



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

Conference Program

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Hosted by:



GLOBALSKIN.ORG

International Alliance of
Dermatology Patient
Organizations

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

Saturday, September 16

07:00-08:30	Breakfast Optional: Mentoring Tables – meet with an ‘expert’ for breakfast
08:30-08:45	Greetings <i>Remarks by dermatology stakeholder organizations – EADV and others TBC</i>
08:45-09:15	Plenary Session: The Power of the Patient Voice – influencing decision makers <i>Exploring the significance of data and its positive impact on evidence-based advocacy. Also learn how IADPO’s Global Research on the Impact of Dermatological Diseases (GRIDD) will play a leading role.</i> Panelists: Jean-Marie Meurant, President, IADPO (and l'Association Française du Vitiligo) and other experts TBC
09:15-09:35	Plenary Session: Why GRIDD? <i>Find out how your organization fits into the GRIDD project, and how you can make this a ground-breaking patient initiative that directly helps organizations that get involved to improve the power of their voices, their attractiveness to funders, and their visibility with decision-makers and the media.</i> Panelists: Christine Janus, IADPO; Dr. Chris Bundy, University of Cardiff
09:35-10:35	Plenary Session: Healthcare Value assessments - Injecting the Patient Voice <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> Panelists: Julie Block, National Eczema Association; Eva Maria Ruiz de Castilla, Esperanta; Jasmin Barman, Swiss Society for Porphyria; HTA experts
10:35-10:55	Health Break
10:55-11:25	Break-out Sessions: <ol style="list-style-type: none"> 1. Grassroots Fundraising –Raising funds from your base and beyond – Jean Pickford, Basal Cell Carcinoma Nevus Support Network 2. Tools that Work – Learn and share the tools that work hard, so you don’t have to – Jennifer Austin, IADPO 3. Leveraging your Brand: Your Brand has value. How do you use it so you can grow? – Susan Thornton, Cutaneous Lymphoma Foundation

11:30-12:00	Break-out Sessions: <ol style="list-style-type: none"> 1. Patient organization-initiated Research – How to create value for your organization while building a credible patient voice – Julie Block, National Eczema Association 2. Social Media: What works, what doesn't, tools to help you meet your communications goals – Helen Crawford, Canadian Skin Patient Alliance 3. The Power of Story-telling – Ogo Maduewesi, VITSAF; Leigh-Anne Nel, XP Society
12:00-13:30	Lunch Break
13:30-17:00	Patients' Perspectives Symposium <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>
18:30-21:30	Patients First Dinner – Edelweiss Restaurant, Geneva <i>Official conference banquet for all delegates</i> <i>Transportation of all delegates has been arranged by coach buses.</i> Meet in lobby at 18:00

Sunday, September 17	
07:00-08:30	Breakfast Optional: Mentoring Tables – meet with an ‘expert’ for breakfast
08:30-09:15	Plenary Session: How Patient Organizations Can Lead through 'Thought Leadership' <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> Panelists: Jennifer Austin, IADPO; Antoine Gliksohn, Genespoir; Catie Coman, Health Advocacy Partners
09:15-10:00	Plenary Session: Shared Objectives – the benefits and challenges of collaboration between patient organizations and pharma <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> Panelists: Vanina Laurent-Ledr, Sanofi; Tobias Cottmann, LEO Pharma; François Blanchette, Galderma; TBC, Novartis
10:00-10:20	Health Break
10:20-10:50	Break-out Sessions: <ol style="list-style-type: none"> 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. – Murray Turner, Psoriasis Australia 2. Advocacy campaigns: Guided planning session – we will help you create your own targeted advocacy strategy. Wendy Sauvé, Canadian Association for Porphyria 3. Awareness Raising – Developing a National Awareness Campaign to support advocacy goals – Carla Jones, Allergy UK
10:55-11:25	Break-out Sessions: <ol style="list-style-type: none"> 1. Ask the Expert – Building strong organizations – Jean Pickford, Basal Cell Carcinoma Nevus Support Network 2. Burn-out: Strategies to avoid volunteer and staff burn-out – Susan Thornton, Cutaneous Lymphoma Foundation 3. Working Ethically with Industry – Julie Block, National Eczema Association
11:30-12:00	Break-out Sessions: <ol style="list-style-type: none"> 1. Using YouTube and Vimeo to raise your profile – Steve Clarke, IADPO 4. Newsletter and Other Outreach Tools to Reach Patients and Other Audiences - Helen Crawford, Canadian Skin Patient Alliance 2. Challenge of the Taboo (How to raise the profile of the diseases no one wants to discuss) – Fabia Brackenbury, Association for Lichen Sclerosus and Vulval Health

12:00-13:00	Lunch Break
13:00-13:20	Special Guest Speaker - Margareta Barchan Brave Leadership
13:20-14:30	Plenary Session: Advances in Dermatological Care <i>TBC</i>
14:30-14:50	Plenary Session: Building the Movement <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> Panelists: Kathy Redmond, Christine Janus, IADPO
14:50- 15:00	Closing Remarks <i>Jean Marie Meurant, IADPO Board President</i>
Post Conference Activities	
15:00-17:00	Disease- & Region-specific Discussions (Reserve your meeting space) <ol style="list-style-type: none"> 1. Rare Diseases – Group meeting 2. Vitiligo – Groups meeting (TBC) 3. Psoriasis – Groups meeting (TBC) 4. Bullous diseases – Groups (TBC) 5. North American Associations <p>If you have another group that would like to meet, please feel free to ask for assistance.</p>
18:00	Informal Dinner (on your own)

Monday, September 18	
Morning — Time to be Announced	Post-Conference Activity: World Health Organization (WHO) Meetings and Tour <i>TBC</i>