro Ernani de São Thiago
- The Teledermatology Center in Florianopolis
- Salvador Department of Dermatology of the University Hospital
- Professor Edgar Santos, Federal University of Bahia
- The Immunotherapy institute of Bahia
- Centro Universitario Saude ABC in São Bernado do Campo

## Global Collaboration: Tanzania

The UK government provided £1.5 billion to support projects in developing countries. A portion of this money was devolved to The University of Manchester from the Global Challenges Research Fund (GCRF).

As part of a systematic review led by Professor Darren Ashcroft, the GPA research team identified a shortage of epidemiological information on psoriasis in Sub-Saharan Africa. The team secured a grant from the GCRF of almost £40,000 to run a workshop and undertake a pilot survey on psoriasis epidemiology in Tanzania.

The workshop and survey were based at the Regional Dermatology Training Centre (RDTC) in Moshi, Tanzania. The RDTC is a supra-regional training, research and clinical centre. It provides care to dermatological

This kind of engagement and outreach work is a clear part of the strategy and future direction of the GPA. Working with the team at the RDTC has laid solid foundations for future collaboration. **Professor Chris Griffiths** 

patients and training to Medical Assistants and Clinical Officers. The GPA team, led by GPA Director Professor Griffiths and Programme Manager Rebekah Swan, were based at the RDTC from 7-12 July 2019. The team included Professor Darren Ashcroft (Manchester University), Professor Ncoza Dlova (GPA Regional Coordinator, South Africa), and Manchester University dermatology trainees Dr Sidra Khan and Dr Tina Tian. In addition to the Manchester team, Nirohshah Trialonis Suthakharan (Researcher, GPA Work Stream 2) and Kathryn Hampton from Janssen participated in the trip. Dr Daudi Mavura, RDTC Director and Co-PI on the GCRF grant, worked with Dr Rune Philemon, Research Coordinator, and supported the team throughout their visit.





The purpose of the trip was to work with RDTC staff and dermatology specialists from across the Sub-Saharan region to conduct a workshop, two pilot field surveys and to learn more about access to care for patients with psoriasis in Tanzania.

Dr Mavura arranged for the team to review 21 psoriasis patients invited to attend a follow-up appointment for their psoriasis management. Many of the patients had travelled long distances, some up to 1,200km, for their review in the clinic in Moshi. The GPA team were able to gain an understanding of the case presentation, medical



history, diagnosis, comorbidities and treatments available to the patients. With a population of 57 million but only 31 dermatologists, access to specialist care in Tanzania is limited. Treatments for psoriasis in Tanzania are prohibitively expensive and so patients tend to opt for cheaper, over-the-counter, products. Patients often receive their diagnosis and treatment from non-specialist healthcare workers, who in many cases misdiagnose psoriasis as a fungal infection. Topical therapies are mainly coal tar, salicylic acid preparations and betamethasone valerate. The only systemic therapy in use is methotrexate. Treatment is invariably intermittent because of the difficulties in travelling which limits follow up and continuity of care. It was the team's impression, on this admittedly small subset of patients, that psoriasis was less severe in Tanzania than in the UK, with fewer co-morbidities.

The team conducted a training workshop for the dermatology specialists, staff and students from the region. This included presentations on the GPA and case studies on psoriasis management from the UK, South Africa and Tanzania. Professor Darren Ashcroft presented on the epidemiology of psoriasis, including the GPA systematic review of psoriasis prevalence and incidence. He also led group work to discuss the development of research methods for future epidemiological studies of psoriasis in the region.

The trip culminated with the team conducting a pilot survey of skin disease, with a particular emphasis on psoriasis, to gather information on the prevalence of the condition in two different locations. On 10 July, the team travelled to a church at Sanya Station, in Maasai Land and on 11 July to a school at Usa River. They saw more than 200 people with a variety of skin diseases but not one of them had psoriasis. Common dermatoses seen included tinea capitis, pityriasis versicolor, late onset eczema and skin trauma. It was concluded that the prevalence of psoriasis may well be close to the estimate for the country of less than 1%.

It is anticipated that the GPA team will utilise the methodological knowledge and networking gained during the





trip to design future research studies not just in Tanzania but in other countries in the region. The planned studies in countries where data on the epidemiology of psoriasis are scarce will help us to understand the burden of psoriasis in the region. Ultimately, this will ensure that all psoriasis patients in those countries will have access to the best available care, which is a key goal of the World Health Organization (WHO).

Successfully securing the GCRF grant has placed us in a strong position to pursue further grant funding in the future. We would like to thank Dr Daudi Mavura and the team at the RDTC for their collaboration on this project. We are particularly grateful for their warmth and hospitality. This trip has laid solid foundations for future collaboration.



# Success Factors for the GPA Programme

The conduct of our studies. validation of our tools and the generation of new epidemiological data on psoriasis are key to our success.

Short-term success will be measured by the publication of our results in leading scientific journals, the citation of those publications and international recognition.

Furthermore, the longer-term success of the GPA relates directly to our mission, 'To ensure that people with psoriasis, wherever they live in the world, have access to the best available care.' The findings from our research will be used to inform clinical guidelines on the diagnosis and management of psoriasis, help address the impact of other co-morbidities, and plan for new services and treatment pathways based on improved knowledge on the epidemiology and economic impact of psoriasis. The key to this success is the strength of our extensive network of psoriasis patient organisations and dermatologists supported by the global reach of our Collaborating Organisations and the WHO. Long-term success will ultimately be determined by the translation of our results into impact on the early diagnosis, and management of people with psoriasis around the world.



People with psoriasis around the world deserve the best available care wherever they live. To date, we only have epidemiological data for 19% of countries. This means that we also lack information on the care available to them. We are determined to change that.

# GPA: Phase II 2020-2023

The next three-year phase of the GPA, which is a longterm iterative initiative, is to build on the strong foundations laid in Phase I.

We will continue with the same operating structure strengthened by: the appointment of Professor Ashcroft as Research Director and Dr Tatjana Maul (Zurich) as Medical Coordinator: and the appointment of a Scientific Advisory Board to provide additional external independent oversight.

Our research programme (2020-2023) will address existing knowledge gaps on: Epidemiology; Improving Diagnosis; Comorbid Disease; and the Economic Impact of Psoriasis. Addressing these key areas and how they differ from country to country and region to region will enable us to provide robust data as we move to implement better access to care for psoriasis patients worldwide.

#### **Epidemiology of psoriasis**

- 1. Implement regular updates to our large international dataset.
- 2. Collaborate with the dermatology workstream of the Global Burden of Disease
- 3. Provide recommendations on the core data to be included in future epidemiological studies of psoriasis.
- 4. Conduct new epidemiological studies in selected countries.

#### Improving the early diagnosis of psoriasis

- 5. Conduct a case-control study to examine the extent of misdiagnosis of psoriasis.
- 6. Conduct validation studies of our recently developed clinical diagnostic criteria.

#### The Scope of the GPA: Phase II

#### **CALL TO ACTION**

In 2014 WHO recognized psoriasis as a major global challenge and requested high quality epidemiological data to understand the burden of disease.

### **UNMET NEEDS**

Many unmet needs in understanding psoriasis: prevalence and incidence, diagnosis, disease mechanisms, treatment options, comorbidity, education, awareness, recognition socio-economic impact

The scope of the research programme for the GPA responds to the World Health Organization's call to fill global knowledge gaps for this serious non-communicable disease.

#### **Recognising the comorbid** disease burden of psoriasis

7. Conduct new studies to improve knowledge about the comorbid disease burden of psoriasis with a particular focus on cancer incidence and associated mortality.

#### **Understand and** characterise the economic impact of psoriasis

- 8. Conduct and publish an extensive systematic review on the economic burden of psoriasis.
- 9. Develop data collection tools to determine the economic impact of psoriasis.
- 10. Conduct new studies to identify, and then quantify, the use of healthcare resources, and associated costs to the healthcare system.

#### **GPA FOCUS**

 Epidemiology Early diagnosis Comorbid disease burden • Economic impact

# **Highlights** 2017-2020

Phase I of the GPA achieved significant success, including the conduct of high-quality research, associated publications and presentations at scientific meetings and not least, the outstanding and ever-increasing number of collaborations with patient organisations, dermatologists and academics from around the world.



The development of a global network of enthusiastic regional and national coordinators



An updated systematic review of the worldwide prevalence of psoriasis revealing data for 19% of the countries of the world



Leveraging of external industry and non-industry funding

Global research collaborations: Denmark, Israel and Taiwan



Healthcare data for psoriasis management from Latin America



Development of new diagnostic criteria for psoriasis



A corporate operational and governance infrastructure



Quarterly newsletter publication



The Atlas has achieved all of its set milestones for 2017-2020 and has established itself as a recognisable and respected brand presence around the world. This is only the start.

# Outreach

American Academy of Dermatology, Washington DC, March 2019

We held our GPA Board, Steering Committee and Funders meetings, presented updates on our research and website development.

Chile, <u>January </u>2020

Professor Griffiths and his team consulted in multiple clinics and hospitals around central Chile to gain further insights on a local and regional level. Dr Tatjana Maul continued to travel through Latin America working with our GPA Regional Coordinators, Dr Claudia de la Cruz and Professor Ricardo Romiti.

IFPA Side Event to the United Nations High Level Meeting on Universal Health Coverage, New York, September 2019

GPA Programme Manager, Rebekah Swan, was invited to attend this event focused on health workforce and non-communicable disease management.

GPA

#### LEO Foundation, Copenhagen, May 2019 and Manchester, October 2019

The GPA team met with the LEO Foundation to report on progress to date and outline plans for the GPA.

#### 24th World Congress of Dermatology, Milan, June 2019

During this congress, we released the video campaign for our new website as well as holding a press conference which were both well received. We also met with our Regional Coordinators with presentations from our work streams.

6th Congress of the Skin Inflammation and Psoriasis International Network, Paris, April 2019

We attended SPIN with the International Psoriasis Council team to promote the GPA, meet our industry partners and showcase our second annual report.

#### IFPAs General Assembly, Barcelona, July 2019

Patient representatives from IFPA were invited to participate in video interviews to recount their experiences of living with psoriasis. These stories were shared on the GPA website.

#### 28th Congress of the European Academy of Dermatology and Venereology, Madrid, October 2019

We held the GPA Board, Steering Committee and Industry Partners' meetings and the team even met up with our friends from the Regional Dermatology Training Centre! Janssen kindly supplied videography services for our Shout Outs about the Atlas and more in-depth interviews.

# News 2019-2020



#### Thank you to **Dr Rosa Parisi**

The GPA team would like to give a special thank you to Dr Rosa Parisi for her hard work and dedication in completing the largest ever systematic review on the prevalence of psoriasis (Parisi R, Iskandar IY, Kontopantelis E, Augustin M, Griffiths CEM, Ashcroft DM. Global, regional and countryspecific prevalence of psoriasis: a Bayesian meta-regression of population-based studies). This paper will be published in the British Medical Journal in the coming months. Rosa secured a promotion at The University of Manchester and we wish her success in her new role.

#### **Story interviews**

GPA Programme Manager, Rebekah Swan, was invited to attend the International Federation of Psoriasis Associations' (IFPA) General Assembly, July 4th-6th, in Barcelona accompanied by our digital agency, Dept. The purpose of the trip was to obtain stories from people with psoriasis from around the world. Patient representatives from IFPA were invited to participate in video interviews to

recount their experiences of living with psoriasis. During these interviews, participants were asked about their experience of stigmatisation, misdiagnosis, impact on work, relationships, experience of flare ups, treatment options and physical and psychological impact. The videos are available to view on our website, launched on World Psoriasis Day, 29th October 2019. We would like to thank IFPA for their support with this work.



#### Website Launch

On World Psoriasis Day, 29th October 2019, we launched the Global Psoriasis Atlas website. Years of hard work culminated in the launch of the atlas. The website contains the data from the systematic analysis and modeling study and stories told by people with psoriasis from around the world.



#### LEO Foundation Meeting, Manchester

The GPA team, including Caroline Bach (ILDS Project Manager), met with the LEO Foundation team in Manchester on 29th October 2019, World Psoriasis Day. This was an opportunity to share the progress of the GPA, the website launch and to hear presentations from the PhD students working on the project at the University of Manchester. It was a privilege to host the LEO Foundation and to share our plans for the future of the GPA.

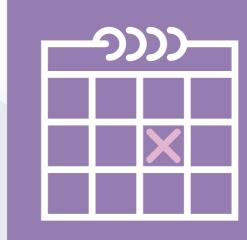
We are grateful to the LEO Foundation for their funding support during Phase I (2017-2020) and are delighted they will continue as the Lead Supporter of the GPA during Phase II (2020-2023).

#### **EADV Shout-outs**

During the EADV Congress 2019, Janssen kindly supplied videography services for our Shout Outs about the Atlas and more in-depth interviews with members of the GPA team.







### Dates for the diary

The GPA Board of Governors and Steering Committee will meet during the 79th American Academy of Dermatology (San Francisco, California)



#### Appointments

#### **GPA** Medical Coordinator

The GPA team would like to welcome Dr Tatjana Maul to the team. Dr Maul was invited to take on the role of Medical Coordinator in order to strengthen our collaborations with dermatology specialists around the world.

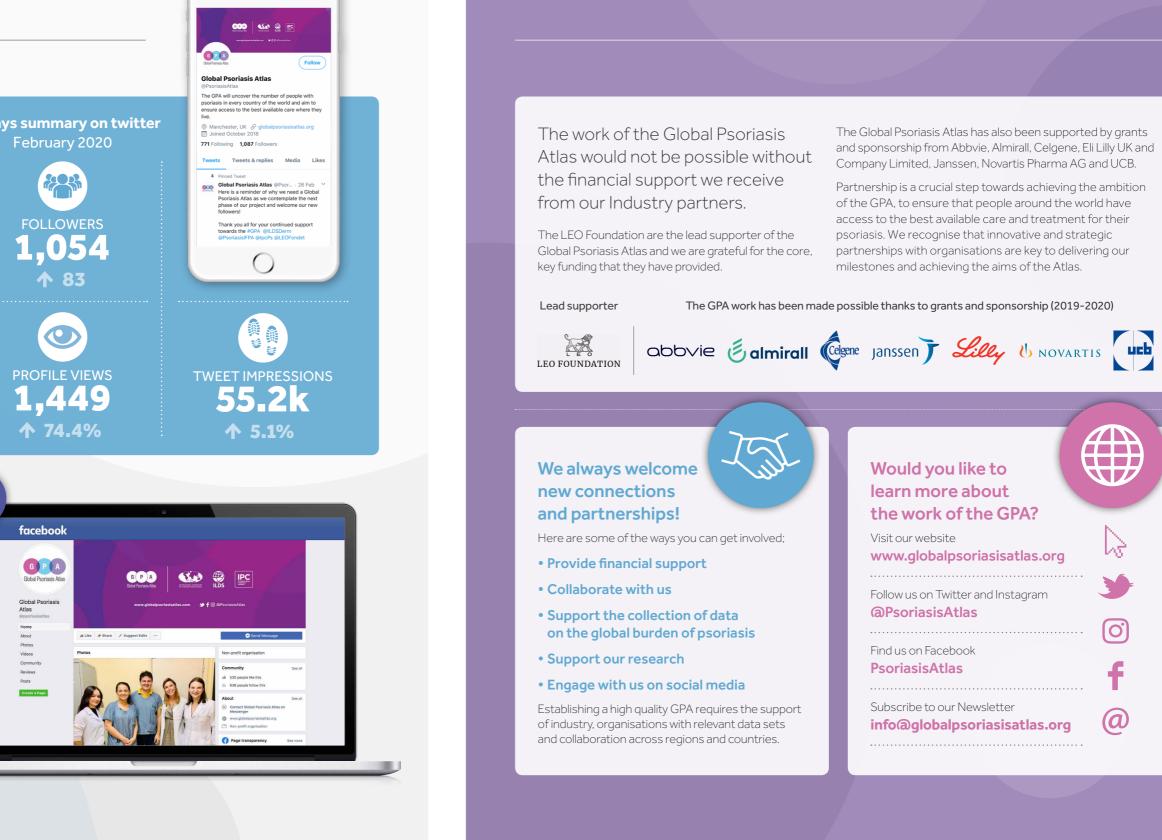
#### **GPA Director of Research**

Professor Darren Ashcroft has been appointed to this new role and is responsible for driving the direction of the research undertaken by the GPA team and our collaborations around the world.

#### 28th-1st November 2020

The GPA Board of Governors and Steering Committee will meet during the 29th Congress of the European Academy of Dermatology and Venereology (Vienna, Austria)

#### 19th-23rd March 2021



Following the successful launch of our social media channels, we are continuing to see growing engagement with the GPA online.

Social Growth

Working with the collaborating organisations we have developed a coordinated social media strategy for the project. This has been achieved by streamlining all time lines and events across our three collaborating organisations and the GPA into one social media content calendar.

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GPA

28 days summary on twitter

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# Engagement

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the work of the GPA?	
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## Publications, Abstracts and Presentations

#### **Scientific Publications**

Parisi R, Iskandar IY, Kontopantelis E, Augustin M, Griffiths CEM, Ashcroft DM. National, regional and worldwide estimates of the epidemiology of psoriasis: A systematic analysis and modelling study. British Medical Journal 2020; in press.

Iskandar I.Y.K, Parisi R, Griffiths C.E.M, Ashcroft D.M. Systematic review examining changes over time and variation in the incidence and prevalence of psoriasis by age and gender. British Journal of Dermatology 2020; submitted.

Trafford AM, Parisi R, Kontopantelis E, Griffiths CEM, Ashcroft DM. Psoriasis and the risk of developing or dying from cancer: a systematic review and meta-analysis of observational studies. JAMA Dermatology 2019; 155(12):1390-1403.

Schonmann Y, Ashcroft DM, Iskandar IYK, Parisi R, Sde-Or S, Comaneshter D, Batat E, Shani M, Vinker S, Griffiths CEM, Cohen AD. Incidence and prevalence of psoriasis in Israel 2011-2017. Journal of the European Academy of Dermatology & Venereology 2019; 33: 2075-2081.

Parisi R, Webb RT, Kleyn CE, Carr MJ, Kapur N, Griffiths CEM, Ashcroft DM. Psychiatric morbidity and suicidal behaviour in psoriasis: a primary care cohort study. British Journal of Dermatology 2019; 180: 108-115.

Parisi R, Webb RT, Carr MJ, Moriarty KJ, Kleyn CE, Griffiths CEM, Ashcroft DM. Alcohol-related mortality in patients with psoriasis: a population-based cohort study. JAMA Dermatology 2017; 153(12): 1256-1262. Griffiths CEM, van der Walt JM, Ashcroft DM, Flohr C, Naldi L, Nijsten T, Augustin M. The global state of psoriasis disease epidemiology: a workshop report. British Journal of Dermatology 2017; 177(1): e4-e7.

Springate DA, Parisi R, Kontopantelis E, Reeves D, Griffiths CEM, Ashcroft DM. Incidence, prevalence and mortality of patients with psoriasis: a UK population-based cohort study. British Journal of Dermatology 2017; 176: 650-658.

#### Abstracts and Poster Presentations

Iskandar IYK, Chen T-C, Chen L-C, Lee M-S, Chan KA, Griffiths CEM, Ashcroft DM. Population trends in the 10-year prevalence and incidence of psoriasis and psoriatic arthritis in Taiwan: Nationwide, population-based cohort study. International Conference on Pharmacoepidemiology and Therapeutic Risk Management, Berlin, 2020.

Tabik M, Parisi R, Willis S, Griffiths CEM, Ashcroft DM. Clinical examination– based diagnostic criteria for chronic plaque psoriasis in adults: A Delphi consensus of international experts. 100th Annual Meeting of the British Association of Dermatologists, Manchester, 2020

Trafford, AM; Parisi, R; Kontopantelis, E; Griffiths, CEM; Ashcroft, D. Psoriasis and the risk of developing cancer: a systematic review and meta-analysis of observational studies. *99th Annual Meeting of the British Association of Dermatologists, Liverpool*, 2019. Trafford, AM; Parisi, R; Kontopantelis, E; Griffiths, CEM; Ashcroft, D. Psoriasis and Cancer Mortality: A systematic review and meta-analysis of observational studies. 27th European Academy of Dermatology and Venereology Congress Paris, 2018.

P.G. Ng'ambi, C. Jones, D. Ashcroft, CEM Griffiths, K. Payne, PNS14 Towards Consistency and coherence in understanding the economic impact of disease, *Value in Health, Volume 22, Supplement 3, 2019, Page S765.* 

Parisi R, Iskandar IY, Kontopantelis E, Augustin M, Griffiths CEM, Ashcroft DM. Global, regional and countryspecific prevalence of psoriasis: a Bayesian meta-regression of population-based studies. *European Academy of Dermatology and Venereology Congress, Madrid, 2019*.

Parisi R, Iskandar IY, Kontopantelis E, Augustin M, Griffiths CEM, Ashcroft DM. The Global Psoriasis Atlas: findings from a systematic review of the incidence and prevalence of psoriasis. *European Academy of Dermatology and Venereology Congress, Paris, 2018.* 

Trialonis-Suthakharan N, Gupta S, Griffith CEM, Ashcroft DM, Augustin M, Developing methodologies for field survey of psoriasis – the Global Psoriasis Atlas. German Congress for Health Science Research (Deutscher Kongress für Versorgungsforschung), 2018.

Trialonis-Suthakharan N , Gupta S, Griffith CEM, Ashcroft DM, Augustin M, Developing methodologies for field survey of psoriasis – the Global Psoriasis Atlas. *German Dermatology Society (Deutsche Dermatologische Gesellschaft), 2018.*  Trialonis-Suthakharan N, Gupta S, Griffith CEM, Ashcroft DM, Augustin M, Developing methodologies for field survey of psoriasis – the Global Psoriasis Atlas. *The 5th World Psoriasis* & Psoriatic Arthritis Conference, Stockholm 2018

Trialonis-Suthakharan N, Gupta S, Griffith CEM, Ashcroft DM, Augustin M, Global Burden of Disease: A systematic Literature Review on Disability Weights for Skin Diseases. The 5th World Psoriasis & Psoriatic Arthritis Conference, Stockholm, 2018.

Trialonis-Suthakharan N, Gupta S, Griffith CEM, Ashcroft DM, Augustin M, Developing methodologies for field survey of psoriasis – the Global Psoriasis Atlas. *European Academy of Dermatology and Venereology Congress, Paris, 2018.* 

Trialonis-Suthakharan N, Gupta S, Griffith CEM, Ashcroft DM, Augustin M, Global Burden of Disease: A systematic Literature Review on Disability Weights for Skin Diseases. European Academy of Dermatology and Venereology Congress, Paris, 2018.

Trialonis-Suthakharan N, Maul JT, Gupta S, Griffiths CEM, Ashcroft DM, Matthias Augustin Analysis of the Psoriasis Health care Survey in 16 Latin American countries (pilot study) – the Global Psoriasis Atlas. European Academy of Dermatology and Venereology Congress, Madrid, 2019.

Trialonis-Suthakharan N, Gupta S, Griffith CEM, Ashcroft DM, Augustin M, Developing methodologies for field survey of psoriasis – the Global Psoriasis Atlas, *World Congress of Dermatology, Milan, 2019.* 

Trialonis-Suthakharan N, Gupta S, Griffith CEM, Ashcroft DM, Augustin M, Global Burden of Disease: A systematic Literature Review on Disability Weights for Skin Diseases, *World Congress of Dermatology, Milan, 2019*.

#### GPA Presentations 2017-2020

Invited presentations on the GPA are delivered at numerous international conferences and meetings.

#### 2020

Psoriasis and the Global Psoriasis Atlas: 1st International meeting of the Burma Skincare Initiative Yangon, Myanmar – Professor Chris Griffiths.

The Global Psoriasis Atlas: Department of Dermatology, Santiago, Chile – Professor Chris Griffiths.

Presentation GPA Phase II: How could we use the Atlas as an advocacy tool?

IFPA Pan-American Meeting to be held in April in Ottawa, Canada: Epidemiology Data on Psoriasis Collected in South America so Far– Dr. Tatjana Maul.

Invitational talk RADLA (Reunion Anual de Dermatologos Latinamericanos), Buenos Aires, Argentina, Dr Julia-Tatjana Maul.

#### 2019

The Global Psoriasis Atlas: Department of Dermatology Chittagong University, Chittagong, Bangladesh.

The 45th Annual Meeting of Taiwanese Dermatological Association, 13 - 15 December 2019, Kaohsiung Exhibition Centre (KEC) – Professor Lars French.

Global Psoriasis Update: IPC Think Tank, Lisbon, Portugal – Professor Chris Griffiths & Professor Darren Ashcroft.

Global Psoriasis Atlas overview: AAD corporate breakfast, Washington, D.C, USA– Professor Jonathan Barker.

Global Psoriasis Atlas overview: EADV corporate breakfast, Madrid, Spain – Professor Jonathan Barker.

Global Psoriasis Atlas overview: IPC Councilor meeting, Milan, Italy – Professor Peter van de Kerkhof.

The Global Psoriasis Atlas: British Association of Dermatologists Global Health Day, London, UK – Professor Chris Griffiths.

The Global Psoriasis Atlas: Regional Dermatology Training Centre, Moshi, Tanzania – Professor Chris Griffiths. The Global Psoriasis Atlas: International Psoriasis Council Masterclass, Cairo Egypt – Professor Chris Griffiths.

The Global Psoriasis Atlas: Clinical experiences on a field trip through Latin America and its psoriasis disease burden, Swiss Psoriasis Day Basel, Dr Julia-Tatjana Maul

#### 2018

Global Psoriasis Atlas overview: AAD corporate breakfast, San Diego, CA – Dr Alexa Kimball.

Global Psoriasis Atlas overview: EADV corporate breakfast, Paris, France – Professor Jonathan Barker.

IPC Symposium: Health care for psoriasis worldwide: What do we know and how could we learn from each other? – Cancun, Mexico – Dr Tatjana Maul.

IPC Latin America working group: Health care for psoriasis worldwide: What do we know and how could we learn from each other? – Cancun, Mexico Dr Tatjana, Maul.

Global Psoriasis Update: IPC Think Tank, Miami Beach, FL – Professor Chris Griffiths.

The Global Psoriasis Atlas: Annual Meeting of the Tunisian Dermatological Society, Tunis, Tunisia - Professor Chris Griffiths.

Global Psoriasis Atlas update: 5th World Psoriasis and Psoriatic Arthritis Conference, Stockholm, Sweden – Professor Chris Griffiths.

#### 2017

Global Psoriasis Atlas overview: AAD corporate breakfast, Orlando, FL – Dr Alexa Kimball.

Global Psoriasis Atlas overview: EADV corporate breakfast, Geneva, Switzerland – Dr Alexa Kimball.

Global Psoriasis Atlas update: IPC Think Tank, London, England – Professor Chris Griffiths.

Global Psoriasis Atlas overview: The World Health Organization Networking Symposium – Professor Chris Griffiths.





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March 2020 | DW.3566.03.20