

Global Psoriasis Atlas

Annual Report

April 2022 – March 2023



Mission

The mission of the GPA is to provide a common benchmark on the burden of psoriasis in all countries and regions worldwide.

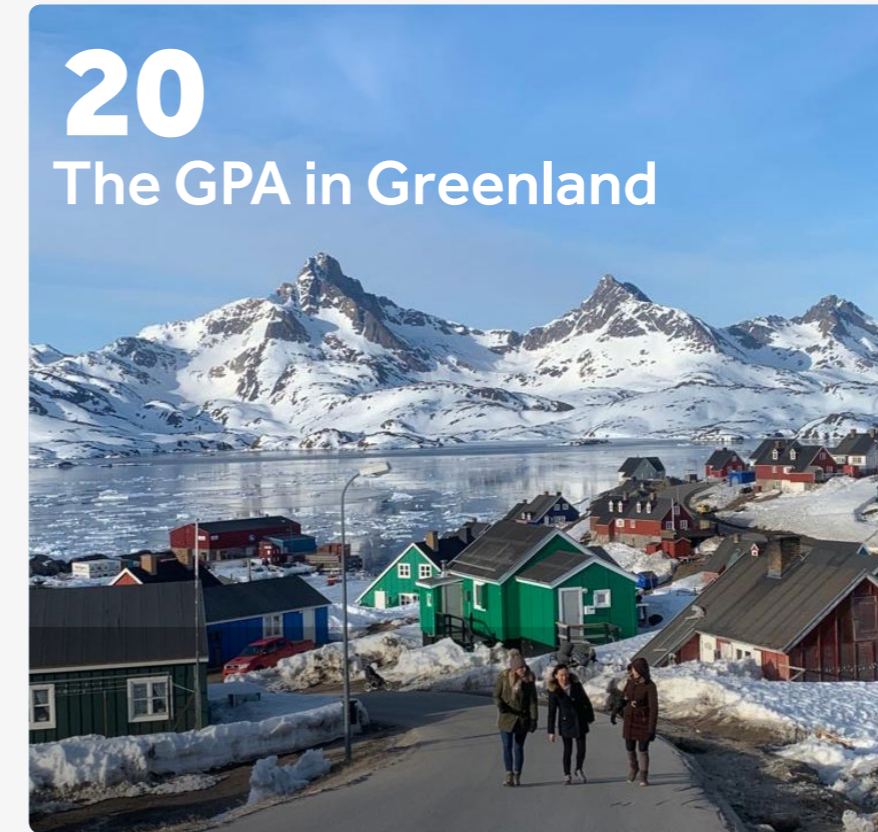
The GPA will leverage existing data from publications and registries; additional studies will be commissioned where gaps are identified.

The GPA is a long-term project that seeks to drive continuous improvement in understanding psoriasis and uncover how it affects both the individual and society at large.

Vision

The vision of the GPA is to become the leading epidemiological resource globally on psoriasis.

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Foreword



Our annual report for 2022-23 marks the end of Phase II of the GPA and reflects a transition to a more normal way of life as the world learns to live with COVID-19.

As travel and movement restrictions were lifted, in May 2022, we travelled to Greenland with a team from Copenhagen to perform a cross-sectional study of skin diseases in the adult population of Tasiilaq, Eastern Greenland. We ascertained that hand eczema was common, and although psoriasis occurred in the indigenous Inuit population, it was subtle in presentation, mainly consisting of thin plaque disease. You can read much more about the field survey in this report.

Our research collaborations continue to develop and have resulted in several notable publications. These include a study examining the incidence and prevalence of psoriasis in Malaysia, published in the British Journal of Dermatology. This is the first data published on the epidemiology of psoriasis in South-East Asia. We are grateful for the contributions made by Associate Professor Choon Siew Eng and her team in Johor, Malaysia, to bring this work to fruition. A second study examining the prevalence, incidence, and mortality rates in people with psoriasis and psoriatic arthritis in Taiwan was recently published in Acta Dermato-Venereologica.

Significant progress has been made over the last year with our programme of work focused on improving the diagnosis of psoriasis by non-dermatologists. We aim to make our diagnostic training tool available on the GPA website and continue the evaluation process in selected countries worldwide.

The resumption of face-to-face meetings meant that the team could once again attend the Congress of the European Academy of Dermatology and Venereology (EADV), which was held in Milan in September 2022. Drs Teng-Chou Chen, Alison Wright and Maha Abo-Tabik presented data from their research projects, and we held successful Steering Committee, Board and Funders' meetings with our Scientific Advisory Board (SAB).

The establishment of our SAB has provided independent and international oversight of the GPA research programme. The Board, chaired by Professor Robert Dellavalle, has responsibility for reviewing research priorities and advising on significant developments, including our recent update

to the GPA website utilising heatmaps to visualise the prevalence data.

The GPA has become a blueprint for other International League of Dermatological Societies (ILDS) linked dermatology atlases, namely the Global Atopic Dermatitis Atlas (GADA), led by Professor Carsten Flohr of King's College London, launched at the International Society for Atopic Dermatitis meeting in Montreal on 17th October. GADA's first report was published by the ILDS and highlighted the worldwide importance of atopic dermatitis as a non-communicable disease. We are looking to collaborate with GADA as joint initiatives will be synergistic, particularly for our proposed field surveys, which you will read more about in this report.

Working closely with David Webb, our graphic designer, and Anna Darzina and Vahid Djamei from the software consultancy company, Swiss4ward, we have continued to elevate the GPA brand. The use of videos, a range of printed materials and infographics explaining the findings from our publications have made the data accessible to a range of stakeholders, both on our website and via our social media channels.

In closing, I would like to thank Dr Craig Leonardi, immediate-past IPC President and member of the GPA Board of Governors, who has recently stepped down from his position, for his support of the GPA. I would also like to recognise the success of our three PhD students, Dr Maha Abo-Tabik, Dr Alex Trafford and Dr Peslie Ng'ambi, who have all completed their programmes of work, strengthening research capacity in the field. I hope you enjoy reading about the results and highlights from 2022 and our plans for 2023 and beyond.

Thanks to our collaborators and supporters, we continue to drive the highest quality global epidemiological research into psoriasis. The GPA team is always keen to engage with clinicians, researchers and patients to explore opportunities for collaboration and advocacy; please do get in contact. I wish you all a safe and productive 2023.

Professor Chris Griffiths OBE
Director, Global Psoriasis Atlas

The GPA: A Strong Organisation Built to Collaborate

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

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

IFPA is a non-profit umbrella organisation uniting all people living with psoriatic disease – regardless of where they live, what type of psoriatic disease they have, or how it impacts their lives. IFPA was founded in 1971 and, together with international member associations, represents and advocates for over 60 million people around the world. Read more about IFPA, our members and our activities at www.ifpa-pso.org.

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 195 Member organisations from more than 90 countries representing over 200,000 dermatologists worldwide. www.ilds.org

The **International Psoriasis Council** is a dermatology-led, voluntary, global, non-profit organization with a network of more than 130 psoriasis experts, thought leaders, and professionals, dedicated to improving patient care around the globe. www.psoriasisCouncil.org

It is thanks to the GPA collaborating organisations that the research and key messages from our work can be shared so readily with the global dermatology community. There is passionate support for the GPA amongst patient groups, dermatologists and funders.

Rebekah Swan,
Programme Manager



Phase II (2020-2023) at a Glance

Publication of the largest systematic review, to date, of the prevalence of psoriasis worldwide. **"National, regional and worldwide estimates of the epidemiology of psoriasis: Systematic analysis and modelling study"**, British Medical Journal.

Publication of **"Development of clinical diagnostic criteria for chronic plaque psoriasis: an international e-Delphi study"**, British Journal of Dermatology.

Paper on **"Fertility trends and adverse pregnancy outcomes in women with psoriasis in the United Kingdom"**, submitted for publication in JAMA Dermatology.

Successful funding application to the LEO Foundation. Grant awarded for Phase III of the GPA project (2023-2026).

Leveraged further external industry funding. Financial support was received during Phase II (2020 – 2023) from Abbvie, Almirall, Amgen, Janssen and UCB.

Capacity building with teams in Israel, Chile, Taiwan and Malaysia by assisting with data analysis and sharing a methodological framework for study.



Publication of **"Systematic review examining changes over time and variation in the incidence and prevalence of psoriasis by age and gender"**, British Journal of Dermatology.

Publication of **"The incidence of psoriasis in Chile: an analysis of the National Waiting List Repository"**, Journal of Clinical and Experimental Dermatology.

Field trip to Tasilaq, East Greenland, to conduct a pilot survey of skin disease with colleagues from Denmark.

Three PhD students trained and successfully completed their programmes of work, strengthening research capacity in the field.

Publication of **"Mapping opportunities for the earlier diagnosis of psoriasis in primary care settings in the UK"**, British Journal of General Practice.

Appointment of the GPA Scientific Advisory Board.




Publication of **"Incidence and prevalence of psoriasis in multi-ethnic Johor Bahru, Malaysia: a population-based cohort study using electronic health data routinely captured in the Teleprimary Care (TPC) clinical information system from 2010 to 2020"**, British Journal of Dermatology.

Our Team


Research Team

-  Professor Chris Griffiths
GPA Director
The University of Manchester
-  Professor Darren Ashcroft
GPA Research Director
The University of Manchester
-  Rebekah Swan
GPA Programme Manager
The University of Manchester
-  PD Dr Julia-Tatjana Maul
GPA Medical Coordinator
University Hospital Zurich
-  Dr Alison Wright
GPA Research Associate
The University of Manchester
-  Dr Teng-Chou Chen
GPA Research Associate
The University of Manchester
-  Jade Kelly
GPA Administrator
The University of Manchester

PhD Graduates

-  Dr Alex Trafford
The University of Manchester
-  Dr Maha Abo-Tabik
The University of Manchester
-  Dr Peslie Ng'ambi
The University of Manchester

Collaborating Organisations

-  Arpita Bhose
ILDS Executive Director
London, UK
-  Caroline Bach
ILDS Project Manager
London, UK
-  Christy Langan
IPC Chief Executive Officer
California, USA
-  Frida Dunger Johnsson
IFPA Executive Director
Sweden
-  Dr Sicily Mburu
IFPA Scientific Officer
Sweden

Board of Governors

-  Professor Lars French
Chair of the Board of Governors
and President of the ILDS
Germany
-  Dr Hoseah Waweru
President of IFPA
Kenya
-  Dr Craig Leonardi
President of the IPC
Missouri, USA

National Coordinators

-  Professor Mario Amaya Guerra
Mexico
-  Dr Cesar Gonzalez
Colombia
-  Dr Andre Carvalho
Brazil
-  Dr Farah Novoa Boza
Peru
-  Dr Cristina Echeverria
Argentina
-  Dr Enrique Rivas
Guatemala
-  Dr Benjamin Hidalgo-Matlock
Costa Rica
-  Professor Fernando Valenzuela
Chile



Regional Coordinators

-  Dr Claudia De la Cruz
Chile
-  Professor Asja Prohic
Bosnia and Herzegovina
-  Professor Chris Baker
Australia
-  Professor Ricardo Romiti
Brazil
-  Professor Mahira El Sayed
Egypt
-  Dr Vermen Verallo-Rowell
Philippines
-  Professor April Armstrong
USA
-  Dr Arnon Cohen
Israel
-  Professor Min Zheng
China
-  Professor Wayne Gulliver
Canada
-  Dr Murlidhar Rajagopalan
India
-  Professor Xuejun Zhang
China
-  Professor Jacek Szepietowski
Poland
-  Dr Colin Theng
Singapore
-  Professor Ncoza Dlova
South Africa
-  Dr Alexander Egeberg
Denmark
-  Dr Hazel Oon
Singapore
-  Professor Nejib Doss
Tunisia



Structure and Governance

Board of Governors

Professor Lars French
Chair of Board of Governors,
President of the International
League of Dermatological Societies



Dr Hoseah Waweru
President of IFPA



Dr Craig Leonardi
President of the International
Psoriasis Council



The 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.

Steering Committee

The GPA Steering Committee is chaired by the GPA Director and is composed of a lead from each of the collaborating organisations (IFPA, ILDS and IPC), along with the members of the Project Management Team comprised of the GPA Research Director, GPA Medical Coordinator, GPA Programme Manager and GPA Administrator.

Regional Coordinators

Part of the GPA Steering Committee.

Collaboration Team

Membership includes executives and members from the collaborating organisations and the GPA Programme Manager.

Researchers

Research Associates and PhD students.

Scientific Advisory Board

The newly appointed Scientific Advisory Board (SAB) provides the Board of Governors with independent and international scientific oversight of the work of the GPA. They are responsible for reviewing research priorities and advising on significant developments which may affect the GPA.



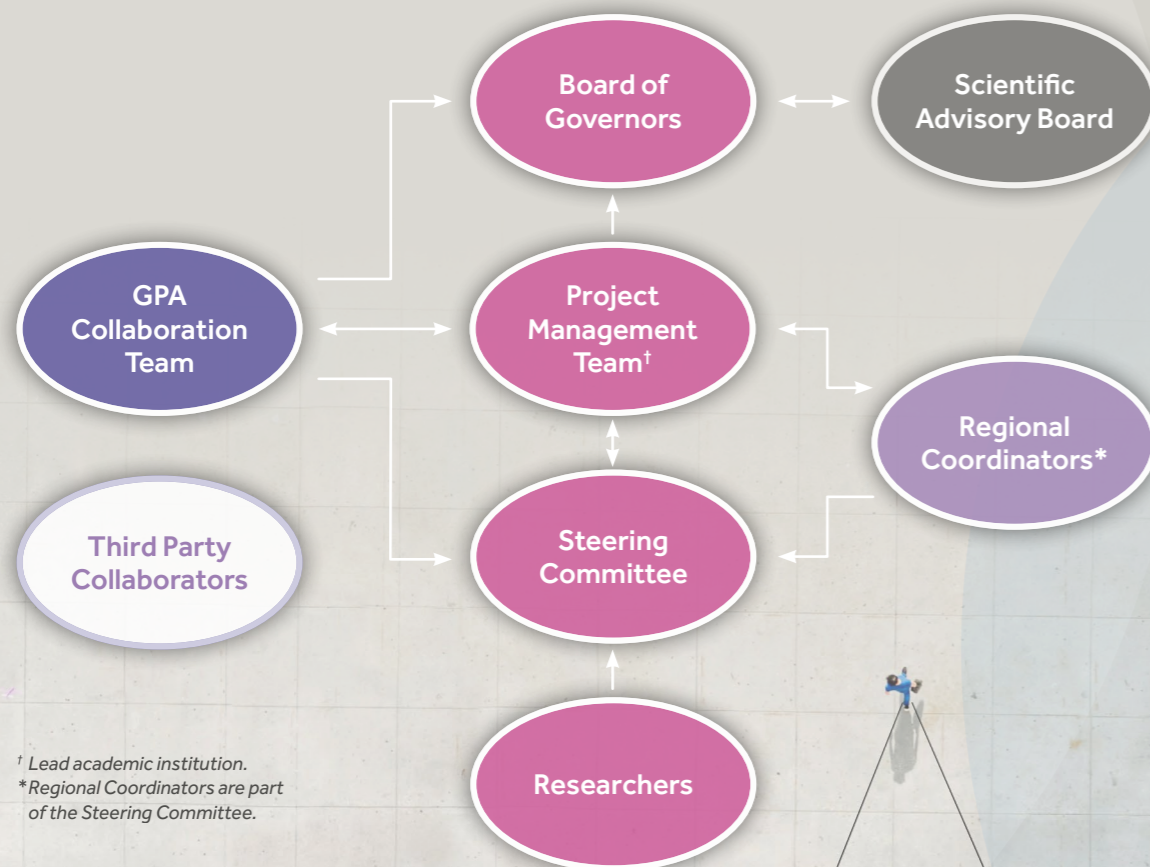
Professor Robert Dellavalle



Professor Mohsen Naghavi



Professor Luigi Naldi



† Lead academic institution.
* Regional Coordinators are part of the Steering Committee.



19% **81%**

We have psoriasis prevalence data for 19% of countries.

Our researchers and collaborators are working to increase the percentage of countries with empirical data on the epidemiology of psoriasis. Our research continues to improve the global understanding of the scale and distribution of psoriasis.

Our Research

Four Key Research Areas

This section explores the GPA research team's progress over the last year, highlighting our global research collaborations and publications.



Epidemiology of Psoriasis



Understand and Characterise the Economic Impact of Psoriasis



Recognise the Comorbid Disease Burden of Psoriasis



Improve the Early Diagnosis of Psoriasis





Professor Darren Ashcroft
GPA Research Director



Dr Alison Wright
GPA Research Associate



Dr Teng-Chou Chen
GPA Research Associate



Introduction from Professor Darren Ashcroft

I am pleased to report that we have had several new papers published over the last year that improve our understanding of psoriasis epidemiology and uncover how it affects both the individual and society at large. In this annual report, Dr Alison Wright and Dr Teng-Chou Chen report on new studies examining the incidence and prevalence of psoriasis in Malaysia and Taiwan. We have also recently completed another new study using the national claims database from Taiwan examining the risks of serious infection in people with psoriasis.

Alongside this, we have published a review of the available data on Generalized Pustular Psoriasis (GPP) prevalence (<https://onlinelibrary.wiley.com/doi/10.1111/jdv.18720>). This paper details the epidemiology of known comorbidities and summarises the available data on mortality and assigned causes of death. Importantly, we discuss the various factors that impact the collection, interpretation, and comparison of these data.

Building on this review and the knowledge gaps highlighted, we have been working closely with Dr Choon Siew Eng and her team examining the epidemiology of generalised pustular psoriasis in Malaysia. We plan to present these new findings at the 25th World Congress of Dermatology later this year.

It has been a pleasure to meet with so many of our collaborators at the EADV annual congress, the IPC Think Tank Meeting, and the AAD Congress to explore opportunities for future research. We are developing plans to take forward new studies using the diagnostic training tool that is highlighted by Dr Maha Abo-Tabik in this annual report, and very much look forward to working with our Regional and National Coordinators on these new initiatives.

Finally, the GPA hosted Dr Jaqueline Barboza da Silva (IPC Fellow, Brazil) and we are delighted that she could spend January and February with us in the UK. Jaqueline is leading a project examining the burden of psoriasis experienced by people in Brazil and we look forward to reporting on these important findings later this year.

Epidemiology of psoriasis in Malaysia

Presently, there is limited epidemiological data on psoriasis globally.

Access to this data is important for determining disease burden and ensuring adequate resource allocation for managing of patients with psoriasis. In 2020, the GPA identified that only 19% of countries had information on the incidence and prevalence of psoriasis. At the GPA, we strive to improve the understanding of psoriasis epidemiology around the world, working with international collaborators to map the number of people who have psoriasis in that country. Our current collaborations include teams in Malaysia (Dr Choon Siew Eng), Newfoundland (Professor Wayne Gulliver), Qatar (Professor Martin Steinhoff), Denmark (Professor Alexander Egeberg), and South Africa (Professor Ncoza Dlova).

In Southeast Asia, there have been no population-based epidemiological studies on psoriasis. To contribute data to this area, we have been working

with Dr Choon Siew Eng and her team to analyse trends in the incidence and prevalence of psoriasis in Johor Bahru, Malaysia, for the first time. We are pleased to report that the results from this study have now been published in the British Journal of Dermatology (<https://doi.org/10.1111/bjd.21768>).

For this study, we used electronic health records routinely captured in the Teleprimary Care (TPC[®]) clinical information system. TPC is a locally developed clinical information system that links public primary and secondary care facilities providing information on routine medical examinations, diagnoses and disease surveillance, laboratory results and pharmacy data. The TPC system contains data on over 1.2 million individuals residing in the Johor Bahru district.

Between 2010 and 2020, 3,932 Malaysians had dermatologist-confirmed psoriasis resulting in a period prevalence rate of 0.34% (95% Confidence Interval 0.33%-0.35%). We observed higher period prevalence rates in men than women (0.39% [0.37%-0.41%] vs. 0.29% [0.27%-0.30%]) and amongst Indians and Chinese than Malays (0.54% [0.50%-0.58%], 0.38% [0.36%-0.40%], 0.29% [0.28%-0.30%]; respectively). The period incidence of psoriasis was 34.2 (95% CI 32.6-35.8) per 100,000 person-years, with higher rates observed in men than women: 40.7 (38.2-43.2) and 28.3 (26.4-30.3) per 100,000 person years, respectively. Patients from Indian and Chinese ethnic groups had the highest incidence rates; Indian 52.5 (47.3-57.7), Chinese 38.0 (34.1-41.8), and Malay 30.0 (28.2-31.8) per 100,000 person years.

The prevalence and incidence of psoriasis increased steadily between 2010 and 2020, from 0.27% to 0.51% and 27.8 to 60.9 per 100,000 person-years, respectively. This increasing trend in psoriasis prevalence was observed across gender and ethnic groups and age, with prevalence peaking in the 50-59 and 60-69 year age groups.

The mean age of psoriasis onset was 39.8±17.4 years, with onset presenting significantly earlier in women than men (36.8±17.3 vs. 42.0±17.2 years, $P < 0.001$) and earliest in Malays followed by Indians and Chinese (36.4±17.5, 40.8±15.2, 47.4±16.9 years; respectively). A modest bimodal age distribution at psoriasis onset was observed, with first and second peaks at 20-29 and 50-59 years of age, respectively. This bimodal age distribution was seen in women and Malays but not in men or other ethnic groups.

As a follow-on to this study, we have been working with Dr Eng to estimate the incidence and prevalence of generalised pustular psoriasis (GPP) in Malaysia and characterise flares and trigger factors of GPP. Generalised pustular psoriasis is a rare, severe form of pustular psoriasis which is potentially life-threatening if left untreated. It is characterised by recurrent, sudden flares in the form of painful, pus-filled blisters over large areas of the body. Flares, the severity of which vary widely between and within patients, are a hallmark of GPP and may either occur de novo or be provoked by triggers, including withdrawal of systemic corticosteroids, infections, stress, pregnancy, and menstruation. While many affected individuals have features only of GPP, some will also develop features of plaque psoriasis either before or after GPP appears.

GPP, with or without associated plaque psoriasis, greatly impacts patients' physical and mental health and quality of life. We look forward to reporting on these findings later this year.

Epidemiology of psoriasis in Taiwan

Psoriasis is a serious non-communicable disease which has a detrimental impact on patients' quality of life.

Hence the World Health Organization emphasised the need to better understand the global burden of psoriasis. The underlying frequency of the HLA-Cw6 allele in Asia is different from the Caucasian population, and the prevalence and incidence of psoriasis can vary according to age, sex and region. However, there is limited information from Asia, and previous studies from Taiwan provided only limited information on the temporal trends of the incidence, prevalence and mortality of psoriasis and psoriatic arthritis (PsA).

Therefore, we used the Taiwan National Health Insurance (NHI) claim database and national death certificates from 2006 to 2017 to determine trends in the incidence, prevalence and mortality of patients with psoriasis and PsA in Taiwan and to examine how these epidemiological factors changed over time. The Taiwan NHI is a single-payer mandatory enrolment program, with more than 99.99% of the Taiwan population enrolled. The NHI claims database provides anonymous longitudinal records, including diagnosis and prescribing from different clinical settings. We identified patients with a diagnosis of psoriasis or PsA recorded by dermatologists or rheumatologists. Each patient was matched to 10 comparators without psoriasis or PsA from the general population by sex and age. In each calendar year, we calculated the annual age- and sex-standardised prevalence (existing patient) and incidence (new patient) rates and the risk of mortality (death).

From 2006 to 2017, Taiwan NHI registrants increased from 22,502,536 to 23,583,524. The incidence of psoriasis in Taiwan remained stable between 2009 and 2017. However, the prevalence of psoriasis increased in Taiwan, and 201,657 patients (0.86% of the Taiwan NHI registrants) had psoriasis in 2017. Psoriasis is more common in males than females (59.2% vs 40.8%), and more than 60% of psoriasis patients were diagnosed after age 40. This differs from the equal sex distribution and the more commonly observed early diagnosis (before age 40) in the Western countries. The prevalence of psoriasis remained stable among children (0-19 years) but increased steadily in all other age groups, which may be attributable to overall improvements in life expectancy. Nevertheless, the mortality risk remained higher in patients with psoriasis (hazard ratio 1.16; 95% confidence interval: 1.13-1.19) compared with the general population. The incidence of PsA in Taiwan also remained stable from 2006 to 2017. Up to 2017, 18,209 patients (0.08% of the Taiwan NHI registrants) had PsA. There is no difference in incidence or prevalence of PsA patients between males and females.

This national cohort study indicated an increase in the prevalence of psoriasis and PsA in Taiwan between 2006 and 2017. The increased prevalence does not appear to be attributable to a corresponding increase in incidence. The life expectancy improved in psoriasis and PsA patients in Taiwan, but patients with psoriasis and PsA still had a higher risk of mortality in Taiwan. The higher mortality may suggest an association between psoriasis and other risk factors, such as cardiovascular diseases and behavioural risk factors. This manuscript is published on the *Acta Derm Venereol*.

Psoriasis in Malaysia



BACKGROUND

1st

This is the first time the proportion of people with psoriasis has been documented in Malaysia

We looked at how many people in the general population had psoriasis **between 2010 and 2020** and how many of these people were newly-diagnosed

We carried out this study using data from General Practitioners and hospitals in Johor Bahru (the 2nd largest city in Malaysia)

We identified **3,932 people** with psoriasis among **1.16 million Malaysians**

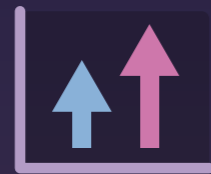


WHAT DID WE LEARN?

Prevalence of psoriasis

0.34%

(95% CI 0.33%-0.35%)
To provide some context, prevalence in East Asia is 0.14%, South Asia 0.36%, UK 1.92%



Annual prevalence and incidence of psoriasis have been increasing steadily over time

Prevalence varied across different ethnicities; highest rates seen in the Indian population, followed by Chinese and Malays



Incidence and prevalence of psoriasis was higher in men than in women

Psoriasis presents earlier in women than men



Psoriasis presents earliest in Malays, followed by Indians and then Chinese



Psoriasis has 2 peaks of onset, the first at age 20 to 29 years and the second at age 50 to 59 years. This pattern was seen only in women and Malays but not in men and other ethnic groups

To provide some context, Western countries report first and second peaks at 30-39 and 60-69 years of age



HOW THIS HELPS?

These findings provide important information to help inform healthcare professionals, healthcare planning, and management for psoriasis patients in the country

Psoriasis in Taiwan



BACKGROUND

We conducted a nationwide cohort study using the Taiwan National Health Insurance claim database which covers

99.9%

of the **23.5m** people in Taiwan

Therefore, our results are highly representative

We calculated the prevalence (existing patient per year), incidence (new patient per year) and mortality (death per year) of psoriasis and psoriatic arthritis in each year from **2006 to 2017**



WHAT DID WE LEARN?

Psoriasis Statistics



201,657 patients

had psoriasis in 2017
0.86% of the 23.5m people in Taiwan

40+

More than 60% of psoriasis patients were diagnosed after age 40 which is different from Western countries



Men

are more likely to have psoriasis than women **59.2% vs 40.8%** which differs from the equal sex distribution in Western countries



Prevalence of psoriasis remained stable among children (0-19 years) but increased steadily in all other age groups, particularly among those aged ≥ 90 years old

Psoriatic Arthritis Statistics



18,209 patients

had psoriatic arthritis in 2017
0.08% of the 23.5m people in Taiwan



There is **no difference** in incidence and prevalence of psoriatic arthritis between men and women

Diagnostic Training Tool



Dr Maha Abo-Tabik
PhD Graduate



Background

In many countries, psoriasis is often misdiagnosed or unrecognised, leading to either inappropriate or delayed care.

Seeking to address this issue, Dr Maha Abo-Tabik, GPA PhD student, conducted an e-Delphi study (in conjunction with the IPC) with 50 expert dermatologists from 27 countries across six continents to ascertain the key, diagnostic features of psoriasis.

During Phase II, Maha subsequently developed an educational resource (training tool) for non-dermatologist healthcare providers to help them identify psoriasis correctly in any skin colour. Dr Abo-Tabik also conducted work that has recently been published in the British Journal of General Practice.

This work looked at potential missed opportunities for the earlier diagnosis of psoriasis in the UK that were identified from the medical records of patients with the disease.

Results

Findings from this case-control study suggest that the diagnosis of psoriasis may be missed or delayed for up to 5 years for some individuals, leading to a potentially detrimental delay in establishing an appropriate treatment regimen. The training tool was designed to allow for differences in diagnosis and treatment of psoriasis in patients from different ethnic backgrounds.

Next Steps

During Phase II, we tested the tool in the UK and showed that the diagnosis of psoriasis by non-dermatologists can be improved. The intention is to work with our Regional and National Coordinators and other collaborators to continue to evaluate the use of the training tool in selected countries around the world as part of the Phase III research programme.

Our aspiration for the future is to investigate whether a newly developed training tool can improve the clinical diagnostic skills of non-dermatologists (such as community healthcare workers) for psoriasis. The aim would be for this to aid early and appropriate treatment of psoriasis, especially in parts of the world where access to specialist dermatology care is restricted.

The training tool utilised illustrations of psoriasis on different skin colours to overcome the limitations of using clinical images, analogous to a birdwatcher's field guide (please see Figure 1).

Figure 1. Illustrations from the Psoriasis Training Tool



Greenland

May 2022

The team

Manchester: Chris Griffiths, Rebekah Swan and Jingyuan Xu

London: Carsten Flohr and Su Lwin

Zurich: Julia-Tatjana Maul

Copenhagen: Morten Bahrt Haulrig, Tove Agner, Jacob Thyssen, Claus Zachariae and Anna Andersson

Greenland: Lone Storgaard Hove and Kunuk Hansen



From left to right: Dr Jingyuan Xu, Professor Chris Griffiths, Dr Su Lwin, Professor Jacob Thyssen, Professor Carsten Flohr, Dr Tove Agner, PD Dr Julia-Tatjana Maul, Rebekah Swan, Associate Professor Claus Zachariae

Why Greenland?

Previous limited literature implied psoriasis was a rare condition in the indigenous Inuit people of the Arctic regions. However, observations by colleagues at the University of Copenhagen contradicted these findings. To address this discrepancy and further our knowledge of the prevalence of psoriasis and patients' access to dermatological care, we undertook a pilot field study to examine the prevalence of skin diseases in East Greenland. This was in collaboration with colleagues from the Universities of Copenhagen, Zurich, Manchester, Nuuk, and King's College London. The intention of the preliminary study was to inform and link with the national population health survey that will take place in Greenland in 2023.



About Greenland

Greenland is the world's largest island, three-quarters of which is covered by a permanent ice sheet. The country has a population of 56,000, concentrated in the capital Nuuk on the West coast, and smaller towns with settlements scattered along the coastline. Transportation is mainly by small plane, helicopter or boat, as there are no connecting roads between towns or settlements. We visited Tasiilaq (formerly known as Ammassalik), the most populous community on the East coast of Greenland, between



Tasiilaq Community Hall

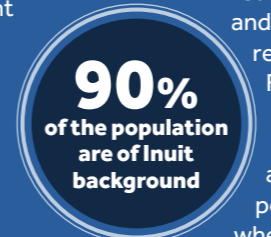
1st to 12th May 2022. Previous work by our colleagues from the University of Copenhagen on atopic dermatitis facilitated contact with the Tasiilaq community. The township is particularly difficult to access, even in early summer, requiring helicopter transportation from Kulusuk island further to the East. Tasiilaq has a population of 1,931 people, a third of whom are under the age of 18¹.

What did we do?

The team gained ethical approval to promote study recruitment prior to our arrival through the local newspaper, radio station, posters and social media. A skin survey clinic for all adults with or without any skin complaints was established in the town community centre with separate areas for consent, examination and consultation. The study was supported by the local district hospital and a team of translators fluent in Danish and/or Greenlandic. Demographic and consultation information were entered into encrypted portable tablet devices. If the participant required treatment, a letter was dictated, and a prescription arranged by a local doctor to be transported to the local dispensary situated in the town's small hospital.

What did we find?

The team reviewed a total of 295 participants, including 17 with psoriasis. 90% of the population are of Inuit background, with public jobs or hunting and fishing as many inhabitants' main way of life. Initial impressions are that psoriasis is present in the Inuit people, but its phenotype is different compared to the European population with thinner plaques, milder disease severity and a sebopsoriasis distribution. Interestingly, the individuals with psoriasis did not appear to have any associated comorbidities. There was a high prevalence of hand eczema, discoid eczema and lichen simplex chronicus. Rare skin disorders were also seen, including pustulosis, annular lichen planus and actinic prurigo.



Challenges and access to care

The field study enabled the team to understand the presentation of skin diseases, comorbidities and treatments available in remote East Greenland. A particular challenge is the provision of medications and long-term follow-up. As there are no pharmacies in Greenland, drugs for each patient are dispensed free of charge by the local district hospitals. The list of drugs kept in stock is minimal and many topical treatments require shipping from Denmark. Furthermore, emollient and moisturiser availability are also limited and expensive to purchase as supplies by ships are only possible during the summer months when the sea ice melts. Prescribed skin care treatments are available for free all year round from the hospital. Follow-up is invariably intermittent and access to specialist care is limited as there are no dermatologists in Greenland and the service is provided by tele-dermatology and two-week consultation tours distributed between towns up to twice a year.



The GPA team travelled to Tasiilaq by helicopter

Impact

The GPA team will use the methodological knowledge and networking gained during the visit to design future research studies and to advocate for outreach engagement, particularly in underserved populations and regions. The shared experience and important data collected have been submitted for presentation and journal publications. Abstracts have been submitted on the prevalence of skin disease in East Greenland, setting up a psoriasis survey, prevalence and phenotype of psoriasis, and hand eczema to the Nunamed Conference, October 2022, and the World Congress of Dermatology in Singapore, July 2023. The GPA project seeks both to drive continuous improvement in the understanding of psoriasis and uncover how it affects both the individual and society at large. Working with our collaborating organisations, we aim to ensure that every person will have access to the best available care for their skin, a key goal of the World Health Organization.



Professor Griffiths and Dr Lwin in clinic



Programme Manager, Rebekah Swan, in the information and consent area of the clinic



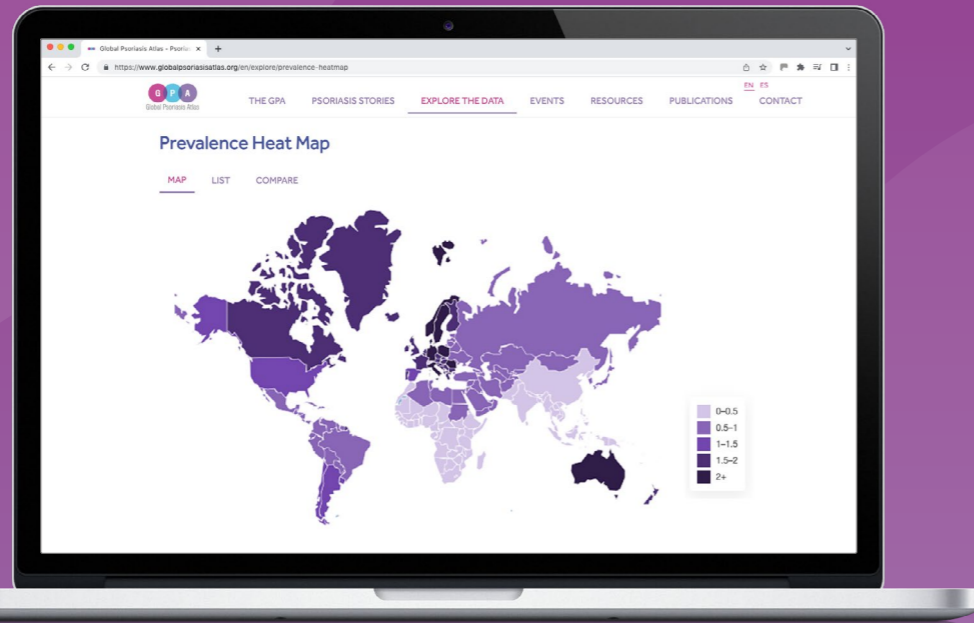
¹ <https://stat.gl/publ/en/GF/2022/pdf/Greenland%20in%20Figures%202022.pdf> [<https://bank.stat.gl/BEESTD>]

Digital Developments and Communications

GPA website

To make our website more accessible and engaging, the prevalence data are now displayed as a **heat map**. You can also learn more about our past and ongoing research collaborations by browsing our updated home page.

As part of our World Psoriasis Day campaign in October 2022, we interviewed some of IFPA's Ambassadors from around the world to understand how living with psoriasis affects their mental health and wellbeing. We then combined these interview clips to create a short video which you can [view here](#).



GPA Social Media

The Global Psoriasis Atlas project has established itself as a recognised and respected brand across a variety of digital platforms.

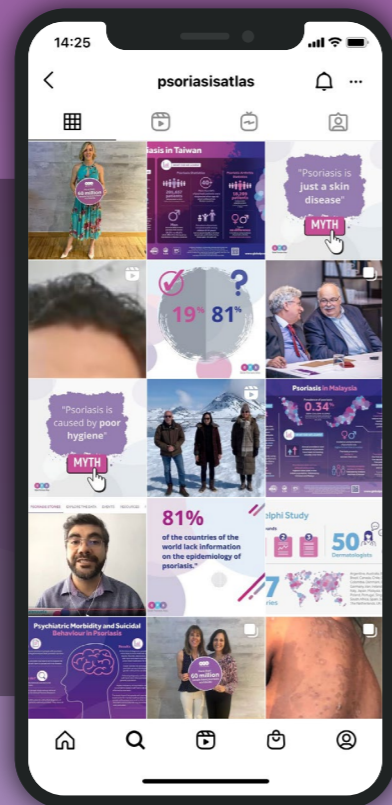
2,449 followers

1,466 followers

1000 followers

744 followers

Please follow [@PsoriasisAtlas](#)



Subscribe to our newsletter for regular updates on research and project progress from Professor Chris Griffiths and the GPA team.

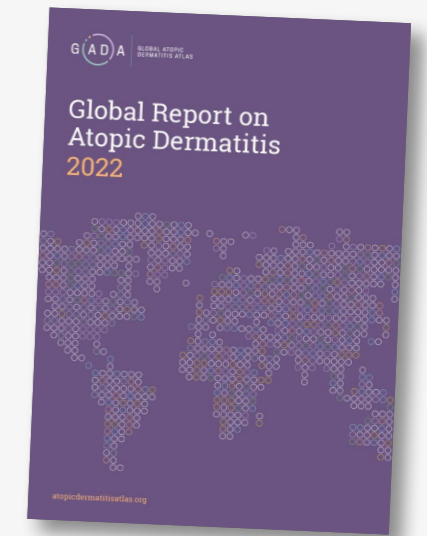


News Bulletin

Global Atopic Dermatitis Atlas (GADA)

Professor Carsten Flohr and the ILDS have published the first report on atopic dermatitis, which summarises the disease burden, geographical gaps in prevalence data, the impact on patients' lives and available treatments.

You can learn more by visiting the GADA website: atopicdermatitisatlas.org



Professor Carsten Flohr

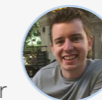
Professor Lars French

PhD Success Stories

Our three PhD students trained and completed their programmes of work during Phase II of the GPA, strengthening research capacity in the field.

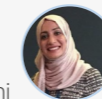
Dr Alex Trafford

Alex was an integral member of the research team in Manchester and accumulated several notable achievements during his PhD. These achievements included the publication of a study examining the concordance and timing of cancer recording between primary care; hospital and death registration data for people with psoriasis; and his systematic review published in JAMA Dermatology in 2019. This publication achieved an Altmetric Attention Score ranking it in the top 5% of all research outputs tracked.



Dr Maha Abo-Tabik

Maha conducted an e-Delphi study (in conjunction with the IPC) with 50 expert dermatologists from 27 countries across six continents to ascertain the key diagnostic features of psoriasis. She subsequently developed an educational resource (training tool) for non-dermatologist healthcare providers to help them identify



psoriasis correctly in any skin colour. Her paper, "Mapping opportunities for the earlier diagnosis of psoriasis in primary care settings in the UK", was published in the British Journal of General Practice. This is a novel and important piece of work as patients often experience delays when being diagnosed with psoriasis and are frequently misdiagnosed.

Dr Peslie Ng'ambi

Peslie's PhD focused on quantifying the economic impact of psoriasis. This included the financial impact of psoriasis on the health care system, and beyond health consequences of psoriasis on the individual. One of Peslie's aims was to estimate the cost of illness of psoriasis using linked Clinical Practice Research Datalink and Hospital Episodes Statistics (CPRD-HES) data to estimate primary and secondary resource use in the English National Health Service (NHS). One notable achievement of this project was adding to the evidence on the financial cost of psoriasis and the health and non-health consequences it poses in individuals. Up to as much as 40% of health care costs were estimated to be attributable to psoriasis.

We wish Alex, Maha and Peslie the best of luck in their chosen careers!



IPC Fellow

Dr Jaqueline Barboza da Silva



In January and February, Professor Ashcroft, Professor Griffiths and the GPA team hosted Dr Jaqueline Barboza da Silva (IPC Fellow) in Manchester and London, UK. Jaqueline has a strong interest in psoriasis and is implementing research in Southern Brazil on behalf of the GPA.



Steering Committee meeting at the AAD 2022

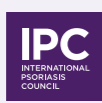
American Academy of Dermatology Annual Meeting 2022

We held our first in person meetings during the 2022 AAD in Boston. We were delighted to see so many of our Regional and National Coordinators and friends of the GPA. Thank you to our industry colleagues for your continued interest in the GPA.

Looking Forward

Collaboration

During Phase III (April 2023-March 2026), the GPA team will be strengthened further by enhanced collaboration with our partner organisations, implementation of regular research and communications meetings, and our planned collaborative work with the Global Burden of Disease team in Seattle, WA.



Team

The GPA has been fortunate to have a team of dedicated and enthusiastic individuals worldwide to help drive each phase of growth. Each team member has contributed time and expertise to the project with enthusiasm and skill. The research team shares a range of skills and knowledge and many years of experience in dermatology, epidemiology, nursing, and project administration. Interdisciplinary teamwork, both in our work on epidemiological mapping and on our field study visits, is supported by positive leadership and management, effective communication strategies, an appropriate skill mix and the individual characteristics of the team. Since its inception, the project has consistently achieved high-calibre research outputs

by the GPA research team members. For example, our publications in the British Medical Journal, by Parisi et al, 2020, and by Trafford et al, 2019, in JAMA Dermatology, were published in high-impact journals with Altmetric Attention Scores ranking them in the top 5% of all research outputs tracked.

Research

Following the success of the GPA PhD programmes of study during Phase I and II and the significant contribution that was made to the research outputs for the project, three PhD students and a research fellow have been included in the overall costings for Phase III. Their projects will directly support the overall aims of the GPA research programme and advance the achievement of our milestones.

Implementation

According to the World Health Organization, noncommunicable diseases account for 74% of deaths worldwide and are associated with health inequality. For psoriasis, these inequalities manifest in a lack of knowledge and understanding of the prevalence of psoriasis, delays in diagnosis and treatment and underestimation of the associated

comorbid diseases, which also contribute to the health burden. Therefore, establishing prevalence rates and raising awareness of the burden of psoriasis among policy makers are crucial elements in improving access to care. Without these data it is impossible to target resources effectively. Effective education and advocacy are the crucial next steps to convince payers, regulators and governments that

effective management of psoriasis is important both on an individual and a societal basis. The GPA will continue to supply data on the national prevalence of psoriasis. These data will allow IFPA, ILDS and IPC to educate on psoriasis diagnosis and management and advocate for better healthcare resources from a stronger and more defensible standpoint.

GPA workshop at the Regional Dermatology Training Centre, Tanzania, July 2019



Field Study Visits – Phase III

Working with our collaborating organisations and GPA Coordinators, we will conduct field study visits in several countries during Phase III.

This work will utilise existing on the ground infrastructure. We will expand on prior epidemiological

mapping in the country/region and interrogate relevant health records. Our collaborating organisations will provide links and support in countries where field study visits occur. IFPA will participate in field visits in countries where there is no member association, with the purpose of

establishing a patient organisation. We are currently exploring the potential for this fieldwork to take place in Southeast Asia – Singapore and Malaysia; Latin America – Chile and Brazil; and in North and South Africa.



Southeast Asia



Latin America



Africa

As part of our plans for 2023-2026 we will:

Implement extensive updates to our large international epidemiology dataset

Conduct field study visits in selected countries

Conduct new epidemiological studies to examine the clustering of comorbid diseases in psoriasis

Conduct studies of clinical diagnostic criteria with our global collaborators

Test data collection tools in field studies with our global collaborators

Develop data collection tools to better understand and characterise the economic impact of psoriasis

Ensure continued publication in high impact journals across our key research areas

Publish the third edition of the Global Psoriasis Atlas

Engagement

We welcome new connections and partnerships!



Here are some of the ways you can get involved;

- Provide financial support
- Collaborate with us
- Support the collection of data on the global burden of psoriasis
- Support our research
- Engage with us on social media

Furthering the high quality research of the GPA requires the support of industry, organisations with relevant data sets, and collaboration across regions and countries.

The GPA Partnership Brochure and video provide details of the types and levels of financial support packages and highlights unique opportunities for involvement in the project.



For further information contact, GPA Programme Manager, Rebekah Swan: rebekah.swan@manchester.ac.uk

Would you like to learn more about the work of the GPA?



Visit our website
www.globalpsoriasisatlas.org

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Subscribe to our newsletter:
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The work of the Global Psoriasis Atlas would not be possible without the financial support we receive from our industry partners.

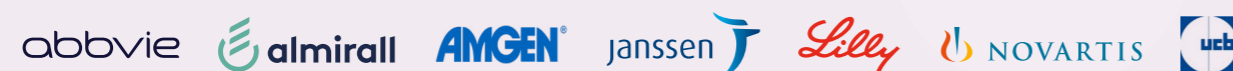
Partnership is a crucial step towards achieving the ambition of the GPA; to ensure that people around the world have access to the best available care and treatment for their psoriasis. We recognise that innovative and strategic partnerships with organisations are key to delivering our milestones and achieving the aims of the Atlas.



LEO FOUNDATION

The **LEO Foundation** is the lead supporter of the Global Psoriasis Atlas and we are grateful for the core, key funding that it has provided throughout Phase I and II.

The GPA work in Phase II (2020-2023) has been made possible thanks to grants and sponsorship from Abbvie, Almirall, Amgen, Eli Lilly and Company, Janssen, Novartis Pharma AG and UCB.



Publications, Presentations and Abstracts

Publications

Prinz, JC, Choon, SE, Griffiths, CEM, Merola, JF, Morita, A, Ashcroft, DM, et al. Prevalence, comorbidities and mortality of generalized pustular psoriasis: A literature review. *J Eur Acad Dermatol Venereol.* 2022; 00: 1-18. <https://doi.org/10.1111/jdv.18720>

Jörg C. Prinz, Siew Eng Choon, Christopher E. M. Griffiths, Joseph F. Merola, Akimichi Morita, Darren M. Ashcroft, Manuelle Viguier.

Abo-Tabik M, Parisi R, Morgan C, Willis S, Griffiths CEM, Ashcroft DM (2022) 'Mapping opportunities for the earlier diagnosis of psoriasis in primary care settings in the UK', *British Journal of General Practice.* doi: 10.3399/BJGP.2022.0137

Choon SE, Wright AK, Griffiths CEM, Tey KE, Wong KW, Lee YW, Suvelayutnn U, Mariapun J, Ashcroft DM (2022) 'Incidence and prevalence of psoriasis in multi-ethnic Johor Bahru, Malaysia: a population-based cohort study using electronic health data routinely captured in the Teleprimary Care (TPC) clinical information system from 2010 to 2020', *British Journal of Dermatology.* doi: 10.1111/bjd.21768

Iskandar I, Chen TC, Chen LC, Lee MS, Yang YY, Wang TC, Hsieh YC, Chan KA, Griffiths CEM, Ashcroft DM (2022) 'Incidence, prevalence, and mortality of people with psoriasis and psoriatic arthritis in Taiwan: A nationwide cohort study'. *Acta Dermato-Venereologica.* doi: 10.2340/actadv.102.1962

Abstracts and Poster Presentations

Development and Evaluation of an Online Training Tool to Aid the Diagnosis of Psoriasis, Abo-Tabik M, European Academy of Dermatology and Venereology Congress, Milan, 2022

Incidence and prevalence of psoriasis in Malaysia between 2010 and 2020, Wright A, European Academy of Dermatology and Venereology Congress, Milan, 2022

Risk of serious infection and infection mortality in patients with psoriasis: a nationwide population-based cohort study in Taiwan, Chen TC, Wang TC, Yiu Z, Lee MS, Chen LC, Chan KA, Griffiths CEM, Ashcroft DM, European Academy of Dermatology and Venereology Congress, Milan, 2022

Presentations

The Global Psoriasis Atlas, Professor Chris Griffiths, RDTIC International CME Conference, January 2022

Access to psoriasis treatment in Brazil and Chile: A prospective multi-centre Global Psoriasis Atlas Study, PD Dr Julia-Tatjana Maul, RDTIC International CME Conference, January 2022

Why Global Health Dermatology Matters, Professor Chris Griffiths, "Celebrating the skin we are in: what is the future of dermatology?" RCP North, Liverpool, May 2022

The Global Psoriasis Atlas, Professor Chris Griffiths, IPC Masterclass, South America, June 2022

The Global Psoriasis Atlas, Professor Chris Griffiths, ILDS-AAD Forum at the EADV, September 2022

Fertility, birth outcomes and adverse pregnancy outcomes in women with psoriasis in the United Kingdom primary care, Teng-Chou Chen, European Academy of Dermatology and Venereology Congress, Milan, September 2022

The Global Psoriasis Atlas, IPC Masterclass for Central and Eastern Europe, Professor Chris Griffiths, October 2022

The Global Psoriasis Atlas, Professor Chris Griffiths, World Skin Summit, Lima, October 2022

Global Psoriasis Atlas Research Update, Professor Darren Ashcroft, IPC Masterclass Southeast Asia, November 2022

The Global Psoriasis Atlas, Professor Chris Griffiths, IPC Masterclass Middle East, January 2023



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