



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

## Conference Program

Hosted by:



[GLOBALSKIN.ORG](http://GLOBALSKIN.ORG)

International Alliance of  
Dermatology Patient  
Organizations



## Friday, September 15

09:00-13:00	<p><b>Registration – Delegates and Speakers</b></p> <p><b>Disease &amp; Region-specific Discussions</b></p>
12:00 – 13:00	<b>Lunch</b>
13:00-13:45	<p><b>Conference Opening</b>  <i>Welcoming remarks by IADPO’s President, Jean-Marie Meurant and GlobalSkin 2017 Conference facilitator Kathy Redmond</i></p>
13:45-14:05	<p><b>Plenary Session:</b>  <b>One Skin – The Common Experience of Dermatological Diseases</b>  <i>Gitte Aabo, President and CEO of LEO Pharma</i></p>
14:05-14:35	<p><b>What do we need to excel in our roles?</b>  <i>Kathy Redmond, facilitated discussion to define needs of delegates and their organizations and to establish shared conference objectives</i></p>
14:35-14:55	<b>Health Break</b>
14:55 - 15:25	<p><b>Break-out Sessions:</b></p> <ol style="list-style-type: none"> <li>1. Putting Patients at the Centre of their Own Solutions – <b>Jorge Luis Perez Hidalgo, Vitiligo Support and Research Group, Cuba</b></li> <li>2. Developing a Communications/Outreach Strategy that Brings Results – <b>Catie Coman, Heath Advocacy Partners, USA</b></li> <li>3. Brave Leaders – <b>Margareta Barchan, Business Advisor in Strategy, Leadership and Sustainability, Switzerland</b></li> </ol>
15:30-16:00	<p><b>Break-out Sessions:</b></p> <ol style="list-style-type: none"> <li>1. Using National Report Cards for Advocacy – <b>Christine Clarke, IADPO, Canada</b></li> <li>2. Key components of Successful Websites - <b>Steve Clarke, IADPO, Canada</b></li> <li>3. Best practices for engaging your patient community with their own health care – <b>Catie Coman, Health Advocacy Partners, USA</b></li> </ol>
16:00-16:30	<p><b>Plenary</b>  <b>The critical importance of the patient voice – A WHO perspective</b>  <i>Dr. Cherian Varghese, Coordinator, Management of NCDs, WHO</i></p>
16:30-17:05	<p><b>IADPO Report from the President</b>  <i>Jean-Marie Meurant, President, IADPO (and l'Association Française du Vitiligo) IADPO’s progress and achievements over the past year</i></p>
17:05-17:20	<p><b>IADPO Annual General Meeting</b>  <i>(Members only)</i></p>
18:30-19:30	<p><b>Networking Reception</b>  <i>Mix and mingle with a fun activity for delegates to meet each other</i></p>
19:30-21:30	<b>One World Dinner</b>

*Delegates are encouraged to wear or carry something with them that signifies their country.*

## Saturday, September 16

07:00-08:30	<p><b>Breakfast</b></p> <p><b>Optional: Mentoring Tables – meet with an ‘expert’ for breakfast</b></p>
08:30-09:35	<p><b>Plenary Session:</b></p> <p><b>The Power of the Patient Voice –</b> <i>Our patients deserve access to excellent care and treatment. In this session, we explore the significance of data and its positive impact on evidence-based advocacy. IADPO’s Global Research on the Impact of Dermatological Diseases (GRIDD) will play a leading role in improving outcomes for the people we all serve. How does your organization fit into the GRIDD project? How can this ground-breaking patient initiative help your organization improve your clout with decision-makers and the media, your attractiveness to funders and boost the power of your patients’ voices?</i></p> <p><b>Panelists:</b> <i>Jean-Marie Meurant, President, IADPO (and l'Association Française du Vitiligo) Christine Janus, IADPO; Dr. Chris Bundy, University of Cardiff</i></p>
09:35-10:35	<p><b>Plenary Session:</b></p> <p><b>Healthcare Value assessments – Injecting the Patient Voice</b></p> <p><i>Who makes decisions on which medications are covered and how do they do it? Our panel of thought leaders will examine and explore Health Technology Assessment (HTA) models from around the world to help you better understand this complex landscape that so significantly impacts patients.</i></p> <p><b>Panelists:</b> <i>Julie Block, National Eczema Association, USA; Jasmin Barman, Swiss Society for Porphyria, Switzerland; Christine Janus, IADPO - Moderator</i></p>
10:35-10:55	<p><b>Health Break</b></p>
10:55-11:25	<p><b>Break-out Sessions:</b></p> <ol style="list-style-type: none"> <li>1. Grassroots Fundraising – Raising funds from your base and beyond – <b>Jean Pickford, Basal Cell Carcinoma Nevus Support Network, USA</b></li> <li>2. Tools that Work – Learn and share the tools that work hard, so you don’t have to – <b>Jennifer Austin, IADPO, Canada</b></li> <li>3. Leveraging your Brand: Your Brand has value. How do you use it so you can grow? – <b>Susan Thornton, Cutaneous Lymphoma Foundation, USA</b></li> </ol>

11:30-12:00	<b>Break-out Sessions:</b> <ol style="list-style-type: none"> <li>1. Patient organization-initiated Research – How to create value for your organization while building a credible patient voice – <b>Julie Block, National Eczema Association, USA</b></li> <li>2. Social Media: What works, what doesn't, tools to help you meet your communications goals – <b>Helen Crawford, Canadian Skin Patient Alliance, Canada</b></li> <li>3. The Power of Story-telling – <b>Ogo Maduewesi, VITSAF, Nigeria; Leigh-Anne Nel, XP Society, South Africa</b></li> </ol>
12:00-13:30	<b>Lunch Break</b>
13:30-17:00	<b>Patients' Perspectives Symposium</b> <i>Your voice matters! Patient organization leaders will openly discuss key issues in rotating round tables. These leaders' experience and insights will inform a series of White Papers to help dermatology stakeholders better understand the challenges and opportunities related to dermatology patient organizations and help better meet patient needs.</i> <ol style="list-style-type: none"> <li>1. <b>What needs to be done so that the true impacts of dermatological diseases are well understood?</b></li> <li>2. <b>How can we best empower dermatology patients so they get the best possible care?</b></li> <li>3. <b>How can we use technology to better serve our patients?</b></li> <li>4. <b>How can we improve the effectiveness of patient advocacy in Dermatology?</b></li> <li>5. <b>How can we best make the GRIDD project work for your organization?</b></li> </ol>
18:30-21:30	<b>Patients First Dinner – Edelweiss Restaurant, Geneva</b> <i>Official conference banquet for all delegates</i>  <i>Transportation of all delegates has been arranged by coach buses.</i> <b>Meet in lobby at 18:00</b>

## Sunday, September 17

07:00-08:30	<p><b>Breakfast</b></p> <p><b>Optional: Mentoring Tables – meet with an ‘expert’ for breakfast</b></p>
08:30-09:10	<p><b>Plenary Session:</b></p> <p><b>Scientific Advances in Dermatological Care</b>  <i>Dr. Jan Dutz MD FRCPC, Professor, Department of Dermatology and Skin Science, University of British Columbia, Canada</i></p>
09:15-10:00	<p><b>Plenary Session:</b></p> <p><b>Shared Objectives –benefits and challenges of collaboration between patient organizations and pharma</b>  <i>Patient organization leaders and industry representatives focus on how to establish excellent partnerships and get the most out of collaborations to achieve our mutual objective of supporting patients.</i>  <b>Panelists: Tobias Cottmann, LEO Pharma; François Blanchette, Galderma; Laura McKeaveney, Novartis</b></p>
10:00-10:20	<p><b>Health Break</b></p>
10:20-10:50	<p><b>Break-out Sessions:</b></p> <ol style="list-style-type: none"> <li>1. Building your Strategic Plan – Key methods and approaches to consider as you build a plan to keep your group well organized and on course – <b>Murray Turner, Psoriasis Australia, Australia</b></li> <li>2. Advocacy campaigns: Guided planning session – we will help you create your own targeted advocacy strategy – <b>Wendy Sauvé, Canadian Association for Porphyria, Canada</b></li> <li>3. Awareness Raising – Developing a National Awareness Campaign to support advocacy goals – <b>Carla Jones, Allergy UK</b></li> </ol>
10:55-11:25	<p><b>Break-out Sessions:</b></p> <ol style="list-style-type: none"> <li>1. Ask the Expert – Building strong organizations – <b>Jean Pickford, Basal Cell Carcinoma Nevus Support Network, USA</b></li> <li>2. Burn-out: Strategies to avoid volunteer and staff burn-out – <b>Susan Thornton, Cutaneous Lymphoma Foundation, USA</b></li> <li>3. Working Ethically with Industry – <b>Julie Block, National Eczema Association, USA</b></li> </ol>
11:30-12:00	<p><b>Break-out Sessions:</b></p> <ol style="list-style-type: none"> <li>1. Using YouTube and Vimeo to raise your profile – <b>Steve Clarke, IADPO, Canada</b></li> <li>2. Newsletter and Other Outreach Tools to Reach Patients and Other Audiences – <b>Helen Crawford, Canadian Skin Patient Alliance, Canada</b></li> <li>3. Challenge of the Taboo (How to raise the profile of the diseases no one wants to discuss) – <b>Fabia Brackenbury, Association for Lichen, UK Sclerosis and Vulval Health, UK</b></li> </ol>

12:00-13:00	<b>Lunch Break</b>
13:00-13:40	<p><b>Plenary Session:</b>  <b>How Patient Organizations Can Lead through 'Thought Leadership'</b>  <i>What is “thought leadership” and why should my organization aspire to this role? Experts challenge us with the power of creating unique content, curating existing information and the significance of “big ideas”.</i>  <b>Panelists: Jennifer Austin, IADPO; Antoine Gliksohn, Genespoir, France; Catie Coman, Health Advocacy Partners, USA; Maya Tulpule, Shweta Association, India</b></p>
13:40-14:00	<p><b>Special Guest Speaker – Margareta Barchan, Business Advisor in Strategy, Leadership and Sustainability, Switzerland</b>  <b>Topic: Brave Leaders</b></p>
14:00-14:50	<p><b>Plenary Session:</b>  <b>Building the Movement</b>  <i>Working together, we will recap outcomes and insights that have emerged throughout the conference and build the next steps to bring about change.</i>  <b>Panelists: Kathy Redmond, Christine Janus, IADPO</b></p>
14:50- 15:00	<p><b>Closing Remarks</b>  <i>Jean Marie Meurant, IADPO Board President</i></p>
<b>Post Conference Activities</b>	
15:00-17:00	<p><b>Disease- &amp; Region-specific Discussions (<a href="#">Reserve your meeting space</a>)</b></p> <ol style="list-style-type: none"> <li>1. Rare Diseases – Group meeting – Main Meeting Room</li> <li>2. Vitiligo – Groups meeting – Main Meeting Room</li> <li>3. Psoriasis – Groups meeting (TBC)</li> <li>4. Bullous diseases – Groups (TBC)</li> <li>5. North American Associations</li> </ol> <p>If you have another group that would like to meet, please feel free to ask for <a href="#">assistance</a>.</p>
18:00	<b>Informal Dinner (on your own)</b>

GlobalSkin Plenary Speaker and Workshop leader biographies and photos can be found on the GlobalSkin Conference website [globalskin.org/program](http://globalskin.org/program).

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