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International Alliance of
Dermatology Patient
Organizations



Global Research of the Impact of Dermatological Diseases (GRIDD)

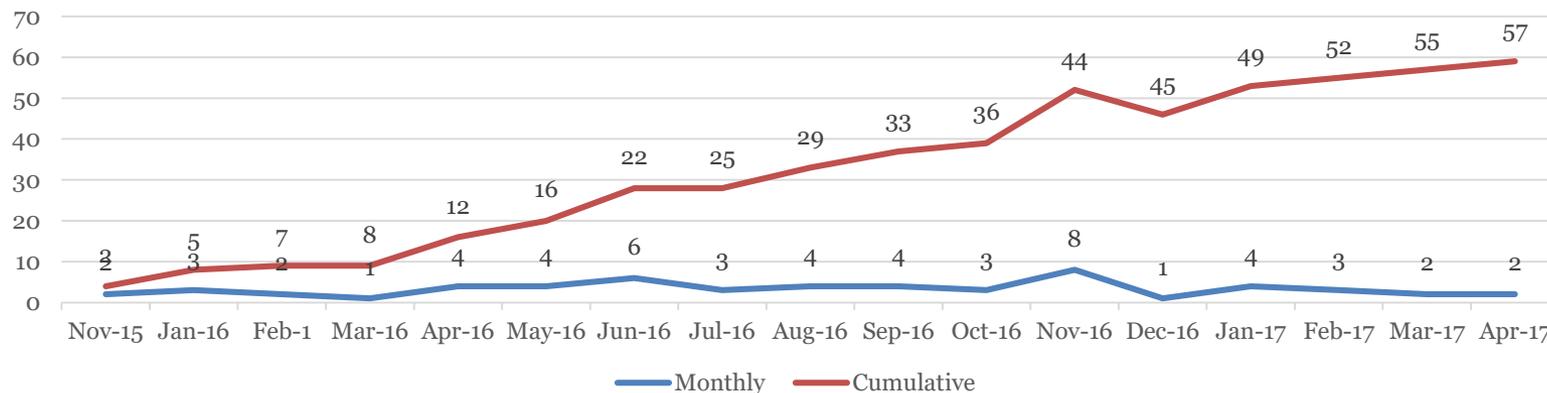
June 2017

Who do we represent?



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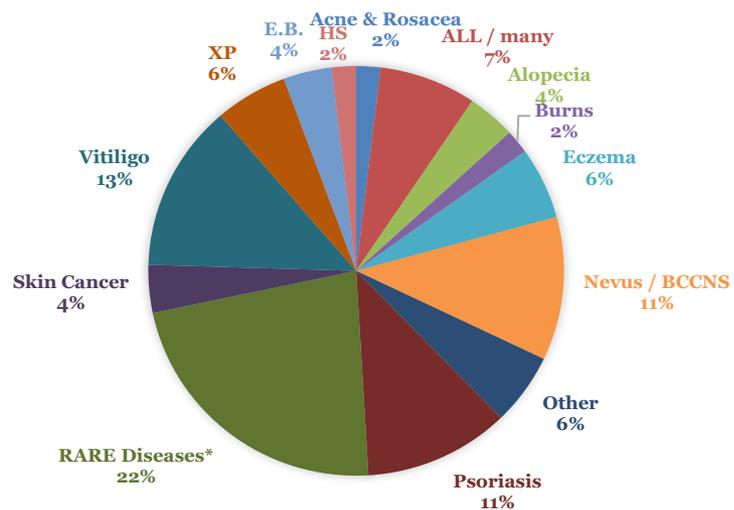
Nearly 60 Patient Organizations and growing...



23 Countries



25 Disease Areas

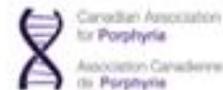
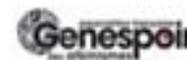
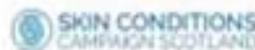
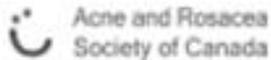


IADPO Members



Association for Lichen Sclerosus and Vulval Health

Cicatricial Alopecia Research Foundation



The Goal: Elevate the importance of dermatology



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A rising tide lifts all boats.

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 false.
- Dermatological diseases are both stigmatized and **minimized**



Quantify Impact?

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



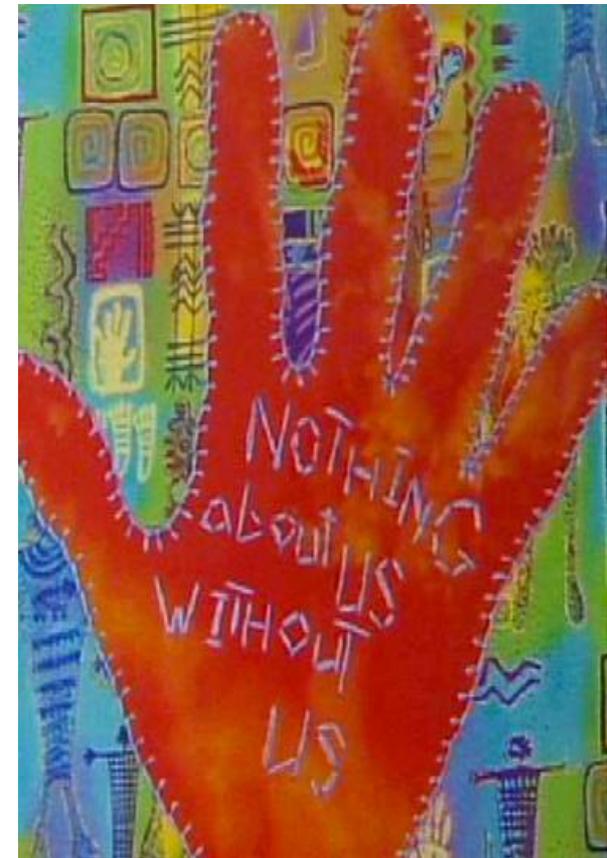
Opportunities



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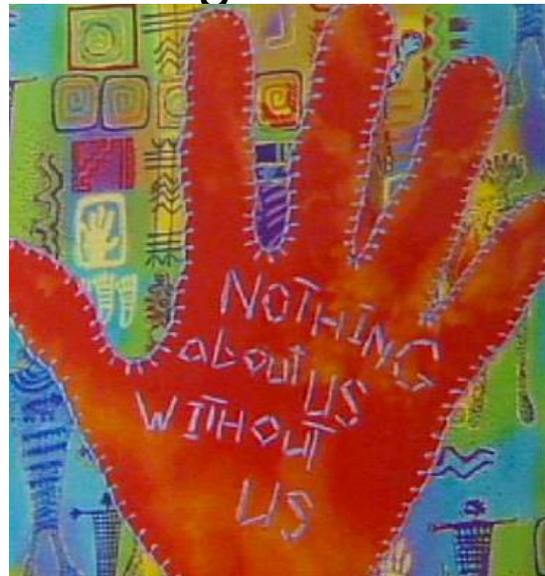
The unique opportunity at this moment in time:

- There is a growing movement worldwide to include “**the patient voice**” in healthcare policy decision-making.
- 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.**

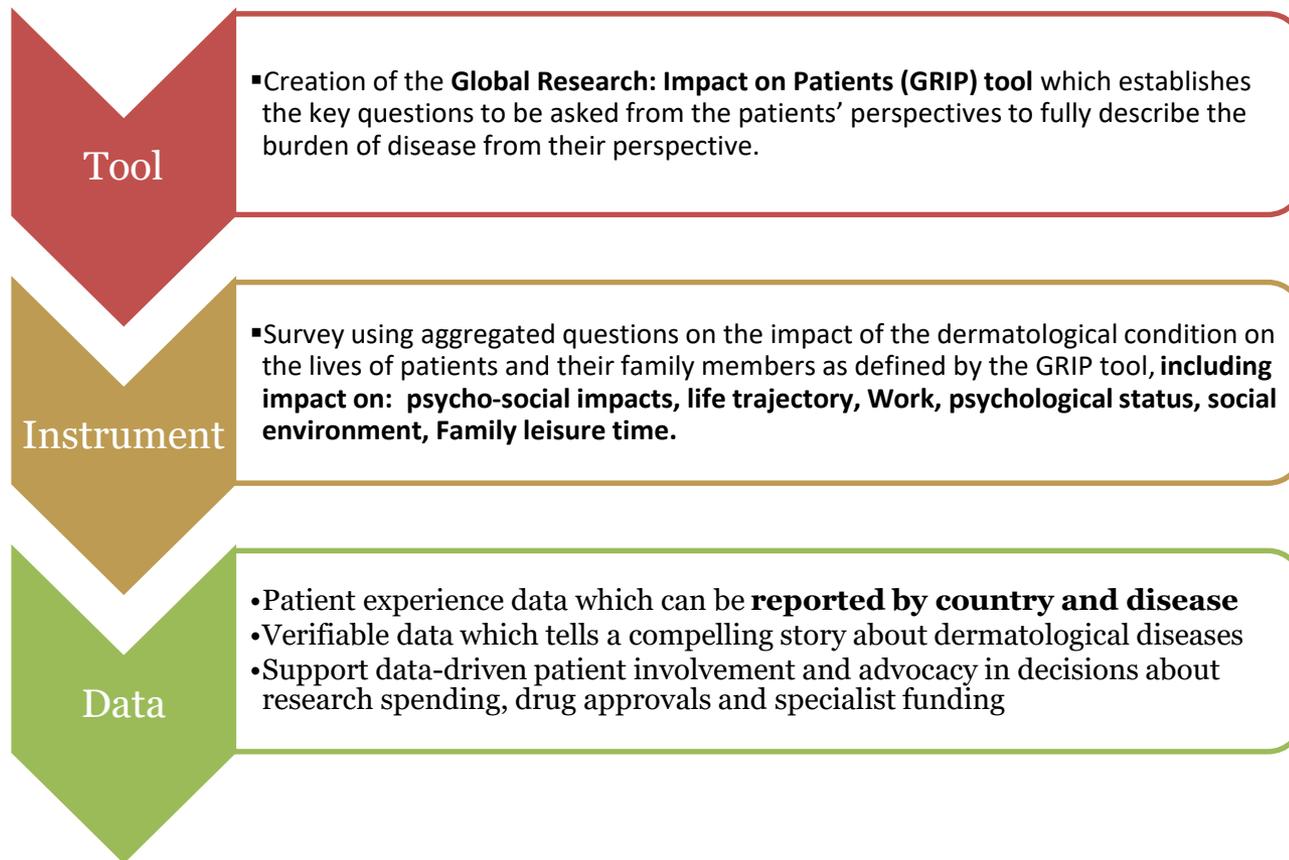


Global Research on the Impact of Dermatological Diseases (GRIDD)

Objective: Using a unique approach, 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.



How GRIDD differs from existing research:



GRIDD
*Global Research on the Impact
of Dermatological Diseases*

- **What is Global Research on the Impact of Dermatological Diseases (GRIDD)?**

- Ground-breaking patient-led impact research
- Questions in Instrument developed by patients, not researchers
- Patient experience data which can be analyzed by country and disease

- **What will this change?**

- Verifiable data which tells a compelling story about dermatological diseases
- Increase credibility for data-driven **patient involvement and advocacy in decisions** about research spending, drug approvals and specialist funding



• The power of data:

- **Patient experience data**
- **Directly from patients**
- Helps **under resourced** patient organizations
- Supports **patient involvement in decisions** about drug approvals
- **Sharper tool** for patient advocacy
- Can be used **in conjunction with clinical outcomes research**





Why GRIDD is important for Dermatology worldwide:

1. Patient–derived measures of impacts to change perceptions
2. Improving advocacy (all levels) to decision-makers
3. Validating existing PROMS and DLQI data
4. Changing the DALY ranking
5. Positive reputational benefits for all organizations and physicians and researchers involved

GRIDD: Outcomes



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- ✓ 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, and give additional support to all stakeholders for **advocacy** for better access to care and treatment



Together we will raise the profile for dermatology



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1. Send us/Give me contact information for all dermatology patient organizations in your country incl. pemphigus /pemphigoid
2. Connect us with your patients who are keen to start a support or advocacy group.
3. Agree to sign up to be a physician supporter. Give me your card or tell Marc Yale.



Calling all patient leaders...



Park & Suites, Genève Aéroport Hotel, 11, rue des Sablonnières • 01 210 Ferney-Voltaire, France



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Thank you



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