



GLOBALSKIN.ORG

International Alliance of  
Dermatology Patient  
Organizations

# Year in Review 2017



# Background

People living with dermatological conditions face stigma, shame and other psychosocial challenges in addition to the physical symptoms of their disease. For many patients, this is a lifelong burden. And in many cultures, this can have devastating social impacts. This simply needs to change.

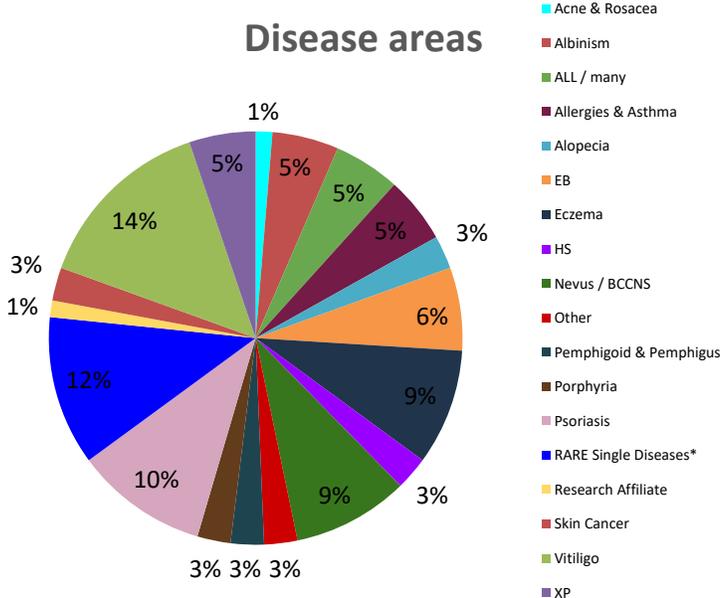
The International Alliance of Dermatology Patient Organizations (IADPO – also known as GlobalSkin) is uniquely positioned to play a leadership role because it serves patient organizations across the full spectrum of dermatological diseases around the world. IADPO is a unique global alliance that is committed to improving the lives of dermatology patients worldwide through research, advocacy and support. IADPO, along with the its members and other dermatology stakeholders, is building a global movement to validate that skin diseases truly impact those with them.

Throughout 2017, IADPO has made significant progress in implementing its highly focused strategic plan centred on research, advocacy and support.

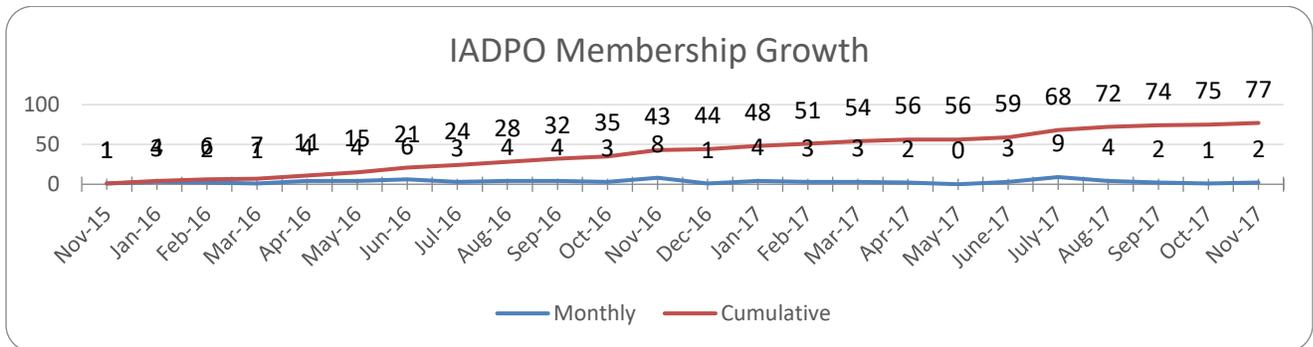
Meet IADPO’s [Board](#) and [staff](#) and find out more about the organization at [www.globalskin.org](http://www.globalskin.org).

# Building the Movement

As of November 2017, IADPO has brought together 77 members from 34 countries, representing 25 disease areas (see IADPO’s [website](#)).



This represents year over year membership growth of 114%. In a year over year comparison, the number of countries IADPO now represents has grown by 94%.



IADPO supported the dermatology patient leader community in 2017 as follows:

- In January, IADPO held its first members-only town hall discussion which attracted 15 patient leaders from around the world. Online networking and interaction is important to our members as many of them have not historically had many opportunities to share their challenges and views with other patient leaders face-to-face. Organizational development strategies, challenges with web site design and the need for a mentorship support program were key topics.
- IADPO hosted two e-learning sessions for members – one on building effective websites and the other on patient advocacy.
- IADPO is helping its members to connect with each other through a new mentorship initiative. Members who have skills to share or who are looking for help are matched with each other through our members-only website.
- IADPO hosted two Skin Matters receptions in 2017 – one at the American Academy of Dermatology (AAD) Annual Meeting in March and one at the European Academy of Dermatology and Venerology (EADV) Congress in September – bringing together patient leaders, physicians, researchers and industry.

*Photos from Skin Matters Reception (AAD):*



## GlobalSkin 2017 Conference

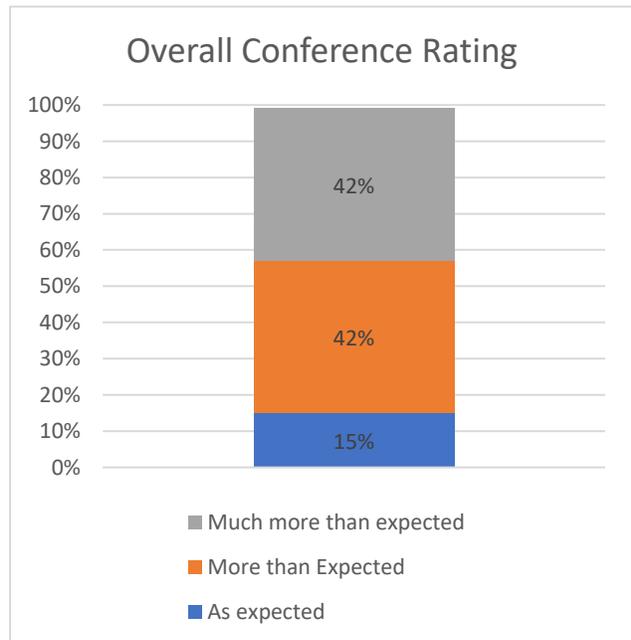
IADPO was pleased to bring together a very diverse group of dermatology patient leaders from around the world representing a significant number of disease areas at its *GlobalSkin 2017* Conference in Ferney-Voltaire in September.

The main objective of the Conference program was to provide patient leaders with real world tools, resources and case studies that will allow them to implement new best practices in their organizations once they returned home following the conference. There were many opportunities to network – a high priority for IADPO members – because they all have so much in common and so

much to share with each other. They all recognized that they are not alone in what they do each and every day to support their patients. Many new mentoring relationships resulted from these interactions.

**GlobalSkin 2017 Conference**

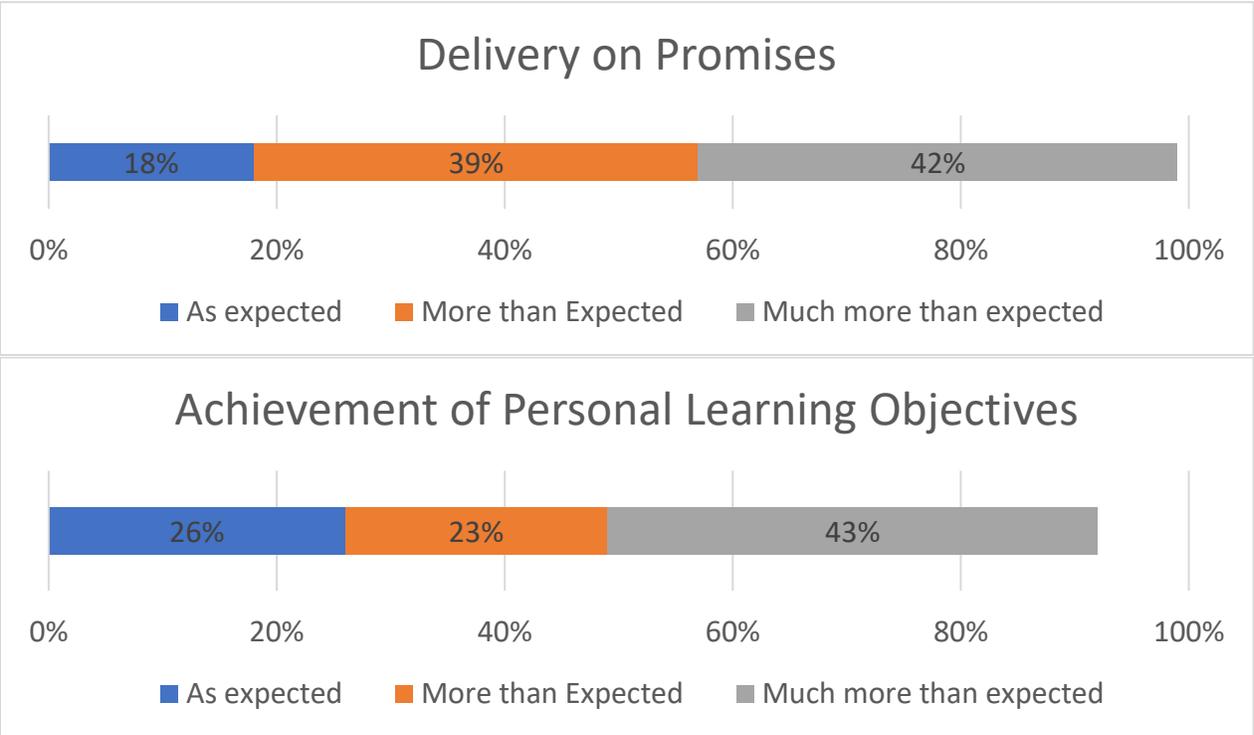
- Nearly 20 countries 14 Diseases
- 20 workshops
- 8 plenary sessions
- ½ day symposium = white papers
- 100% Delegate Satisfaction



It was a very full program which included workshops, IADPO’s Annual General Meeting and a half-day Patient Perspectives Symposium.



IADPO is pleased to report a 100 per cent satisfaction rating among delegates in a post-event evaluation – of which 84 per cent of delegates responded that they benefited either more than expected or much more than expected!



**Here is what some of the delegates had to say:**



*—A truly life-changing experience. I am very excited and filled to the brim with encouragement and fuel for the future.*

*—I loved, loved, loved being able to attend. I will bring all of the information back to my board.*

*—I'm inspired to learn more about our commonalities and develop a plan to work together to raise awareness about ALL skin diseases.*



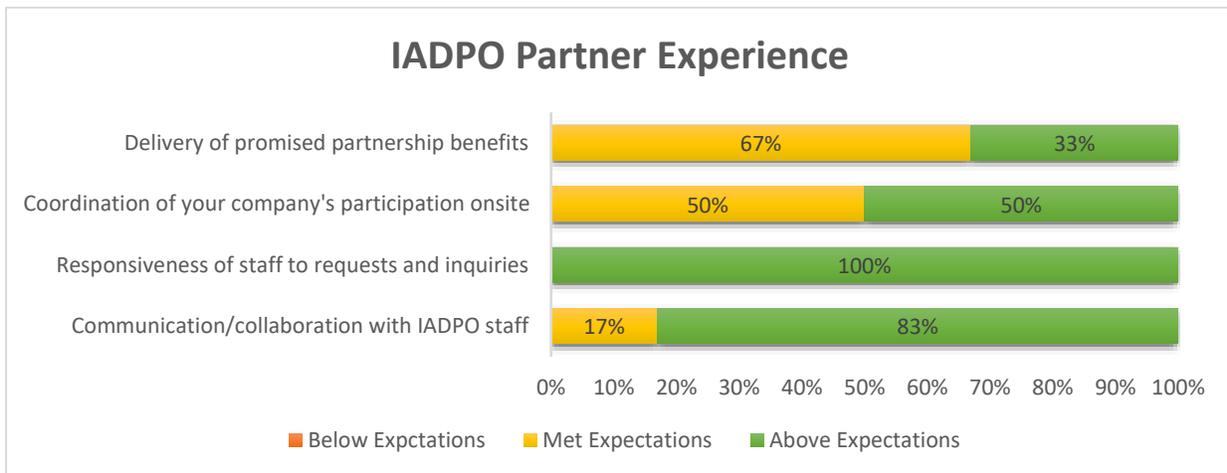
During the conference, IADPO hosted a unique Patient Perspectives Symposium where delegates were tasked with working together to share their valuable input on several key issues that impact them in supporting their patients.



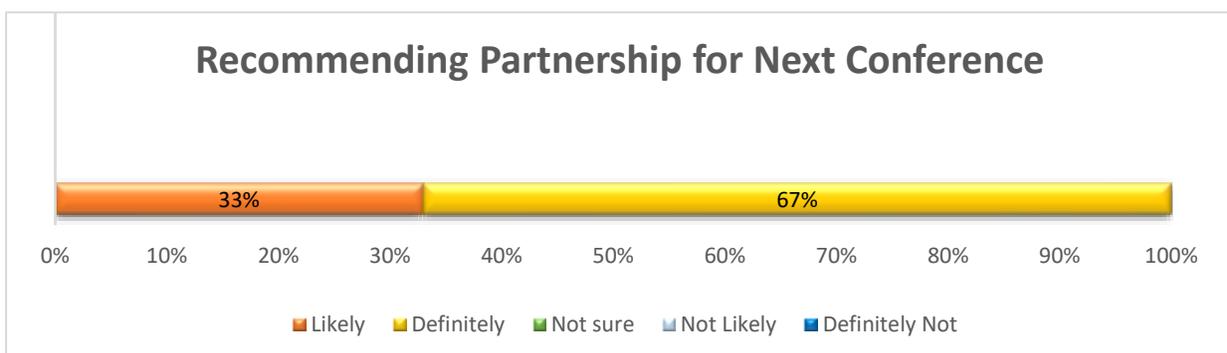
IADPO will publish a series of discussion papers in early-2018 from the input received. Delegates' perspectives are therefore expected to continue to have a direct impact even after the conference has concluded. This is the first time that patient leaders from around the world, representing a host of dermatological diseases have had their collective opinions published. This is but one of the ways that by working together, the GlobalSkin movement will change the way the world sees dermatological diseases.



IADPO's GlobalSkin 2017 industry partners gave the conference top marks in a post-event survey with 83% rating the overall experience of being a conference partner as being above expectations and 88% rating their conference experience as above expectations. More in-depth feedback was also collected:



Based on the survey results (below), IADPO expects most of its partners to be on board again for its 2019 conference in Italy.



## Global Research on the Impact of Dermatological Diseases (GRIDD)

The Global Research on the Impact of Dermatological Diseases (GRIDD) Research Team kick-off meeting took place in July in Hamburg, Germany, where the IADPO team and key researchers — Dr. Christine Bundy, Dr. Matthias Augustin and members of their team — met to further develop the work plan, timelines and team roles for the project.



A second team meeting took place in September in Ferney-Voltaire, France and work is now complete on the methodology — a very significant milestone of the initial phases of this project.

Two important presentations on GRIDD took place in September. In a scientific session that IADPO co-organized at the EADV Congress in Geneva, Dr. Augustin, our Board President Jean-Marie Meurant and our CEO Christine Janus presented on GRIDD.



# Stakeholder Engagement

IADPO has actively engaged with stakeholders in the dermatology community over the past year. Following is a synopsis of collaborations that have taken place:



- IADPO’s CEO Christine Janus had several formal meetings with officials at the World Health Organization (WHO) during the World Health Assembly in June. This served as an opportunity to discuss the GRIDD project and to pave the way for raising the profile for dermatological conditions.
- Dr. Cherian Varghese, Coordinator, Management of Non-Communicable Diseases at the WHO spoke at the GlobalSkin 2017 Conference.



- Christine Janus was invited to participate in the Person-Centred Medicine conference (May 2017) and made two presentations on IADPO’s behalf – one on GRIDD and another on the importance of working with Patient organizations.
- The Coalition of Skin Diseases (CSD) included IADPO on its March Annual General Meeting agenda by providing an opportunity for Christine Janus to speak about the power of a collective patient voice and the benefits of participating in our patient-driven research project, GRIDD.
- IADPO member Marc Yale invited Christine Janus to be a guest speaker, sharing the innovative Global Research on Impact (GRIP) tool and rationale for GRIDD at their International Pemphigus & Pemphigoid Foundation Conference, in March in Lübeck, Germany.
- IADPO was proud to co-organize and co-host an official scientific session at the EADV Congress in Geneva this past September. The session, *“Changing the Way the World Perceives Dermatology”*, was an innovative, interactive 90-minute dialogue session on the big challenges in dermatology – today and tomorrow.



## Partnerships

IADPO is grateful to industry partners for supporting its mission to improve the lives of those affected by dermatological disorders around the world. Their commitment and generosity has allowed IADPO to undertake many important initiatives this past year, which directly helps patient leaders and the patients they serve.

Founding Visionary Partners	LEO and Celgene
2017 Core Mission Partners	LEO (Gold) Sanofi Genzyme (Bronze) Galderma (Contributor)
GlobalSkin 2017 Conference Partners	LEO (Platinum) Sanofi Genzyme & Regeneron (Bronze) Galderma (Bronze) Celgene (Bronze) Novartis (Champion)
GRIDD Partners	Sanofi Genzyme & Regeneron (Contributor) Galderma (Contributor) Novartis (Supporter)
Grant Contribution	AbbVie

## Looking Ahead to 2018

In the coming year, 2018, IAPDO will continue to build and mature as an organization as it delivers on key commitments related to its three strategic pillars: research, advocacy and support. Its focus will be on continued membership building and support, preparing to host the *GlobalSkin 2019* conference and undertaking phases 2 and 3 of the evidence-building GRIDD project.

In order to do all of this, it will be essential for IADPO to grow its membership base; broaden awareness and strengthen its reputation among dermatology stakeholders; continue building relationships with the WHO and at the United Nations (UN), and with key government leaders; continue demonstrating its value proposition as a key patient leader resource; and continue to build capacity to manage a growing number of projects and initiatives.

A rising tide lifts all boats. By shining a spotlight on the importance of all people suffering with a dermatological condition, IADPO, along with its members and the dermatology community, will improve the likelihood that decision-makers see the claims made by people living with a particular dermatological condition as valid and worth supporting.

**For more information on Membership, please contact:**

Shona Fleming, Membership Director

[Shona.Fleming@globalskin.org](mailto:Shona.Fleming@globalskin.org)

**To explore partnership opportunities, please contact:**

Jennifer Austin, Executive Director

[Jennifer.Austin@globalskin.org](mailto:Jennifer.Austin@globalskin.org)