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International Alliance of Dermatology Patient Organizations











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Challenges for Dermatology Patients



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Dispel Myths

Dermatological diseases are largely considered to be of low impact. In a great many cases, this is simply <u>false</u>.



Quantify Impact

- Patient organizations are ill equipped...
- Qualitative information gathered by patient leaders doesn't fit quantitative decision-making rubric.



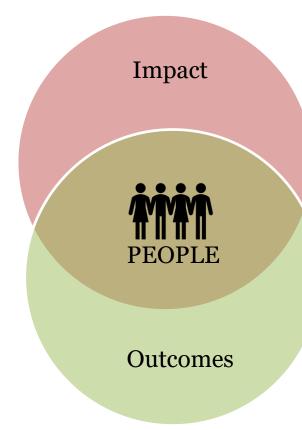
Opportunities



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The unique opportunity at this moment in time:

- There is a growing movement worldwide to include "the patient voice" in healthcare policy decisionmaking.
- If people living with the disease can bring information to the table using the lexicon of decision-makers (i.e. data), then their perspective on the lived experience of the condition can inform healthcare decisions.







Global Research on the Impact of Dermatological Diseases (GRIDD)

<u>Objective</u>: Capture the voice of the people and their experience living with the condition in their own skin and to bring those perspectives to the attention of those making decisions on our behalves.



GRIDD

Questionnaire

Data

How GRIDD differs from existing research:

- Creation of the Global Research: Impact on Patients (GRIP) tool which establishes the key questions to be asked from the patients' perspectives to fully describe the burden of disease from their perspective.
 - Survey describing the impact of the dermatological condition on the lives of patients and their family members as defined by the GRIP tool, including impact on: psycho-social impacts, life trajectory, Work, psychological status, social environment, Family leisure time.
 - Patient experience data which can be analyzed by country and disease
 - Verifiable data which tells a compelling story about dermatological diseases
 - Support data-driven patient involvement and advocacy in decisions about research spending, drug approvals and specialist funding







GRIDD: Outcomes

- Greater understanding and respect for dermatological diseases
- Global Research of Impact on Patients (GRIP) tool allows patients living with dermatological diseases to co-create questions
- ✓ Unique measurement instrument
- Global Report on the Impact of Dermatological Diseases with a breakdown by country, region and disease
- Tools that empower dermatological patient leaders



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Why this matters...



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Person-centred healthcare policy should be informed by information collected directly from the people living and grappling with the disease.

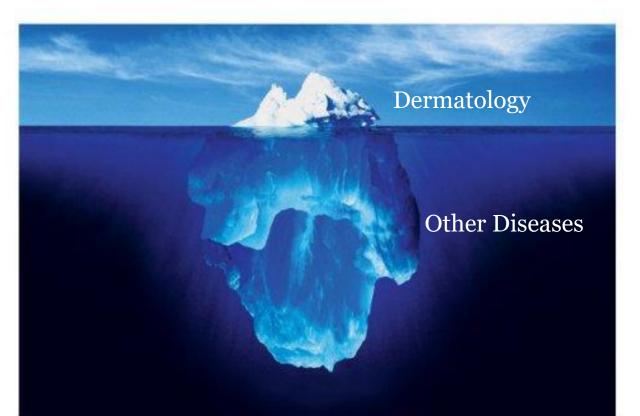


Why this matters...



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GRIDD sets the stage for other (overlooked) disease areas to use the same model and bring the patient/person-centric voice into decision-making about access to care and treatment, and funding for residency places, research and much more.







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Christine Janus, CEO Christine.Janus@globalskin.org

