GlobalSkin Conference Speakers List

GLOBALSKIN 2019
Milan

International Alliance of Dermatology Patient Organizations

GLOBALSKIN.ORG

Jennifer Austin

Jennifer Austin is a skilled executive with over twenty years' experience in communications and marketing in NGOs, government and the private sector.

She has significant leadership background in working with member-based organizations including Scouts Canada, the Canadian Internet Registration Authority and 4-H Canada.

Jennifer has a strong track record of significantly increasing organizations' profile and brand; building and leading high-performing teams; establishing thought leadership platforms and effective social and traditional media outreach; and meaningfully engaging and mobilizing employees, members, volunteers, donors, corporate sponsors and other key stakeholders. Throughout her career, Jennifer has developed and fine-tuned organizational best practices across a variety of sectors. She has received a number of professional awards for raising the profile of her organizations.

Jennifer holds a Bachelor of Arts degree in Political Science from Dalhousie University and an Advanced Certificate in General Management at Queen's University School of Business.

The mother of a child born with a port-wine stain birthmark on his face, Jennifer is personally committed to IADPO's mission to improve the lives of those affected by dermatological conditions throughout the world.

Nathalie Bere

Nathalie Bere, MPH - Patient Engagement - European Medicines Agency (EMA)

Nathalie has been working with the European Medicines Agency in London for over 2 years and is currently responsible for its engagement with patients and consumers. Patients bring specific knowledge and expertise from their real-life experience of the condition and its treatment to the scientific discussions, and their contributions have led to better outcomes for all concerned.

Over the years, she has been dedicated to creating opportunities for the inclusion of the patient's voice in every aspect of the regulatory lifecycle of a medicine. Experience at EMA has demonstrated that it is essential to be flexible and to test and implement a range of engagement methodologies to best suit the various engagement activities.

As a steady increase in patient engagement at EMA has been observed, Nathalie will look to further strengthen these activities through constant exchanges with stakeholders in order to ensure interactions are as mutually beneficial as possible.

Nathalie holds a Master's in Public Health from the University of East London (UEL) and has a Bachelor of Science in Psychology.

Neil Bertelsen

Neil Bertelsen is an independent consultant with over 25 years of experience bringing the patient voice to health care decision makers and communicating the science of health care to patients in a way that truly informs their own personal health choices. Neil is passionate about bringing the patient experience and perspectives to decision-makers including industry and health technology assessment (HTA) bodies.

Today, Neil is the chair of ‘Health Technology Assessment International’s Patient and Citizen Involvement Interest Group’, an international group whose remit is to work closely with HTA organizations and patient organizations to bring patient insights and experiences into decision making process.

In the 1990s Neil was a patient advocate in the field of HIV and since that time has devoted his activities to supporting the role of patients in healthcare decision making. He was the editor of Positive Times, the UK’s first national magazine for people with HIV. This pioneering magazine tackled the relevant issues of the day in a time before the advent of combination therapy.

As well as an individual patient advocate, Neil served for 6 years on the board of trustees of Terrence Higgins Trust, Europe’s largest HIV and sexual health advocacy group. Neil has also worked within the pharmaceutical industry at Bayer Pharma AG where he worked to bring the patient perspectives into the research and development organization.

Prior to this, Neil was the managing director of several specialist health care consultancies where he developed integrated strategy, education, communication and engagement programs that considered the patients as an equal partner in the health care landscape.

Christine Bundy, PhD.

Over the last 30 years I have conducted translational research, applying psychology to improve patient care. I focus on the role of patient beliefs and how this impacts on mood and health behaviour through to interventions that support motivation for self-management. I design and deliver psychological interventions for mood management and behaviour change in long-term inflammatory conditions and train motivational interviewing skills to health care staff as part of their routine consultations.

I was President of the UK Society for Behavioural Medicine from December 2014-2016 and have served on two NICE clinical guideline development groups. I am currently working on 2 EU Guideline development groups.

I have over 100 peer review publications including four key reports on the development of NHS patient services. I lead or collaborate on NIHR, industry and patient charity partners with research awards totalling over £20M.

Professor Behavioural Medicine, Cardiff University, Wales, UK.

Honorary Professor University of Manchester, UK.

Honorary Consultant Psychologist, Salford Royal Foundation Trust and Manchester Foundation

Trust, UK. Cardiff and Vale University Health Board.

Lisa Butler

Lisa Butler is currently serving as the Vice President, Strategic Partnerships and Programs at the National Eczema Association (NEA). In the 5 years since joining NEA, Mrs. Butler has focused on building and expanding relationships with external stakeholders in the greater eczema landscape, including industry, professional societies, health care providers, and patient advocacy organizations. As interest and advancements in eczema research continue to increase, it is critical that the National Eczema Association is able to underpin the scientific progress with the patient experience, patient burden, and patient care gaps - engaging partners in programs to support this effort has been a highlight of Lisa’s current role.

The majority of Lisa’s professional career has been devoted to patient advocacy in Dermatology. Prior to joining NEA, Lisa spent over ten years with the National Alopecia Areata Foundation (NAAF) where she focused on partner development, as well as communications and advocacy. In addition, Lisa has assumed leadership positions within the Coalition of Skin Diseases (CSD).

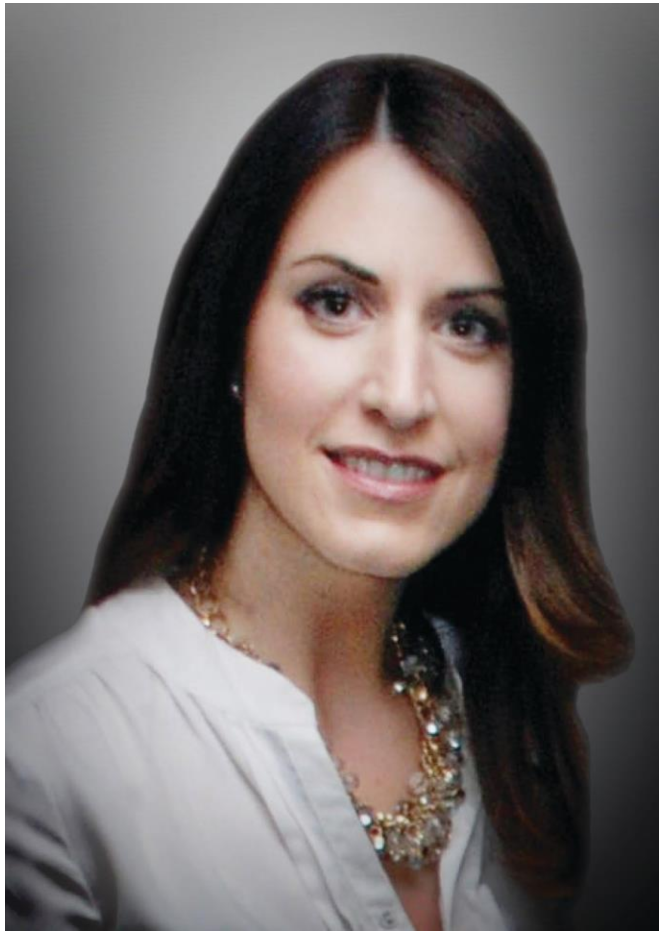
Lisa received her MBA from Dominican University of California, and lives in Marin County, CA, USA with her husband and two daughters.

Helen Crawford

Helen is the Manager, Social Media for both the Canadian Skin Patient Alliance and the Canadian Association of Psoriasis Patients. She is responsible for planning and executing the Social Media Strategy for both organizations, focusing on content, audience engagement, and metrics analysis. She also manages and maintains the websites of both organizations, as well as develops many of their communication materials, including a quarterly e-newsletter on psoriasis. She is a graduate of the Social Media Certificate program from Algonquin College, and she holds a Bachelor's Degree in Linguistics from Carleton University.

In her free time, Helen is an active community volunteer and proud hockey mom of two teenaged boys. She lives in Ottawa, Canada.

Amanda Cresswell-Melville



Amanda Cresswell-Melville is the Executive Director of the Eczema Society of Canada (ESC), a national registered Canadian charity dedicated to improving the lives of Canadians living with eczema.

Amanda leads the organization in planning, operations, programming, communications, fundraising, finance, human resources, and patient advocacy. Amanda has fostered significant growth for the organization, recently earning a Canadian Dermatology Association Public Education Award. Amanda has earned both an Honours Bachelor of Arts degree, a Bachelor of Education, has completed the University of Toronto Rotman School of Management MBA Essentials program, and has completed the Institute of Corporate Directors Not-For-Profit Governance program.

She has served various organizations in a leadership capacity in the education, arts, and the health sector. Amanda lives in the greater Toronto area with her husband and two young children. Her family is impacted by eczema, which inspires and drives her work with ESC.

Silvia Fernandez Barrio

Radio and TV journalist since 1979. Psoriasis patient since 1973

In 2005, after her treatment was denied by her health insurance she founded Aepso, Civil Association for the Psoriasis patient, being its current president. Since then over 24.000 patients have contacted AEPSO to get help.

In 2007, to date, Silvia is part of the IFPA executive board. IFPA is the International Federation of Psoriasis Associations, based in Stockholm, Sweden, umbrella organization for this disease.

In 2009 , Founded LATINAPSO, Latinamerican network of Psoriasis.

In 2012, after 4 years of work 3 biologics were approved to be covered by health insurance. All anti TNF. Now work is being done so that all treatments are covered.

Has been distinguished several times for her advocacy work.

Hildy Gottlieb

Hildy Gottlieb is a social scientist and asker of powerful questions. She is the co-founder of Creating the Future, where she teaches people how to change the systems they find themselves in, all by changing the questions they ask.

Hildy is a TEDx speaker, as well as a contributor to the Stanford Social Innovation Review and a blogger at //medium.com/@HildyGottlieb" target="_blank" rel="noopener">Medium.com. She was the creator and host of the *Making Change* podcast, where she interviewed dozens of leaders from around the world about the factors that create powerful, positive change. Hildy has lectured at universities around the world, including the University of Waikato in Hamilton, New Zealand, and at both the Haas School of Business and the Masters in Development Practice program at UC Berkeley.

All Hildy's work is rooted in a combination of research and practical experience, built upon her decades as a consultant, a social change researcher and theorist, and a serial social entrepreneur. Hildy helped develop (and then taught) the current Masters degree program in Community Leadership at Duquesne University (pron. Dew-cáyne). She and her partner, Dimitri Petropolis, also co-founded the world's first Diaper Bank, sparking the diaper banking movement across North America, and garnering them a Points of Light Citation from President Bill Clinton.

Hildy's best-selling books on the nuts and bolts of social change have all become industry standards and are used as texts in both undergraduate and graduate programs around the world.

When not working, Hildy can be found in the garden, at the movies, shooting photos, or traveling the world in search of a quiet cafe to write.

Christine Janus

Christine Janus, B.A., B.Ed, MBA, FICB is CEO of the International Alliance of Dermatology Patient Organizations (IADPO) and has held that role since 2015. She has a proven track record as a strong patient advocate and was instrumental in founding IADPO and conceiving of the organization's ground-breaking Global Research on the Impact of Dermatological Diseases (GRIDD) project. It has long been Christine's view that people living with dermatological conditions around the world deserve much better access to care and treatment, and that by working together with like-minded organizations, this goal is achievable.

Christine served as Executive Director and then CEO of the Canadian Skin Patient Alliance (CSPA), 2007-2015. In those roles, Christine built the CSPA into a vibrant and effective voice for skin patients and led the development of five national award-winning initiatives including *Skin Deep, A Report Card on Access to Dermatological Care and Treatment in Canada*. In 2013, Christine helped the CSPA launch a subsidiary organization specifically to serve psoriasis patients, called the Canadian Association of Psoriasis Patients (CAPP) and followed up by releasing the *Psoriasis Report* to shine a light on the access issues for the millions of Canadians living with psoriasis.

Christine's experience and expertise also include working with organizational start-ups, specialized marketing, business development and management consulting services, as well as training development to the health care, banking, venture capital, real estate, sporting management, HR services and University sectors. She has also taught marketing at the university level. Christine was named to the first Patient Commando list of Women Changing Healthcare in 2013.

Christine lives in Ottawa, Canada and is the fiercely proud mother of three fine young men.

Jitske Kramer

Jitske Kramer, Corporate Anthropologist, believes in a world that is safe for diversity. She is committed to helping leaders and organizations create environments with the right rhythm of power and love.

Jitske is an expert in the fields of diversity, international teamwork and corporate culture. As a trained ethnographer, she did research in Botswana, Uganda before becoming an organizational consultant. Jitske is dedicated to cracking the code to powerful leadership, while teaching and championing inclusive decision-making processes. It is her desire to fix human fragmentation by (re)connecting people through their differences. She seeks to build strong tribes, safe for diversity and ready for change.

A highly sought after speaker who energizes audiences to really make an impact, Jitske is co-founder and director of the Culture Academy. In 2013 she received the “Trainer of the Year” award from the Association of Dutch Training Professionals (NOBTRA). She is the best-selling author of Deep Democracy (Dutch), Managing Cultural Dynamics and Wow! What a Difference, and is co-author of The Corporate Tribe (Dutch Management Book of the Year 2016).

Klaus Legau

Klaus Legau joined LEO Pharma headquarters October 2018 as senior manager in Global Public Affairs. He has a background working with political communication in public health and in public social affairs in Denmark. Hereafter, he joined the civil society sector and has worked with disease advocacy as CEO for the Danish AIDS Foundation and after that as CEO for the Danish Stroke Association. Klaus Legau has in these functions worked in national and international civil society networks to coordinate and leverage patient agendas. He has also been collaborating with the pharmaceutical sector throughout his career in patient advocacy.

He holds a Masters Degree in Digital Communication from RUC, a degree of Journalism (DJ), Danish School of Media and Journalism and a bachelor in Human Nutrition, Suhr University College Denmark.

Jean-Marie Meurant

Jean-Marie has served as the President of *L'Association Française du Vitiligo (AFV)* since 2013 and has grown the organization into a vibrant association well known in France. AFV produces bulletins, and hosts sessions for patients, provides telephone counseling and an annual conference.

His organization organizes support groups, provides advocacy and liaises with other patient groups in France and internationally. Jean-Marie is involved with patient advocacy both in France and internationally and his organization supports research into vitiligo. He is leading the French Skin Federation (18 skin patient organizations) and is founder of a new global coalition: Vitiligo International Patient Organizations Committee.

Jean-Marie has been part of the GlobalSkin board as its president since the organization was created in Vancouver in 2015.

Jean-Marie is currently an HR and Change Management Consultant with over thirty years business experience as an HR Director, specializing in large change situations like major mergers and acquisitions and adapting to multi-cultural environments for large European and International Companies.

He is adept at working with businesses to ensure that structures and practices are in place to allow them to achieve their objectives. He brings this excellent business acumen to his volunteer work in the skin patient sector.Jean–Marie holds a Master's in Human Resources Management from the Sorbonne and is an alumnus of ISCG. He is the proud father of three children and an avid sailor.

Dr. Luigi Naldi

Professor Dr. Luigi Naldi

Director, Department of Dermatology, Ospedale san Bortolo, Vicenza, and President Centro Studi GISED, Bergamo (Italy)

Dr. Luigi Naldi is a qualified Full Professor of Dermatology and Director of the Department of Dermatology of Ospedale San Bortolo in Vicenza (Italy). He is the founder and president of the Research Organization "Centro Studi GISED," an independent academic research entity, dedicated to clinical research and Evidence Based Medicine in Dermatology. He has been an adjunct professor of Dermatology at the University of Milan and Modena, a visiting Professor at the Department of Dermatology of the University of Genève (Switzerland), and the Head of the Unit of Clinical Pharmacology and Epidemiology at Ospedali Riuniti di Bergamo (Italy). He has been a founding member of the European Dermatoepidemiology Network (EDEN), and an Editor of the Cochrane Skin Group.

Dr. Naldi has authored a total of 360 papers in indexed journals with the following parameters of scientific impact: citations= 53,429 , Hirsch index (h-index)=74 (source, Google Scholar, May 2019). His research interests focus on epidemiology and clinical research in Dermatology, and on methods to assess the safety of medical interventions.

Following his mentor Dr. Gianni Tognoni, he has always considered the health care system as the "natural laboratory" for a clinically oriented scientist. From populations to single cases and back again!

Leigh-Anne Nel

I am a 30 year old, white, South-African female. I have a beautiful 8-year-old Daughter, she tends to keep me on my toes.

I currently work full time for a company called FESTO. Festo is a leading world-wide supplier of automation technology and Performance leader in industrial training and education programs. I am also partner director for a non-profit organization: Xeroderma pigmentosum society. This society is extremely close to my heart as my mother is a patient and lives with XP. My mother is my inspiration in life. She is my go to person.

I enjoy reading, travelling, music, family time and last but not least, helping as many people as I can through the XP society. My daughter is also a volunteer on the XP society, and has been since the age of 2.

I am particularly ambitious, self-motivated and self-disciplined. My assertiveness and strong initiative ensure that I approach new challenges with ease. I have the ability to handle pressure and always present myself with utmost professionalism. I believe I am essentially practical by nature and enjoy dealing with others from senior levels of management. My above average ability to learn at a fast pace ensures that I efficiently and effectively complete tasks.

Kathy Redmond

Lugano-based Kathy Redmond is a strategist, facilitator and coach. On qualification as a nurse in 1983 she worked in a number of clinical positions before becoming a lecturer in cancer nursing at University College Dublin, Ireland. In 1993 she was awarded a Master of Science from the University of Surrey, UK.

Kathy has served as President of the European Oncology Nursing Society and as a Board member of numerous European and International organisations. She played a pivotal role in the establishment of a number of international patient alliances including the European Cancer Patient Coalition, Lung Cancer Europe and the International Neuroendocrine Tumor Alliance.

Kathy is owner of Redmond Consulting – a highly-specialized, independent firm founded over 15 years ago - that provides strategic consultancy services to both commercial and non-profit organizations active in the health arena. In 2015 she completed an executive masters in Coaching and Consulting for Change run jointly by the University of Oxford, UK and HEC in Paris, France.

Kathy has also completed an advanced facilitation training course and is a Tavistock-trained executive coach at senior practitioner level.

Tine Rikke Joergensen

Tine Rikke Jørgensen joined LEO Pharma headquarters January 2018 heading up LEO Pharma’s Global Public Affairs function. She has a background working on public health and disease advocacy with the World Health Organization on advocacy, patient access and financing of public health interventions in resource limited settings. Hereafter, she joined the pharmaceutical industry working and patient access and sustainable financing models including health economics.

She has worked with Lundbeck, Sanofi Pasteur MSD, and Medivir where she was responsible for the patient access and reimbursement and lately with Janssen Pharma under J&J family of companies on Immunology; rheumatology, inflammatory bowel disease and dermatology. In addition, she has been a lecturer at the Danish American study abroad programme developing curriculum and teaching the full programme on “Health care in Scandinavia” to American university student.

She holds an MSc in Human Biology, a Master of Public Health degree from University of Copenhagen and a MSc in Health Economics from University of York, UK.

Susan Thornton

Susan Thornton serves as the CEO of the Cutaneous Lymphoma Foundation, a worldwide nonprofit that empowers, educates and supports people diagnosed with this rare cancer. In addition, she serves in leadership positions as Vice Chair of the Board of the Lymphoma Coalition and Vice Chair of the International Alliance of Dermatology Patient Organizations.

She also served on the planning committee that hosted the first International Dermatology Patient Organization Conference recently held in Vancouver, BC and is former Vice Chair of the Coalition of Skin Diseases. Prior to joining the CLF in a professional capacity, Susan served on the Board of Directors and provided consulting services to the Foundation.

Her professional career before coming into the nonprofit sector, was in healthcare technology where she spent over 25 years in various consulting, marketing and sales positions. Susan holds a business degree from The University of Pennsylvania Wharton School and completed the Non-Profit Certification Program at the University of Pennsylvania. In addition to her CLF Board service, she served on the boards of the Leukemia & Lymphoma Society, Eastern Pennsylvania Chapter, Tristate Multisport Association and the Sierra Club, Philadelphia

Marc Yale

Marc Yale was diagnosed in 2007 with Cicatricial Pemphigoid, a rare autoimmune blistering skin disease. Like others with a rare disease, he experienced delays in diagnosis and difficulty finding a knowledgeable physician. Eventually, Marc lost the vision in his left eye from the disease. This inspired him to help others with the disease. In 2008, he joined the IPPF as a Peer Health Coach. He works with people to improve their quality of life, and encouraged them become self-advocates. In 2009, he helped develop the Pemphigus and Pemphigoid Comprehensive Disease Profile giving experts insight into the patient perspective. In 2016, he was asked by the IPPF leadership to become the Executive Director of the foundation.

Marc is currently a member of the American Academy of Dermatology Drug Pricing Task Force and serves on the Global Skin GRIDD Scientific Advisory Board. He is a representative of the Coalition of Skin Diseases, a two-time Rare Voice Award Nominee, a Global Genes RARE Champion of Hope nominee and a national advocate for rare diseases.

Marc currently resides in Ventura, California with his wife Beth and daughter Hannah.

Maggie Young

Maggie joined Allergy UK in 2016 with a wide range of experience in the development and management of integrated communications campaigns for organisations in the health education and charity sectors.

In her role as Communications Manager for Allergy UK Maggie worked on a range of projects with partners and key industry stakeholders to raise awareness of allergic disease and the work that the charity does to help improve the lives of people who live with allergy. Her current role, as Public Affairs Manager is focused on the issues and health policies that impact on those living with allergic disease.

Maggie provides a major supportive role for the CEO and wider team on many of the engagement pieces Allergy UK is involved with partners in government agencies, pharma and other corporate partners.