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2015 IDEOM Fall Newsletter

Chair's Message

Alice Gottlieb, MD, PhD – IDEOM Founder and Chair

Exciting things are happening at IDEOM. The Delphi went out to both patients and health care providers and other stakeholders this month. These results will be presented at the Annual Meeting on March 2, 2016 in Washington DC. Formal invitations to the meeting will be emailed soon so please keep an eye out for them. At the Annual meeting, we will use our interactive devices to pick domains for psoriasis and form workgroups in order to review and develop outcome measures that satisfy the needs of all stakeholders. Once again, Dr. Kendall Marcus has agreed to speak at our meeting. IDEOM is working with the NPF to meet with payers. IDEOM would like to understand what payers want to assess quality of treatments and health care providers. NPF representative, Leah Howard, will present the results of our meeting with payers at the annual meeting in Washington DC. Finally, we will start work on our second disease, hidradenitis suppurativa, at the 2016 meeting.

We are growing in size, getting stakeholders from all over the world and new pharmaceutical members. 2016 will be a great year! Thank you for your support.

Patient Perspective

My name is John Latella and I was diagnosed with psoriasis in 1964 and with psoriatic arthritis in 1976. I'm still a patient because there is no cure for psoriasis, so I have learned to live and adapt to life with psoriasis. In 2013 I was invited to attend my first IDEOM meeting in Toronto, Canada and from that point on I saw the clarity of the mission and came away with a renewed sense of desire to help others who had been diagnosed with psoriasis. In subsequent meetings I began to see the formation of a set of ideals that brought all of us (patients) into the forefront of helping to make a difference. By participating in discussions on Delphi item inclusions, IDEOM realized the benefit of patient interaction with researchers and clinicians. Recently, after submitting a letter of interest, I was asked to be the patient stakeholder on the IDEOM Board of Directors and I was humbled by the prospect of it and I saw it as opportunity to continue to help those who will be diagnosed with psoriasis in the future. I have volunteered with the National Psoriasis Foundation for many years as an Advocate, Mentor and Ambassador and my inclusion into IDEOM was another opportunity to be of greater help to others. I look forward to the challenges and vow always to put my best effort forward.

IDEOM 2016 MEETING - SAVE THE DATE!

Thanks to Our Corporate Sponsors & Donors

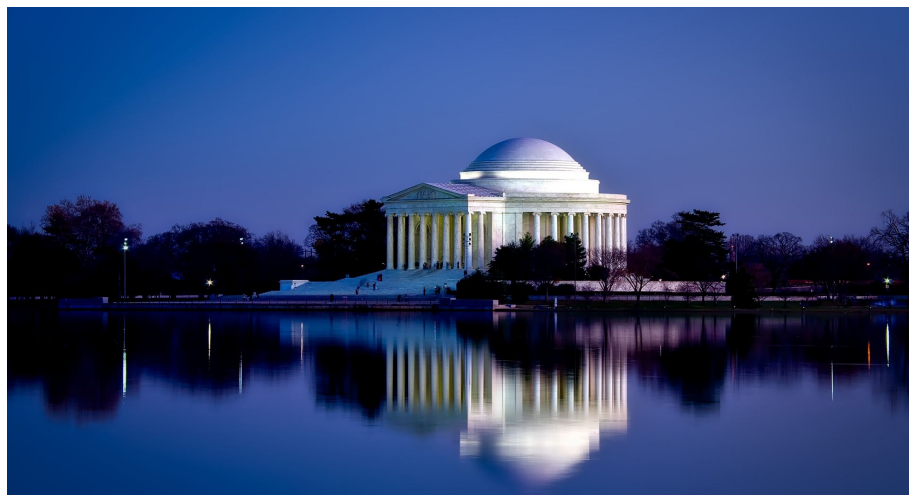
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AMGEN



IDEOM's Mission



Wednesday, March 2, 2016
The Westin Washington, D.C. City Center
1400 M Street Northwest, Washington, D.C. 20005

KEYNOTE SPEAKER: Kendall Marcus, MD
 Director, Division of Dermatology and Dental Products
 Food and Drug Administration

Right before the AAD!

[more...](#)

Hidradenitis Suppurativa

IDEOM's 2nd Working Group

Amit Garg, MD, IDEOM Stakeholder and on the Board of Directors, is spearheading IDEOM's second working group to measure outcomes on Hidradenitis Suppurativa (HS). HS is a chronic inflammatory skin condition that is potentially debilitating and has an impact on several quality of life domains. The inherent unpredictability in HS, both with respect to course of disease and response to treatment, poses significant challenges for patients and physicians alike.

The IDEOM HS Working Group aims to develop a core set of patient-centered outcome measures in Hidradenitis Suppurativa through the alignment of relevant stakeholders with the goals of supporting clinical decision making at the point of care and of identifying which therapies add value in its treatment.

IDEOM is currently seeking grant support and corporate membership support to assist with the HS initiative and will hold its first in person meeting at the IDEOM 2016 meeting in Washington, D.C. this March. Initial stakeholders and leaders of this working group are:

Amit Garg
 Alice Gottlieb
 Robin Christensen
 Linnea Rishøj Thorlacius
 Gabrielle Vinding
 Iben Miller
 Solveig Esmann
 Alexa Kimball
 Gregor Borut Ernst Jemec

For further information, or to get involved, please contact Amanda Pacia by [Email](#) or call (650) 288-5339.

- To establish patient-centered measurements to enhance research and treatment for those with dermatologic disease
- Perspectives of patients, health economists, payers, physicians and regulatory agencies are included from the onset
- IDEOM's goal is to establish validated and standardized outcome measures that satisfy the needs of all stakeholders and can be applied to clinical research and clinical practice

2016 IDEOM CALL FOR ABSTRACTS

Submission deadline: [January 4, 2016](#) for presentation on March 2, 2016 in Washington, D.C.

Eligibility: Stakeholders, trainees, and Industry representatives at any level are eligible to submit an abstract

Submission: Submit abstract by [Email](#) to Amanda Pacia

Abstract Processing fee: There is no processing fee to have your abstract considered if you are an IDEOM stakeholder.

INDUSTRY:

Corporate members of IDEOM may submit the allowed amount of posters per your membership category.

Industry representatives who are not corporate members and wish to submit shall pay a \$1,000 fee per abstract.

Abstracts dealing with one of the topics below can be submitted:

- Outcomes in Psoriasis
- Outcomes in Hidradenitis Suppurativa
- Outcomes in other areas of dermatology

The IDEOM Board of Directors will select abstracts for poster presentation. Please note that all abstracts will be presented during breakfast, breaks and lunch only. There will not be an opportunity to present at the podium during the working meetings.

Additional details can be found online at www.dermoutcomes.org or call 650.288.5339 or [Email](#) Amanda Pacia.