

# Global Skin conference September 15-17<sup>th</sup> 2017 Geneva

## Opening Global Skin conference:

The IADPO (Global Skin) was founded two years ago in Canada. The International Alliance of Dermatology Patient Organizations (IADPO) is a unique global alliance, committed to improving the lives of skin patients worldwide. IADPO works to empower over 60 patient associations – located in 23 countries representing 25 disease areas – to reach more patients, and provide them with greater support, education and advocacy.

Poor skin conditions and diseases have a large impact on lives of people. They often deal with shame and feel stigmatized. The impact of living with a skin disease is underestimated. Together we can help the voices of our skin populations be heard: “One skin, One world, One voice” in IADPO.



IADPO's work is based on the three pillars of research, advocacy and support.

The strategy for 2018 and beyond will be the GRIDD project, more infrastructural growth and more support for members, advocacy stage setting/relationship building and maybe global campaigns.

Jean Marie Meurent at the ‘Skin Matters Reception’ at the combined reception for Global Skin conference and EADV congress (European Academy Dermatology and Venereology)



## Patient Village:

Only 5 kms away from the IADPO Global Skin congress, was the 26<sup>th</sup> EADV congress (European Academy of Dermatology and Venereology) congress. On Friday there was a Patient Village where patient organizations could present themselves.

Patient delegates were invited to a session with dermatologists to learn how we can we work together to increase the visibility of and respect for a skin disease, the quality of care, patient support and funding for dermatological research. We talked about the use of social media, people with skin disorders who are famous (for example a model), how patient organizations can bring ‘data’ to life with patient stories, guidelines, centers of expertise, sharing information, translating and information and working together. The aim is a better quality of life.



Bibi Montfrans (dermatologist Erasmus, organization EADV) and Christine Janus (CEO staff IADPO)

Impression Patient Village:



## Presentations at the Global Skin conference:

### The common experience of Dermatological Diseases

Gitte Aabo, CEO Leo Pharma.



Gitte Aabo describes her defining moment, when a small event grew into a big change. Leo Pharma started making steroid treatment available for patients with psoriasis in 1950. A patient told Gitte Aabo for the first time in her life, she could wear a swimsuit.

Gitte Aabo hopes before 2050 we will not only be able to treat but also cure skin diseases. The last and only Nobel prize ever won for dermatology was in 1903 for light treatment. It's time for another Nobel prize.

### What do we need to excel in our roles?

Kathy Redmond, Switzerland

This Global Skin conference is about:  
How to measure the impact of a skin disease?

- How do we change the perception?
- How to define skin conditions?
- How can we push for a cure?
- How can we win a Nobel prize for advances in dermatology?
- How can we change lives?
- How can we work together?
- How can we make connections?
- How can we increase advocacy impact?
- How can we raise awareness?
- 1:4 people have a skin disorder!



**WHO targets: The critical importance of the patient voice**

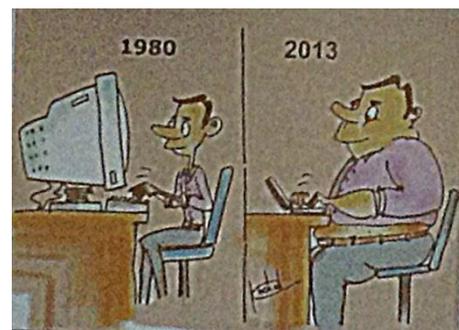
Dr. Cherian Varghese, coordinator Management of NCDs

Aim for the WHO is to reduce premature mortality from NCDs (Non-Communicable Diseases) by one third by 2030. NCD's are diseases like heart disease, stroke, cancer, diabetes, and chronic respiratory disease: with preventable morbidity.

Changing times:

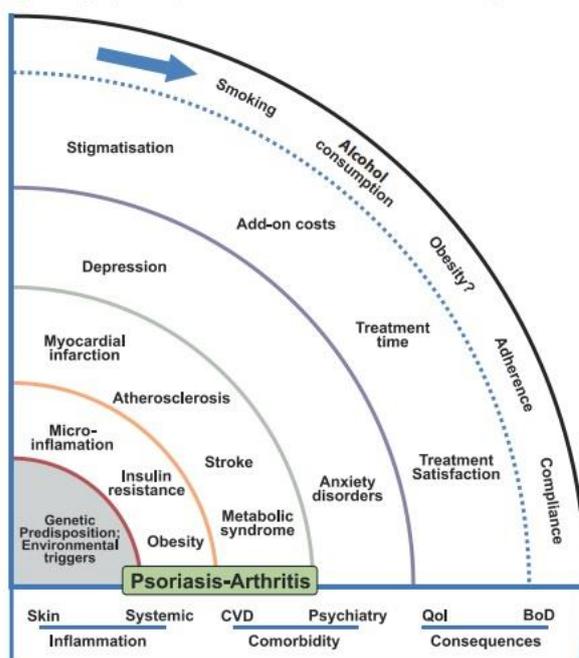
We need to:

- strengthen the prevention and treatment of substance abuse (drugs and alcohol)
- achieve universal health, like access to essential quality health care



Global report on psoriasis (WHO)

In the diagram everything that influences psoriasis:



The average patient gets a depression disorder.

How many doctors do we need to treat a patient? This person deals with multi-morbidity.

Challenges for the patients is how to handle:

- conflicting medical advice
- adverse drug events
- duplicate lab tests
- poor compliance to medicines
- poor functional status
- unnecessary hospitalizations
- high mortality

BoD, burden of disease; CVD, cardiovascular disease; QoL, quality of life  
Source: Mrowietz et al. 2014 (26).



A funny picture to show how a lot of profit is made:

Dr. Varghese's statement is to take the profit out and put the patient in.

Therefore, healthcare must be honest in communication and set realistic goals. The patient should be in interaction with doctors, pharma companies, diagnostic centers, chemists, hospitals-nursing homes, services (e.g. blood banks), medical insurance, alternative medicine, medical equipment, etc. The person has to be centered.

Be the **CHANGE**  
you wish to see in  
the **WORLD**  
-Gandhi

### **The power of the patient voice**

Dr. Chris Bundy, University of Cardiff

How can you measure Quality of Life (QoL)? Some clinicians think QoL is too subjective. Doctors need to understand their patients better. More than 50% of patients don't use medication the way it was prescribed.

Most clinicians agree QoL information can be used to compare similar treatments, to help explain reasons for poor adherence to some treatment or aid in policy making. QoL can be used best as an indicator rather than a definitive value.

Skin conditions impact on all aspects of life (work, leisure, relationships, self-image and confidence). A research proved many feel isolated.

Chris Bundy did research on the impact of psoriasis and the treatment. She used qualitative interviews in talking to patients with psoriasis. She researched the beliefs of taking medication. Patients described how they believe medication will influence their life on the long term. It might be the reason for not taking medication. She asked about their feelings, low mood and motivation for self-care. Last, she asked about behaviors, life style and self-management.



## **The power of the patient voice**

Christine Janus (CEO staff IADPO)

GRIDD: Global Research on the Impact of Dermatological Diseases

In dermatology, to date, no research has been conducted on a global level to study the impact of dermatological diseases. For a very small amount of specific conditions, some country-specific impact studies have been done. There is virtually no research that has been driven by the patients themselves, in ANY disease area, where they themselves create the questions that will elicit responses that will answer the question of the true impact.

GRIDD is unique because patients come up with the questions they will answer themselves. We'll collectively own the data. Data will be provided to any member or organization of IADPO. It can be used for advocacy. The media will have facts to tie to your patient stories. It can boost fundraising.

### **The phases of the GRIDD project:**

phase 1, 2: Global research of impact on patients (GRIP) tool. In this phase patients will be facilitated in involvement constructing the measurement instrument. Patients will set up their own questions.

phase 3: Patient reported measures. Data will be collected different from countries, regions and global levels for a wide range of dermatological diseases.

Phase 4, 5: Data will be analyzed and reported. Local and regional decision makers and the WHO for its DALY ranking will be informed. The WHO global burden of disease (GBD) measures burden of disease using the disability-adjusted-life-year (DALY). This time-based measure combines years of life lost due to premature mortality and years of life lived in states of less than full health.

A positive prestigious timeline has been set up where phase 2 will be finished May 2018 and the project will be finished by the end of 2019.

In phase 2 Global Skin members will be asked to reach out to our patients to develop the GRIP tool. In phase 3 Global Skin members will be asked to get the GRIDD specific to our disease and language. Data comes back to the GRIDD team directly and they will code and analyze it.

In phase 5 the team hopes they can present the results at the Global Skin conference in 2019. Then we'll discuss how to use it for advocate, awareness campaigns. Global Skin members will receive full toolkits and support.



### **Plenary session Healthcare Value assessments – injecting the patient voice**

Julie Block

Health technology assessment (HTA) refers to the systematic evaluation of properties, effects, and/or impacts of health technology. Julie Block described the influence in HTA per country. She works for the National Eczema Association (NEA) in the USA. Patient engagement has changed from where doctors looked at patients as ‘barbarians at the gate’ to working together and ‘everyone wants a patient’, running together.



Julie Block



Jasmin Barman

### **Plenary session Healthcare Value assessments – injecting the patient voice**

Jasmin Barman-Aksözen

Jasmin is a biologist herself, when she discovered and got diagnosed with Porphyria (EPP). She's very sensitive to light. Medication became available in Europe. Poor research was done that gave false results of the benefit of the medication. Research for instance would not take into account rainy days (less light/staying inside) or work situations (staying inside). An Australian research company on melanoma found a drug that was useful for the patients with Porphyria. Jasmin showed how her work on advocacy was successful – from talking to insurance companies to organizing a demonstration. The medication is now available to patients with Porphyria.

### **Scientific Advances in Dermatological care**

dr. Jan Dutz professor, department of dermatology and skin science

The skin is human's largest organ. It's a barrier to keep fluids in or out of the body. It protects the body against radiation, microorganisms (using antibiotics on the skin). It protects the body from heat or cold through blood vessels in the skin. The skin is also a sensual organ with a lot of nerve endings. For a not well understood reason humans lost most hair on their skin.

## **Immune system:**

In the top layer of the skin are keratinocytes that produce chemicals to cause cells to grow when damaged. Dendrocytes are cells that 'reach out' (see shape) and 'eat' bacteria and fungus. The epidermal compartment has keratinocytes, Langerhans cells and lymphocytes. The dermal layer has dermal dendrocytes, mast cells, and vasculature.

Tcells are cells that will 'kill' a tumor and take the repaired cell back into the skin. Tcells that react (cure virus or cause disease) stay in the skin. When Tcells fight it's against a virus, when the cause pathology it's psoriasis or dermatitis.

Psoriasis is a disease where there are too many Tcells. The treatment in the past would have been light therapy. It worked. Now we understand it kills the Tcells. An allergy is when the Tcells are overstimulated. Research discovered 'skin' has a memory. The Tcells respond like they have a memory. In tests when the skin was exposed to bacteria and the skin would also be protected in another part of the body to this particular bacteria.

Treatment with psoriasis were done with a drug (steroid) that causes the Tcells to stop working. But as soon as you stop the drug, the patient deals with inflammation again.

A new treatment in psoriasis is done by an inhibitor. An inhibitor is a small molecule that goes inside the cell and blocks inflammation cells. Side effect is a slightly increased risk of viruses to come in, for instance shingles.

CAR-T treatment in psoriasis: against blistering and inflammation. Better use of 'good' bacteria's in the skin. With newer techniques we can distinguish the bacteria's better.

## **Cancer/melanoma:**

Until now, the most used treatment in cancer is chemo therapy. It kills dividing cells. Research in new treatment is getting the immune cells from a patient (because the body is already fighting the cancer), multiplying them and injecting it back in the body. It kills the tumor and is very specific. Jimmy Carter was first diagnosed with metastatic melanoma (poor prognoses). This treatment cured him.

## **Plenary session shared objectives – benefits and challenges of collaboration between patient organizations and pharma**

Leo Pharma, Galderma, Novartis, Celgene

Panel talk about patient organizations and pharmaceutical industry working together. Patient organizations don't know who's the contact person in pharmaceutical industry. Another discussed problem: when the pharmaceutical industry does a publication, they'll do it in a medical journal or Pub Med. Pub Med only gives free summaries and when you want to read the full article you have to pay a large amount of money (~\$300). Therefore, publications are not available for patient organizations. Francois Blanchette talked about an itch-app. The panel listened and understands the problems of the current situation.

<https://www.nestleskinhealth.com/shield/itch-tracker>



**New connections:**

**Western Africa:**



Ogo Maduwesi, founder of Outer Shell Africa, an organization to support different skin conditions. Their mission is Social wellness and Social inclusion for Sub-Saharan Africans living with Skin conditions and Visible differences

[outershellafrica@gmail.com](mailto:outershellafrica@gmail.com) or [contact@outershellafrica.org](mailto:contact@outershellafrica.org)  
[www.outershellafrica.org](http://www.outershellafrica.org)

**North Africa (Tunisia, Algeria, Morocco):**



Myriam Lamine is president of the vitiligo association of Tunisia. She would like to be a contact person for other skin conditions as well in North Africa.

[laminemyriam@atvitiligo.org](mailto:laminemyriam@atvitiligo.org)  
[www.atvitiligo.org](http://www.atvitiligo.org)