



GLOBALSKIN 2019
CONFERENCE PROGRAM

JUNE 7 – 9, 2019



GLOBALSKIN.ORG

International Alliance of
Dermatology Patient
Organizations



Friday, June 7

08:00 – 17:00	Patient Organization Village
08:00 – 17:00	Partner Village <i>Set up 08:00 – 10:00</i>
08:00 – 10:00	GlobalSkin 2019 Conference Registration <i>Located in the hotel lobby</i>
10:00 – 10:10	GlobalSkin 2019 Official Opening Ceremony <i>Jean-Marie Meurant, GlobalSkin President</i> <i>Christine Janus, GlobalSkin CEO</i>
10:10 – 10:40	Plenary Session: Power of the Patient Voice (Platinum Partner) <i>Tine Rikke Joergensen, Global Public Affairs - LEO Pharma</i>
10:40 – 11:00	Succeeding Together <i>Kathy Redmond – Facilitator</i>
11:00 – 12:00	Plenary Session: Leading Edge Science of the Skin With moderated Questions and Answers <i>Professor Dr. Luigi Naldi (Italy), Dermatology Expert</i>
12:00 – 13:00	Lunch in Hilton's Atmosphere Restaurant
13:00 – 14:15	Plenary Session: Advancing Dermatological Care and Treatment (Expert Panel) This multi-stakeholder panel session will focus on current trends in dermatology, including biologics, which demonstrate a turning point in patient care and build hope for the future. A moderated discussion with questions and answers will follow. <i>Presenters:</i> <i>Dr. John Su (Australia)</i> <i>Professor Dr. Luigi Naldi (Italy)</i> <i>Susan Thornton, Cutaneous Lymphoma Foundation (USA)</i>
14:20-16:00	Break-out Sessions: <i>(Each 45 min session will be offered at an Introductory and In-Depth level)</i> <i>14:20 – 15:05 – Session 1 (Introductory)</i> <i>15:15 – 16:00 – Session 2 (In-Depth)</i>
	1. Building Funding Proposals that Demonstrate Value Through this workshop you will understand how partnerships evolve and the key elements contained in most proposals and resources to help guide you in your next proposal development exercise. (Session 1 and Session 2) <i>Lisa Butler – National Eczema Association (USA), Asia Room</i>
	2. Creating Compelling Public Awareness Campaigns Building a skin disease awareness campaign for the general public to improve their understanding. (Session 1 and Session 2) <i>Leigh-Anne Nel – XP South Africa (South Africa), Oceania Room</i>
	3. Developing Advocacy Strategies in Dermatology Learn how to build an effective advocacy strategy with tools, tactics and tips to strengthen your efforts. (Session 1 and Session 2) <i>Kathleen Gallant – International Federation of Psoriasis Associations (USA), Africa Room</i>

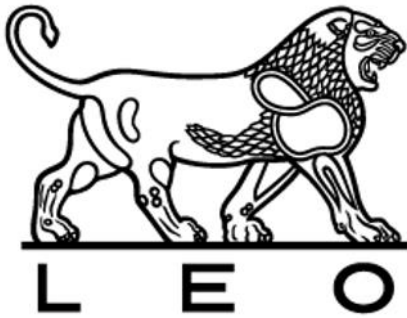
16:00 – 16:20	Health Break
16:20 – 16:35	Plenary: IADPO's Code of Conduct: Raising the Bar for Patients <i>Christine Janus, GlobalSkin CEO</i>
16:35 – 17:00	IADPO Board President's Report <i>Jean-Marie Meurant, GlobalSkin President</i>
17:00 – 17:30	Special Meeting of the Members <i>Jean-Marie Meurant, GlobalSkin President</i>
18:00 – 19:00	Networking Reception <i>Bar area of hotel</i>
19:00 – 21:30	One World Dinner with Keynote <i>Atmosphere Restaurant – Hilton Hotel</i> <i>19:00 – 20:00 Keynote: Jitske Kramer – Human Dimensions (Netherlands)</i> <i>20:00 – 21:30 Dinner</i> <i>Delegates are encouraged to wear or bring something that symbolizes their country.</i>
Saturday, June 8	
07:00 – 08:45	Breakfast
08:00 – 17:00	Patient Organization Village
08:00 – 17:00	Partner Village
09:00 – 09:05	Day 2 Opening Remarks <i>Kathy Redmond – Facilitator</i>
09:05 - 10:30	Plenary Session: Evidence Based Advocacy This panel discussion will focus on the need for evidence to advance a patient organization's advocacy efforts. Covering the challenges, pitfalls, and successes of gathering the evidence, sharing experiences and why this information is so important to decision makers. Questions & Answers session will follow. <i>Presenters:</i> <i>Neil Bertelsen – Neil Bertelsen Consulting (Germany)</i> <i>Amanda Cresswell-Melville – Eczema Society of Canada (Canada)</i> <i>Silvia Fernandez Barrio – Psoriasis Association of Argentina (Argentina)</i> <i>Nathalie Bere – European Medicines Agency (United Kingdom)</i>
10:30 - 10:50	Health Break
10:50 - 12:00	Plenary Session: The Increasing Demand for Patient-initiated Research: the GRIDD Response Presentation on the importance of the Global Research on the Impact of Dermatological Diseases (GRIDD) project. Learn about this ground-breaking research project, current milestones and patient organization involvement. Questions and Answers will follow. <i>Presenters:</i> <i>Professor Christine Bundy, Cardiff University (UK)</i> <i>Christine Janus, GlobalSkin CEO</i>
12:00 - 13:00	Lunch in Hilton's Atmosphere Restaurant
13:00 - 14:40	Break-out Sessions: <i>(each 45 min session will be offered at an Introductory and In-Depth level)</i> <i>13:00 – 13:45 – Session 1 (Introductory)</i> <i>13:55 – 14:40 – Session 2 (In-Depth)</i>

	<p>1. Building Mutually Beneficial Partnerships How to build effective and beneficial relationships with pharma partners and other key industry stakeholders. (Session 1 and Session 2) <i>Maggie Young – Allergy UK (United Kingdom), Oceania Room</i></p>
	<p>2. Qualitative and Quantitative Research How to collect qualitative and quantitative data through questionnaires and surveys. (Session 1) How to utilize focus groups to collect rich and informative patient data. (Session 2) <i>Jennifer Austin – GlobalSkin (Canada), Asia Room</i></p>
	<p>3. Building Your Organization’s Research Culture This workshop is designed to help delegates understand the fundamentals necessary to engage your organization, patient community and researchers. (Session 1) Learn how you can develop programs that will change and shape the direction of research for your community. (Session 2) <i>Marc Yale – International Pemphigus & Pemphigoid Foundation (US), Africa Room</i></p>
14:40 -15:00	Health Break
15:00 -16:40	Break-out Sessions: (each 45 min session will be offered at an Introductory and In-Depth level) 15:00 – 15:45 – Session 1 (Introductory) 15:55 – 16:40 – Session 2 (In-Depth)
	<p>1. Fundraising Approaches that Work Taking the Fear Out of Fundraising - Learn effective strategies to help diversify your organization’s fundraising efforts from grassroots fundraising to engaging with donors. (Session 1 and Session 2) <i>Madeline Miller – Cicatricial Alopecia Research Foundation CARF (USA), Oceania Room</i></p>
	<p>2. Strategic Planning How Strategic Planning can lead to organizational success. (Session 1), Stakeholder Mapping – identify and define your organization’s stakeholders (Session 2) <i>Kathy Redmond, Redmond Consulting (Switzerland), Asia Room</i></p>
	<p>3. Member Engagement and Communications <i>What to say and how to say it</i> - An Introduction to Social media and other communication tools to help you spread your message and maximize your engagement with your members (Session 1) <i>Is Anybody Listening?</i> - How to tell if you are actually reaching your audience. Tips and tools to analyze your reach within your communities and if your message is really being heard. (Session 2) <i>Helen Crawford – Canadian Skin Patient Alliance (Canada), Africa Room</i></p>
16:40-17:00	Revisiting Themes and Key Learnings <i>Kathy Redmond (Facilitator)</i>
18:00	Bus transportation to Crola Winery departing from Hilton Hotel (meet in Lobby at 17:50)
18:15	Bus transportation to Crola Winery departing from Best Western Hotel (meet in Lobby at 18:05)
18:45 - 22:00	Patients First Dinner (off-site) co-hosted by GlobalSkin and Albinet (Partner Awards)

Sunday, June 9

07:00 – 08:20	Breakfast
08:00 – 13:00	Patient Organization Village
08:00 – 13:00	Partner Village
08:30 – 08:40	Remarks: Professor Harvey Lui, Past President - International League of Dermatological Societies (ILDS)
08:40 – 10:10	<p>Plenary Session: Supporting Patients Together – collaboration between patient organizations and industry</p> <p>Industry representatives focus on how patient organizations can establish excellent partnerships with industry and get the most out of these collaborations to achieve our mutual objective of supporting patients. Questions & Answers session to follow.</p> <p><i>Pharma Presenters:</i> <i>Klaus Legau, LEO Pharma</i> <i>Ilana Tabak, Regeneron (representing Sanofi Genzyme Regeneron)</i> <i>Sylvie St-Laurent, Pfizer</i></p>
10:10 – 10:30	Health Break
10:30 – 11:30	<p>Living Library Sessions</p> <p>The <i>GlobalSkin 2019</i> Conference Living Library is a highly interactive and lively session that provides participants with the opportunity seek out mentorship with delegates who have experience on topics of interest. (Delegates participate in 2 topics with an expert x 30 min each)</p> <ol style="list-style-type: none"> 1. Governance and Organizational Effectiveness – Lex van der Heijden (Netherlands) 2. Service brand, advantage of network (client service) – Xingxiang Shi (China) 3. Working directly with Government Decision Makers – Ogo Maduewesi (Nigeria) 4. Coalition Building – Brian Fisher (USA) 5. Working with Media – Cheryl Talent (Australia) 6. Building global network to further your disease awareness – Antoine Gliksohn (France) 7. Market Research – Shona Fleming (Canada) 8. Digital Communications – Signify (Denmark) 9. Building online networks – Maria Picone (USA) 10. Building research partnerships to find a cure – Michelle Hall, (USA)
11:30 – 11:40	<p>Introduction of Keynote</p> <p>Christine Janus</p>
11:40 – 12:40	<p>Closing Keynote</p> <p>Hildy Gottlieb – Creating the Future</p>
12:40 – 12:50	<p>Closing remarks</p> <p>Christine Janus, Kathy Redmond, Jean-Marie Meurant</p>
12:50 – 13:00	Delegate Satisfaction Survey and Prize entry
13:00 - 14:00	<p>Lunch in Hilton's Atmosphere Restaurant</p> <p><i>Draw for Delegate Survey Prize 13:30</i></p>
14:00 – 16:00	<p>Post Conference Networking</p> <p>Disease and Region-Specific Discussions</p> <p>Time has been set aside after the conference so that you and your colleagues from specific diseases or regions can meet and have in person discussions.</p>

Thank you to our generous Conference contributors:



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