International Psoriasis Council

Steve O’Dell
Chief Executive Officer
IFPMA Meeting
May 09, 2014
Agenda

- Introduce and provide an overview of the IPC
- Introduce the importance of the need for a better understanding of the prevalence and incidence of psoriasis
- Introduce the partnership with ILDS and IFPA to execute the Global Psoriasis Atlas project
Who is the International Psoriasis Council?

- Founded in 2004, The International Psoriasis Council (IPC) is a dermatology led, voluntary, global nonprofit organization dedicated to innovation across the full spectrum of psoriasis through research, education and patient care.

- Founded by:
  - Alan Menter, MD, Baylor University, Dallas, Texas, USA
  - Christopher EM Griffiths, MD FRCP FMedSci, University of Manchester, Manchester, UK
  - Craig Leonardi, MD, St. Louis University, St. Louis, MO, USA
11 Board Members

- Christopher EM Griffiths, MD FRCP VMedSCI, President, United Kingdom
- Peter van de Kerkhof, MD PhD, Immediate Past President, the Netherlands
- Alexa B. Kimball, MD MPH, Vice President and President-Elect, United States
- Craig L. Leonardi, MD, Treasurer, United States
- Hervé Bachelez, MD PhD, Secretary, France
- Jonathan Barker, BSc MD FRCP FRCPPath, United Kingdom
- Robert Holland III, United States
- Wolfram Sterry, MD, Germany
- Bruce Strober, MD PhD, United States
- Alan Menter, MD, Founding President, United States
- Steve O’Dell, CEO, United States
IPC Representation

• 11 Board members
• 86 Councilors
• Represent key opinion leaders from 24 countries
• Multi-specialties in medicine and pediatrics, and include representatives from basic science, translational, genetic clinical research and patient care.
  - Leaders of or past leaders of almost every professional and patient psoriasis organization worldwide
  - Constitute >80% of all global psoriasis research and publications over the past 25 years
  - Majority of global educational programs involve an IPC board member or councilor
Be recognized as:

• The preeminent professional voice in regards to the spectrum of psoriasis worldwide

AND

• The preferred professional organization with whom to collaborate to provide leadership and guidance with respect to the full spectrum of psoriasis
“Empower our network of global key opinion leaders to advance the knowledge of psoriasis and its associated comorbidities, thereby enhancing the care of patients worldwide”
The IPC identifies, prioritizes, and leads collaboration with worldwide experts to facilitate discussions through the following Strategic Imperatives:

- **Research:**
  - Identifies, prioritizes, and leads collaboration with worldwide experts to facilitate discussions and execute exceptional research initiatives addressing key needs with the goal of advancing the knowledge of psoriasis and its associated comorbidities.

- **Education:**
  - Develops and delivers high value, unbiased, evidence based, educational programs to all healthcare providers involved in the treatment of psoriasis and its associated co-morbidities to drive the delivery of enhanced care to psoriasis patients worldwide.

- **Patient Care:**
  - Lead the collaboration of worldwide experts to facilitate discussions and develop a globally accepted definition of psoriasis, consensus treatment guidelines and provide advice to regulatory authorities ensuring psoriasis patients worldwide have access to the best treatments.
Major IPC Lead/Collaboration Projects

- Psoriasis and its associated co-morbidities
- Genetic and Mechanistic Susceptibility
- Multiple regulatory therapeutic agent reviews
- Delphi project to identify & prioritize global psoriasis research
- Pathogenic mechanisms of psoriasis
- Multiple Working Groups
  - Systemic and topical therapies, biosimilars, pediatrics
- Psoriasis Stratification to Optimise Relevant Therapy (PSORT)
- Meet The Experts (MTE) forum at major congresses
- *Global Psoriasis Atlas*
Identified Key Issues

- Lack of understanding of the natural history of the disease and its impact (comorbidities, genetics, immunopathogenesis, progression, severity, subtypes)
- There is not an internationally recognized and accepted common definition of psoriasis
- There are not internationally recognized treatment goals, guidelines and standards involving the continuum of care for the psoriasis patient.
- The full impact of psoriasis worldwide has not been quantified; prevalence, burden of disease, health outcome of the patient, indirect societal impact.
- There is an opportunity to enhance access to the right HCP and thus the appropriate treatments and burden of psoriasis worldwide.
- Psoriasis patients are undertreated, treatments are not optimal, current therapies do not effectively treat all patients equally and there is a lack of understanding of the safety and efficacy of treatments at the stratified or individual level.
Prevalence and Incidence of Psoriasis

• Prevalence and incidence data:
  − It provides the core indicators of public health
  − It informs policy decisions and evidence-based practice by identifying risk factors for disease and targets for preventive healthcare
  − Indicators provide guidance and prioritization to all stakeholders; governments, regulators, policy makers and industry
  − Helps develop methodology used in clinical research, public health studies and, to a lesser extent, basic research in the biological sciences
  − And last but not least, prevalence and incidence data is used by industry to provide research direction and financial forecasting
Global Epidemiology of Psoriasis: A Systematic Review of Incidence and Prevalence

Rosa Parisi¹, Deborah P.M. Symmons²,³, Christopher E.M. Griffiths⁴, Darren M. Ashcroft¹ and on behalf of the Identification and Management of Psoriasis and Associated ComorbiditiTy (IMPACT) project team

The worldwide incidence and prevalence of psoriasis is poorly understood. To better understand this, we performed a systematic review of published population-based studies on the incidence and prevalence of psoriasis. Three electronic databases were searched from their inception dates to July 2011. A total of 385 papers were critically appraised; 53 studies reported on the prevalence and incidence of psoriasis in the general population. The prevalence in children ranged from 0% (Taiwan) to 2.1% (Italy), and in adults it varied from 0.91% (United States) to 8.5% (Norway). In children, the incidence estimate reported (United States) was 40.8/100,000 person-years. In adults, it varied from 78.9/100,000 person-years (United States) to 230/100,000 person-years (Italy). The data indicated that the occurrence of psoriasis varied according to age and geographic region, being more frequent in countries more distant from the equator. Prevalence estimates also varied in relation to demographic characteristics in that studies confined to adults reported higher estimates of psoriasis compared with those involving all age groups. Studies on the prevalence and incidence of psoriasis have contributed to a better understanding of the burden of the disease. However, further research is required to fill existing gaps in understanding the epidemiology of psoriasis and trends in incidence over time.

Journal of Investigative Dermatology advance online publication, 27 September 2012; doi:10.1038/jid.2012.339
Prevalence and Incidence of Psoriasis

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- Three electronic databases were searched from their inception dates to July 2011. A total of 385 papers were critically appraised; 53 studies reported on the prevalence and incidence of psoriasis in the general population.
Prevalence and Incidence of Psoriasis

- Parisi et al:

- The worldwide incidence and prevalence of psoriasis is poorly understood.
  - Some evidence to suggest an increasing trend of incidence of psoriasis over 30 years
    - Better data collection?
    - Improved diagnostic methods?
    - Genuine increase?
Prevalence and incidence of psoriasis

• Parisi et al outcome:
  – Studies on the prevalence and incidence of psoriasis have contributed to a better understanding of the burden of the disease. However, further research is required to fill existing gaps in understanding the epidemiology of psoriasis and trends in incidence over time.

• Need for prospective studies on determinates of natural history of psoriasis remission and flares
• Need for global study of current disease incidence and prevalence
IFPA, ILDS and IPC form partnership to develop Global Psoriasis Atlas

The International Federation of Psoriasis Associations (IFPA), the International League of Dermatological Societies (ILDS) and the International Psoriasis Council (IPC) have formed a partnership to develop a Global Psoriasis Atlas to fill the gaps in the understanding of the prevalence and burden of psoriasis.
The objectives of this joint project are to:

- Build an evidence base that stakeholders can use to advocate for improved treatment, access to care and recognition of psoriasis as a priority of public healthcare policy.
- Unite all stakeholders on one mutually beneficial agenda that works towards improving the lives of people with psoriasis and psoriatic arthritis.
- Encourage collection of data and research into psoriasis that could ultimately lead to better use of resources, as well as improvements in treatment and care.
- Enable benchmarking within and between countries by providing all stakeholders with local and regional evidence that is consistent and comparable.
The Global Psoriasis Atlas is being developed within the framework of the ILDS Grand Challenges of Global Skin Diseases project – a project set up to identify and address some of the challenges associated with skin diseases and raise awareness of these issues within the global health agenda.
In Closing

- Introduce and provide an overview of the IPC
  - Nonprofit organization of the world's leading key opinion leaders in psoriasis

- Introduce the importance of the need for a better understanding of the prevalence and incidence of psoriasis
  - The worldwide incidence and prevalence of psoriasis is poorly understood.

- Introduce the partnership with ILDS and IFPA to execute the Global Psoriasis Atlas project
  - The IPC, IFPA, and ILDS have formed a partnership to develop a Global Psoriasis Atlas to fill in the gaps of prevalence and burden of the disease of psoriasis
Thank you!