



Global Psoriasis Atlas

Global Psoriasis Atlas

# Annual Report

Year 1: April 2017–March 2018



# Vision

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The Global Psoriasis Atlas is the leading epidemiological resource on psoriasis globally; thus informing research, policy and health care provision for the disease worldwide.

# Foreword

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**I am delighted to present the first annual report for the Global Psoriasis Atlas.**

It is an honour to have been asked to direct the Global Psoriasis Atlas (GPA). As this first year report attests the GPA has started in fine style with the appointment of a worldwide group of enthusiastic and highly motivated regional coordinators – updates from two of whom can be found in this report. The two workstreams run by Professors Darren Ashcroft and Matthias Augustin have made excellent progress with tangible outcomes in the form of scientific abstracts produced already. I am particularly excited that we have begun to realise the vision of the World Health Organisation to start to understand the true burden of psoriasis worldwide and by so doing work towards enabling people with psoriasis to access the best available care wherever they may reside.



I am very grateful to the International League of Dermatological Societies, the International Psoriasis Council and the International Federation of Psoriasis Associations for their tripartite support of the GPA and to our sponsors for their invaluable support.

A handwritten signature in black ink that reads "Chris". The signature is stylized and includes a horizontal line at the end.

**Professor Chris Griffiths**

# Our Mission

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The mission of the GPA is to provide the common benchmark on the complete burden of psoriasis in all countries and regions throughout the world. The GPA will leverage existing data from publications and registries; where gaps are identified additional studies will be commissioned.

The GPA is a long-term project that seeks to drive continuous improvement in the understanding of psoriasis and to uncover how it affects both the individual and society at large. Whilst the first edition of the GPA will focus on the incidence and prevalence of psoriasis, future additions will be expanded to include access to treatment, comorbidities and cost to society.

# Scope of the Global Psoriasis Atlas

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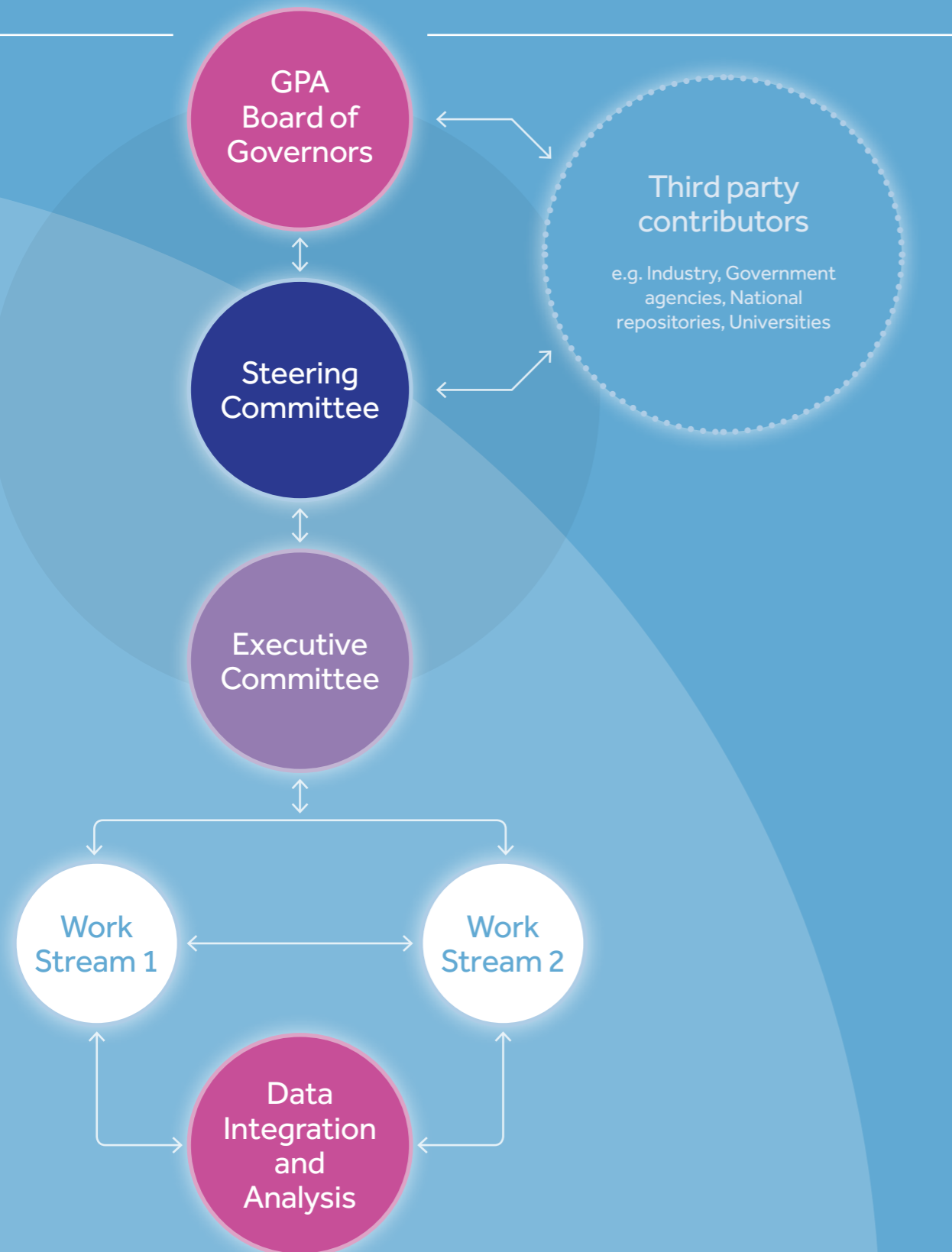
The GPA will maximise the value of epidemiological research into psoriasis by facilitating international collaboration and greater standardisation in study methodology whilst meeting the highest scientific standards for epidemiological data collection and estimation. The scope of this project incorporates scientific publications including: a methodology paper and; studies conducted to form a foundation for development of the GPA.

The two phases are designed to allow comparisons of the incidence and prevalence of psoriasis between populations in different countries, and create a first time global 'picture' of the disease burden.

Through two work streams we will:

- conduct an extensive systematic review of currently available literature with the desired outcome of a publication(s) in suitable high impact journal(s).
- determine a methodology to serve the framework for compiling the GPA, thus providing a Standard Operating Procedure to execute the GPA under a "hub and spoke" model.

# Structure and Governance



# Members of the organisation

## Board of Governors

IFPA President: Lars Ettarp (Sweden)  
 ILDS President: Harvey Lui (Canada)  
 IPC President: Alexa Kimball (USA)  
 GPA Programme Director: Chris Griffiths (UK)  
 Independent epidemiologist: Hywel Williams (UK)  
 Independent rheumatologist: Chris Ritchlin (USA)

## Executive Committee

(of the steering committee)

GPA Programme Director: Chris Griffiths (UK)  
 GPA Programme Manager: Rebekah Swan (UK)  
 Work Stream 1 Lead: Darren Ashcroft (UK)  
 Work Stream 2 Lead: Matthias Augustin (Germany)

## Project Steering Committee

IFPA representative: Hoseah Waweru (Africa)  
 IPC representative: Mark Pittelkow (USA)  
 Dermato-epidemiologist: April Armstrong (USA)  
 Dermato-epidemiologist: Luigi Naldi (Italy)

## Regional Representatives (part of steering committee)

Ncoza Dlova (South Africa), Moussa Diallo (Senegal), Yves Poulin (Canada),  
 Jashin Wu (USA), Claudia de la Cruz (Chile), Ricardo Romiti (Brazil),  
 Peter van de Kerkhof (The Netherlands), Arnon Cohen (Israel),  
 Jacek Cezary Szepietowski (Poland), Asja Prohic (Bosnia and Herzegovina),  
 Mahira El Sayed (Egypt), Murlidhar Rajagopalan (India), Jianzhong Zhang (China),  
 Xuejun Zhang (China), Colin Theng (Singapore), Verme Verallo (Philippines),  
 Chris Baker (Australia)

## Academic Project Staff

### Manchester, UK

GPA Programme Director: Chris Griffiths  
 GPA Programme Manager: Rebekah Swan  
 Work Stream 1 Lead: Darren Ashcroft  
 Work Stream 1 Research Associate: Ireny Iskandar  
 Work Stream 1 Research Associate: Rosa Parisi  
 PhD student: Alex Trafford  
 PhD student: Maha Abo-Tabik

### Hamburg, Germany

Work Stream 2 Lead: Matthias Augustin  
 Work Stream 2 Research Assistant: Nirohshah Suthakharan

## Collaboration Project Staff

ILDS GPA Project Manager: Caroline Bach (UK)  
 ILDS Executive Director: Joanna Groves (UK)  
 IFPA Representative: Kathleen Gallant (USA)  
 IPC Chief Executive Officer: Christy Langan (USA)



**Global Psoriasis Atlas Launch, Vienna, 2016**

Left to right: Chris Griffiths, IPC President;  
 Harvey Lui, ILDS President; Lars Ettarp, IFPA President;  
 Matthias Augustin, Work Stream 2 Lead.

# Overview of Year 1

## Highlights in Year 1

The first meetings of the GPA Board of Governors and Steering Committee were convened in Geneva, Switzerland in September 2017.

All Regional Coordinators now appointed.

Facilitation of local research projects using the agreed methodology is imminent.

The second meetings of the GPA Board of Governors and Steering Committee were in convened San Diego, USA in February 2018.

GPA Office established  
Steering Committee/  
Board of Governors

Key personnel recruited to lead academic institution website/branding/logo initiated

Global and regional network of coordinators appointed

Promotional material developed – aimed at Industry and Organisations wishing to provide a contribution (in-kind or monetary) to the GPA

First population based epidemiological study utilising UK electronic datasets on prevalence, incidence and mortality now published

Data from systematic review to support development of first iteration of the prototype Global Psoriasis Atlas

# The Work Streams

## Darren Ashcroft



**Work Stream 1 Lead for the Global Psoriasis Atlas (GPA) shares his insight into the epidemiological research programme.**

Our earlier systematic review on the global epidemiology of psoriasis identified 53 published epidemiological studies reporting on the prevalence and/or incidence of psoriasis in the general population<sup>1</sup>. In this review, we found marked variations in the reported prevalence and incidence of psoriasis, both within and between countries. Much of the variation within countries is likely due to methodological differences in study design, such as in assessing or reporting the disease (self-report, dermatologist or physician diagnosis and point, period or lifetime prevalence). Differences between countries are likely due to different age and sex distributions in the general population, and variation in genetic predisposition to the disease. The systematic review identified important knowledge gaps in understanding the natural history and burden of psoriasis internationally. Specifically:

- Few studies focussed on the incidence of psoriasis and on trends in the incidence of psoriasis over time;
- Most of the studies contributing data on disease prevalence were conducted in Europe and the USA, with far fewer studies identified from Asia, Africa and South America.

Our ongoing work within work stream 1 is focussed on addressing many of these important knowledge gaps.

We have recently published new findings examining changes in the prevalence and incidence of psoriasis, and mortality rates over a 15-year period in the United Kingdom<sup>2</sup>. In this large population-based study, we found an increasing population living longer with psoriasis in the UK, which has important implications for healthcare service delivery and for resource allocation. We are currently planning similar studies in other countries; the next in Israel, working closely with Prof Arnon Cohen who is one of our GPA Regional Co-ordinators.

Extensive literature searches have also recently been completed to update our earlier systematic review. We are currently extracting data from many new studies and we will be publishing this updated review later in the year. The review findings will form the foundation for the first version of Global Psoriasis Atlas.

1. Parisi R, Symmons DPM, Griffiths CEM, Ashcroft DM. Global Epidemiology of Psoriasis: A Systematic Review of Incidence and Prevalence. *J Invest Dermatol* 2013;133(2):377-85

2. Springate DA, Parisi R, Kontopantelis E, Reeves D, Griffiths CEM, Ashcroft DM. Incidence, prevalence and mortality of patients with psoriasis: a U.K. population-based cohort study. *Br J Dermatol*. 2017;176(3):650-658.

## Matthias Augustin



**Work Stream 2 Lead for the Global Psoriasis Atlas (GPA) on identifying worldwide data-sources**

The investigation of Work Stream 2 is being conducted by CVderm, the German Center for Health Services research in Dermatology located at the University Medical Center of Hamburg.

Currently, a review on different methodologies for integrating multisource-data is projected. In parallel, potential data sources relevant for the GPA are explored in a three-step process. In the first, a desk research is conducted in order to identify, analyze and integrate non-published sources into a common database. The second is a global survey conducted in >150 countries worldwide addressed to dermatologists and non-dermatologists. The online questionnaire identifies local, regional and national data sources including registries, research institutes, projects, publications and other relevant sources supporting the GPA project. The final step compiles the data sources on the basis of established pooling criteria. Furthermore, technologies for data adjustments and interpolation (e.g. for hard-to-reach areas) will be developed and the global disease burden of psoriasis will be operationalized.

First investigations show that there is a plurality of potential data sources on health care for psoriasis in almost all countries. Specification of such sources is subject of the current study phase. In the next steps of Work Stream 2, a database will be created in order to insert all identified data sources which will provide health data for decision makers, stakeholders and patients worldwide. Additionally, survey responses will be analyzed and added to the database. This database will be updated regularly and will support positioning psoriasis as a global disease. The methodology of global disease burden has been explored in a systemic literature review and further improvements of the current concepts have been suggested.

# Regional Coordinators

Global network of Regional Coordinators established.



# Regional Coordinator updates

## Prevalence of Psoriasis in the Philippines is estimated at 1.5-2.0% of 106 million Filipinos.

**Verm Verallo-Rowell**

Incidence reports are sparse but, as this "emerging" country's GDP now is among the highest in Asia, health resources including electronic database usage is expanding.



In 2016, I initiated a request to the Philippine Dermatological Society (PDS) – the accredited dermatological governing group in the Philippines – to start a Psoriasis Study Group. The main mission of the Group is to develop a Philippine Psoriasis Registry. A dermatology resident of the Skin and Cancer Foundation, Inc. that I head, developed last year a Questionnaire Validation Study protocol that was IRB approved. Just five pages long, with dermatologist – friendly tick boxes, the answers will also help us develop a Philippine Psoriasis Guidelines of Care. To simplify digital reporting, Doctors will email or text to the Study Coordinator smart phone photographs of patients in four poses and all pages of the questionnaire. The study is on-going, for completion, and to be presented to the PDS in July 2018. With a protocol that includes the validated questionnaire, the PDS and the Department of Health can continue to develop the nationwide Psoriasis Registry.

Among my Asian neighbors, Malaysia has the oldest Psoriasis Registry, started in 1998, revised in 2007, with annual reports of findings that they publish, and present at meetings. At the Updates in the Immunology Meeting in Manila in April, 2018, I shall ask my dermatology colleagues from the region regarding their country's epidemiological studies and psoriasis registries.

## Latin America: short overview

**Claudia De la Cruz**

In Latin America, epidemiology studies are lacking and methods for data collection in each country may differ. It will be critical to include all cases of psoriasis, from mild to severe, in both cities and rural areas to accurately estimate the burden of the disease in the region. In Brazil, there is a prevalence study of 9,000 adults, the data was collected by a telephone survey. This is the largest study in the region. In Chile, there is a study that estimates the prevalence in pediatric population in the Metropolitan Region 0,51% (0,57% women, 0,45% men).



In May 2017, a group of Latin American IPC councilors met with Dr Matthias Augustin during the Annual Latin American meeting RADLA, held in Sao Paulo, where we discussed aspects of GPA and how can LATAM work to collect the data. A Register is now being done in Colombia, in the

region of Antioquia. Several other epidemiology studies are being done in Chile, Brazil, Argentina. Next April, we have another meeting at RADLA in Cancún with Dr Augustin, this time with more dermatologists who work in psoriasis to discuss the way GPA is planning to do this. We have hard work ahead of us, but we are sure that we can do this and motivate colleagues from different countries in our region to raise up the data we need to better understand the burden of this disease.

**IFPA 5th World Psoriasis and Psoriatic Arthritis Conference  
June 2018, Stockholm  
Chris Griffiths will deliver a keynote lecture on the GPA**

## Upcoming Steering Committee Meetings

**EADV Congress  
September 2018, Paris  
AAD Congress  
March 2019, Washington DC**

# About the researchers

## Ireny Iskandar

**Research Associate  
The University of Manchester**



Ireny is a research associate working on the epidemiological aspect of the Global Psoriasis Atlas, an international project which aims to develop a web-based resource holding information on the epidemiology of psoriasis worldwide. Her role involves systematically reviewing the literature on the worldwide incidence and prevalence of psoriasis. She would also search for relevant information coming from the grey literature (official reports, conference abstracts and national registries) which could contribute to a broader understanding of the occurrence of psoriasis worldwide.

Ireny graduated from Cairo University in 2012 with BSc (Honours with distinction) degree in Pharmacy and Pharmaceutical Sciences (Clinical Pharmacy). In September 2013, she was awarded with the President's Doctoral Scholars award from the University of Manchester to develop skills in pharmacoepidemiological research whilst examining the use of biologic therapies in the management of psoriasis. In particular her research focused on examining the utilisation patterns and comparative effectiveness of biologic therapies on improvements in health related quality of life in patients with psoriasis in routine clinical practice. Ireny completed her PhD in Pharmacoepidemiology at The University of Manchester in 2017.

## Rosa Parisi

**Research Associate  
The University of Manchester**



Rosa is a Research Associate in the Centre for Pharmacoepidemiology and Drug Safety at the University of Manchester. She analyses large primary care databases in order to investigate epidemiological and pharmacoepidemiological research questions, with a focus on the epidemiology of psoriasis and related comorbidities.

She is part of workstream 1 of the Global Psoriasis Atlas. She is involved in updating the systematic review of the worldwide incidence and prevalence of psoriasis and using the results to predict estimates of the occurrence of the disease in those countries where there is no available information.

She graduated from the University of Bologna with a Degree in Statistics, Demography and Social Sciences. In 2010 she completed a PhD in Genetic Epidemiology from the University of Leeds funded by Cancer Research UK. The research focussed on discovering genetic variants that increase the risk of common complex diseases. In particular the aim of her project was to develop statistical methods for the analysis of Genome-wide Association studies with a focus on melanoma.

## Nirohshah Suthakharan

**University Medical Center Hamburg**



Nirohshah is a research associate and an important member of Work Stream 2 in the Global Psoriasis Atlas (GPA) project at the University Medical Center Hamburg. Her main role involves the development of a rigorous methodology which compiles multi-source GPA data that will enable to set guidelines for future psoriasis epidemiological work. She is conducting desk research and a global online survey (addressed to dermatologists and non-dermatologists) to identify non-published data sources. In addition, she is developing a common database integrating all the identified data sources and solving interpolation issues for less accessible regions.

Nirohshah completed her BSc. in European Public Health (2014) and MSc. in Global Health (2015) at the Maastricht University in the Netherlands. During her stay at Manipal University, India, she worked closely with an interdisciplinary team on a project proposal to improve indoor air quality and educated health concepts to low-income families/slum-dwellers. A noteworthy milestone in her career was working at the Center for Disease Control and Prevention in China on a project in collaboration with Maastricht University. Her main focus was on "Assessing and responding to outbreaks and potential threats: Syndromic infectious disease surveillance in China and the Netherlands". At the time of writing this, she is underway with her PhD. on the topic of Global Burden of Disease studies, by looking closer into the disability weight approach for skin diseases, in particular psoriasis.

# Looking ahead

## In 2018/19 the work of the GPA will focus on;

- Continued marketing and promotion of the GPA.
- Briefing and updates for funders on year 2 progress.
- Launch the prototype 'Global Psoriasis Atlas' based on findings from the updated and extended systematic review.
- Complete second large-scale epidemiological study using electronic health care datasets.
- Establish consensus on core criteria for the design of future epidemiological studies of psoriasis.
- Meetings of the GPA Board of Governors and GPA Steering Committee to be held during 2019 AAD meeting in Washington and 2018 EADV meeting in Paris.
- Systematic Review of epidemiology of psoriasis on course to be completed in August 2018.

## In 2019/20 the work of the GPA will focus on;

- Developing research tools to support future international field studies examining the epidemiology of psoriasis.
- Complete third large scale epidemiological study using electronic healthcare datasets.
- Complete and publish systematic reviews.
- Update the Global Psoriasis Atlas to incorporate new data.
- Promote the GPA at the World Congress of Dermatology in Milan, Italy June 2019.

### Funding of the GPA Project

The GPA project is funded through donations. Details of the current supporters are included in this report. The IPC, IFPA and ILDS are contributing, in kind, to the project.

# About the partners



## The International League of Dermatological Societies (ILDS)

ILDS is a non-governmental organisation that brings together over 170 member societies from more than 80 countries.

It was formed to:

- Stimulate the cooperation of societies of dermatology and societies interested in all fields of cutaneous medicine and biology throughout the world
- Encourage the worldwide advancement of dermatological education, care and sciences
- Promote personal and professional relations among the dermatologists of the world
- Represent dermatology in commissions and international health organisations
- Organise a World Congress of Dermatology every four years

To learn more about ILDS please visit [www.ilds.org](http://www.ilds.org)

## The International Federation of Psoriasis Associations (IFPA)

IFPA is a nonprofit organisation comprising psoriasis associations from around the world. IFPA unites psoriasis associations so that their global campaign for improved medical care, greater public understanding and increased research will improve the lives of people who live with psoriasis and psoriatic arthritis.

To learn more about IFPA please visit [www.ifpa-pso.org](http://www.ifpa-pso.org)

## The International Psoriasis Council (IPC)

IPC is a dermatology led, voluntary, global nonprofit organisation dedicated to innovation across the full spectrum of psoriasis through research, education and patient care. The mission of the IPC is to advance the care of people with psoriasis worldwide, through education, research and advocacy.

To learn more about IPC visit [www.psoriasisCouncil.org](http://www.psoriasisCouncil.org)

Engaging industry in multi year partnerships with the GPA supports our efforts to be the leading epidemiological resource on psoriasis globally. To this end, we were delighted to hold a meeting for sponsors and funders at the AAD in San Diego in February 2018 and we continue to actively promote the GPA to potential funders.

The Global Psoriasis Atlas is supported by grants from LEO Foundation and Novartis Pharma AG and is sponsored by AbbVie and Eli Lilly UK and Company Limited.





[www.globalpsoriasisatlas.com](http://www.globalpsoriasisatlas.com)

April 2018

DW.3328.04.18