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2017 IDEOM Winter Newsletter



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



IDEOM's Work: A Review of 2016

Report from the President
Alice Gottlieb MD, PhD

This has been a productive year for IDEOM. We held two meetings in 2016 which culminated in the identification of the essential domains for psoriasis clinical trials. In collaboration with HISTORIC, we are well on our way to provide the domains for clinical trials in hidradenitis suppurativa. The results of our meeting with payers were published in 2016. The acne outcome group (ACORN) is collaborating with IDEOM on their selection of outcome measures in acne. IDEOM has reached out to the National Alopecia Areata Foundation as they are actively working on health care provider and patient reported outcome measures in alopecia areata. We look forward to a lively and productive meeting in Washington DC on May 5, 6. We hope you will join us there.

IDEOM Peer Reviewed Publications our first 3 years

- Thoriaci L, Ingram JR, Garg A, Vilumsen B, Esmann S, Kirby JS, Gottlieb AB, Merola JF, Dellavalle R, Christensen R, Jemec GBE. Protocol of the development of a core domain set for hidradenitis suppurativa trial outcomes, BMJ Open, in press.
- 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.
- Gottlieb AB, Levin AA, Armstrong AW, Abernethy A, Callis Duffin K, Bhushan R, Garg A, Merola JF, Maccarone M, Christensen R: The International Dermatology Outcome Measures Group: Formation of patient-centered outcome measures in dermatology. JAAD 2016 Feb; 72(2):345-8. doi:10.2016/j.jaad.2014.11.002. Epub 2014 Dec

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IDEOM's Mission

- Varada S, Kim N, Abernethy A, Armstrong A, Callis-Duffin K, Garg A, Gottlieb AB: IDEOM: International Dermatology Outcome Measures – Proceedings from the First Meeting. *Psoriasis Forum* 20:66-72, 2014
- 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 Outcome Measures initiative as applied to psoriatic disease outcomes. *J. Rheumatology*, 41:1227-9, 2014.
- Gottlieb AB, Swerlick R: IDEOM: The International Dermatology Outcome Measures: A Call to Action. *Psoriasis Forum* 19: 107-109, 2013.

Sessions at the AAD March, 2017 meeting at which IDEOM activities will be presented:

- Practical Approaches to Assessing Psoriasis and Psoriatic Arthritis Patients in Clinic, Friday, March 3, 1-3 pm
 - Research Gaps in Psoriasis: Opportunities for Future Studies and Development of New Outcome Measures for Clinical Trials, Sunday, March 5, 3:30-5:30 pm.
 - Dermatologists in Industry Meeting, Monday, March 6, 7-9 am
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SAVE THE DATE

Friday, May 5 – Saturday, May 6, 2017



The Mayflower Hotel in Washington, D.C.

[Click here to see photos from this event!](#)

Towards global consensus on core outcomes for hidradenitis suppurativa research

Substantial progress has been made toward global consensus on hidradenitis suppurativa core outcomes throughout 2016. The Hidradenitis Suppurativa cORE outcomes set International Collaboration (HISTORIC) was formed as an international initiative arising from collaboration between the International Dermatology Outcome Measures organisation (IDEOM), the Cochrane Skin Group – Core Outcome Set Initiative (CSG-COUSIN) and Zealand University Hospital, Roskilde. The HISTORIC steering committee met in person for first time at the IDEOM annual meeting 2016 in Washington, where some initial HISTORIC goals were defined:

- Development of a global core outcome set (COS) of *what* should be measured and reported in HS trials
- Achieve consensus on the measures related to each core outcome, i.e which outcome measurement instruments should be selected (*how* to measure)

- 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

- Implement the COS on a global level

A great deal has happened in the HISTORIC initiative's first life year. An initial list of candidate items has been identified by combining the results of 3 existing data-sets; a systematic review of literature, US and Danish qualitative interview studies involving HS patients and an online HS expert item generation survey.

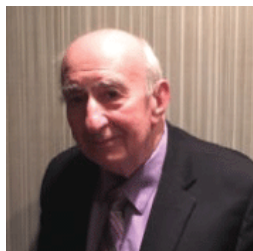
3 rounds of the online Delphi exercise among major HS stakeholders involving 94 participants (42 HS patients and 52 health care professionals) from 19 countries across four continents have been conducted, together with 3 in-person consensus meetings.

At the consensus meetings, we worked with the participants on considering which items to nominate for exclusion and which to cluster into outcome domains. This method differs a bit from other COS processes and this concept of involving more patients and other Delphi participants in the creation of the domains is based on the principle of inclusivity, in keeping with the philosophy of our HISTORIC initiative.

Many tasks are still awaiting the HISTORIC initiative in 2017 and the years to come. At the IDEOM annual meeting 2017, we plan to present a proposal for final core domain set. Furthermore, we plan to start the formation of workgroups for the core outcome measurement set. For this task, we hope to welcome new manpower in the project, who share our common interest in the care of patients living with HS and the related outcomes.

For further information, please contact:

MD, PhD student on outcomes measures in HS, Linnea Thorlacius at: lrit@regionsjealland.dk



PATIENT PERSPECTIVE

John Latella

IDEOM Board of Directors and Patient Research Partner

What are your expectations when you have a doctor's appointment? Are you looking for something that has immediate results or something to cope with a chronic condition? I know I can't answer this for you, as for myself I have mixed reactions. Since I have been dealing with psoriatic disease for such a long time I thought that there was nothing that could make any difference so my expectations were not very high and I wasn't seeing any long-term results from my treatments. So this brings me to what we are trying to accomplish at IDEOM, determine outcomes (results) from core domains and use established measures that fit a particular condition. Each of us has a different expectation or desired outcome so it's extremely important that we make our voices heard when the measures are associated with the core domains. Our October meeting provided us with a deluge of measures that covered many aspects of our disease, now in May of 2017, it's time to form work groups to reach consensus on what measures to use for each these domains. We need to listen to the medical professionals and add our voice as appropriate. We all want to have a say in our treatment, so in May it's time to speak out and voice our concerns. It's a step towards meeting our expectations during our doctor's appointments.

Amanda has previously sent out a save the date email giving you the dates of May 5-6, 2017 for the spring IDEOM meeting in Washington, DC at the Mayflower Hotel. The date of the email was Jan 11, 2017. More information will be forthcoming.

IDEOM: Peer Reviewed Publications our first 3 years

- Thorlacius, L, Ingram JR, Garg A, Vilumsen B, Esmann S, Kirby JS, Gottlieb AB, Merola, JF, Dellavalle R, Christensen R, Jemec GBE. Protocol of the development of a core domain set for hidradenitis suppurativa trial outcomes, BMJ Open, in press.
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- Gottlieb AB, Levin AA, Armstrong AW, Abernethy A, Callis Duffin K, Bhushan R, Garg A, Merola JF, Maccarone M, Christensen R: The International Dermatology Outcome Measures Group: Formation of patient-centered outcome measures in dermatology. JAAD 2016 Feb; 72(2):345-8. doi:10.2016/j.jaad.2014.11.002. Epub 2014 Dec
- Varada S, Kim N, Abernethy A, Armstrong A, Callis-Duffin K, Garg A, Gottlieb AB: IDEOM: International Dermatology Outcome Measures – Proceedings from the First Meeting. Psoriasis Forum 20:66-72, 2014
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