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2017 IDEOM SPRING NEWSLETTER



IDEOM is an international group of stakeholders which includes dermatologists, rheumatologists, patient research partners, methodologists, industry representatives, payers, and regulators.



IDEOM Annual Meeting

**May 5 – 6, 2017
Washington DC
Report from the President
Alice Gottlieb MD, PhD**

I am excited to share a summary of our very successful meeting in Washington DC May 5 – 6, 2017. I want to start by thanking all our stakeholders and sponsors for their support. Four diseases were represented at this meeting: psoriasis/psoriatic arthritis (PSA), hidradenitis suppurativa (HS), acne and alopecia areata. Attendees included health care providers, patients (psoriasis/psoriatic arthritis and hidradenitis suppurativa), FDA physicians and scientists, pharmaceutical health economists and clinicians, and non profit groups such as the AAD, NPF, NAAF and Advancing Innovation in Dermatology.

The Omeract framework was discussed by both Kristina Callis-Duffin and Vibeke Strand. Kristina presented the process and the results of the psoriasis Delphi. The core domains, middle and research domains of the "onion" were presented. April Armstrong presented results of the workshop that was held in October, 2016 in New York City which went over existing outcome measures (both physician and patient reported outcome measures) and how well they measure the domains we selected.

Diane Thiboutot presented the process and results of ACORN's generation of acne outcomes. Kendall Marcus updated us on the new drugs approved by the FDA in the past year. FDA's approval of brodalumab and etanercept (for pediatric psoriasis) were highlighted. Multiple scientists from the FDA were active and much appreciated participants in this year's meeting. Their willingness to share their wisdom with us is wonderful.

In the afternoon the two psoriasis domains with the least data were worked on: treatment satisfaction (April Armstrong and Kristina Callis Duffin) and patient reported psoriatic arthritis symptoms (in psoriasis clinical trials) (Joseph Merola, Alice Gottlieb and Alexis Ogdie). The HS group met separately. The details of these workshops will be published in manuscripts to be submitted to peer reviewed journals.

On Saturday, we heard how the National Alopecia Areata Foundation (NAFF) is developing their patient-centric outcome measures. This effort was presented by Dory Kranz, President and CEO of NAAF. Via Skype, we heard from Matthais

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IDEOM's Mission

Augustin, who gave a comprehensive update on all outcomes initiatives in Europe. The meeting ended with the HS group presenting results of their work and voting.

Thank you again and see you at the next IDEOM meeting. Please look out for future Delphis coming your way!



PATIENT PERSPECTIVE

John Latella
IDEOM Board of Directors and Patient Research Partner

I would like to offer my sincere thanks to all the patients who were in attendance and participated in the IDEOM Annual Meeting on May 5th and 6th, 2017. Twenty Psoriasis/Psoriatic Arthritis(PSO/PSA), Hidradenitis Suppurativa(HS) Patients and 3 medical representatives gathered on Thursday afternoon to discuss the agenda and homework assignments that were completed prior to the Annual IDEOM Meeting.

We began with the introductions of attendees to help us feel comfortable with fellow patients. The agenda was packed with presentations and workshops for the two groups and it was important that the mechanics were understood. On Friday afternoon groups were going to be divided into three distinct groupings; HS and PSO/PSA with the later changing from Treatment Satisfaction to Psoriatic Symptoms and vice versa during the afternoon. We held an open forum for both areas in which the medical representatives were able to clarify and questions about the homework assignments so that we were prepared to participate. Several areas were discussed and clarified, it was also apparent that those in attendance would benefit from additional knowledge of each other disease groups.

The PSO/PSA patients described their journey, providing a description of successes and disappointments and the HS patients provided the same insights with regard to their journey. I believe both groups came away with a better understanding and appreciation for what each patient's journey involved. Since both are autoimmune diseases it was also brought to everyone's attention the HS patients could also suffer with PSO and the same for PSO patients potentially suffering with HS. We culminated the afternoon with a buffet dinner and patients had the ability to network with each other this added to the comfortableness of the sessions.



Hidradenitis Suppurativa Workgroup

Amit Garg, MD
HISTORIC Steering Group
Folding Board Member, IDEOM

HISTORIC (the Hidradenitis Suppurativa cORe outcomes set International Collaboration), a scientific collaboration among IDEOM, the Cochrane Skin Group, and Zealand University Hospital, has made significant progress towards its goal of developing a core outcome set suitable for interventional trials in Hidradenitis Suppurativa. Over 100 participants comprise our stakeholder group, within which patients and experts have roughly equal representation. Our stakeholder come from 19 different countries spread over 4 continents, making our collaborative truly multinational.

Our COS development process began approximately one year ago with a review of the literature as well as a nominal process which yielded approximately 60 items deemed relevant for measurement in trials by stakeholders. Since then, and through five rounds of e-Delphi and three international in-person meetings in Vienna (September 2016), New York City (October 2016), and Copenhagen (February 2017), we have with consensus arrived at our core set of candidate domains which were ratified at the recent IDEOM meeting in Washington, DC (May 2017).

Topics at the IDEOM annual meeting included the following: Measurement properties, selection of measurement instruments, patient involvement in instrument selection, along with three of the core domains (pain, physical signs and quality of life). We will be establishing workgroups that will be charged with evaluating measures for each of the candidate

- 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

domains and presenting their findings at our next in-person meeting which will be in Geneva adjacent to the EADV in September 2017. With initiation of phase II in the development of the core outcome set, there is an opportunity to include new participants in our work ahead. If you (experts, patients, other stakeholders) are interested in participating in a workgroup, please email Amanda Pacia (amanda@dermoutcomes.org) with copy to Amit Garg, MD (amgarg@northwell.edu).

IDEOM: Peer Reviewed Publications Since 2013

- Elman SA, Merola JF, Armstrong AW, Callis Duffin K, Latealla J, Garg A, Gottlieb AB: The International Dermatology Outcome Measures (IDEOM) Initiative: A Review and Update. *J.Drugs Dermatol.* 16:119-124, 2017
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- Greb JE, Merola J, Garg A, Latella J, Howard L, Acharya N, Gottlieb AB: The Psoriatic Disease Payer Advisory Panel. *J. Drugs in Dermatol.* 15: 641-644, 2016.
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- Solomon JA, Schuering BS. An Update on the IDEOM (International Dermatology Outcome Measures) Initiative to Restructure Current Psoriasis Outcome Assessment Measures to a Globally Uniform Set of Patient-Centric Outcome Measures for Use in Clinical Trials and Clinical Practice. *Psoriasis Forum* 21(1); 50-52, 2015.
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- Gottlieb AB, Armstrong A, Christensen R, Garg A, Callis-Duffin K, Boehncke WH, Merola J, Gladman D, Mease P, Abernethy A: IDEOM: The International Dermatology Outcomes Measures initiative as applied to psoriatic disease outcomes, *J. Rheumatology*, 41:1227-9, 2014.
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