



**Empowering and Advocating for
Dermatology Patients**

GlobalSkin White Paper

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International Alliance of
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Empowering and Advocating for Dermatology Patients

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Cover photo: Participants of the Patient Perspectives Symposium at the GlobalSkin 2017 Conference in September 2017.





Background

According to the British Skin Foundation, 60% of British people will suffer from or have suffered from a skin condition or disease in their lifetime¹. Many such patients are passive regarding their care – seeing their situations as unchangeable and immovable. It’s been well established that this lack of treatment is in many cases both unnecessary, with the advent of new and effective treatments, and unhealthy, as there are both primary and secondary risks associated with diseases that affect the skin.

In September of 2017, leaders of dermatology patient organizations from around the world convened in France at the *GlobalSkin2017* Conference, hosted by the International Alliance of Dermatology Patient Organizations (IADPO). During this two-and-a-half-day conference, representatives from over 40 dermatological patient organizations participated in a unique Patient Perspectives Symposium, where they discussed how patients can be empowered to seek effective and treatment and what role dermatology patient organizations play in advocating for access to timely care on behalf of people suffering from skin conditions and diseases. Their comments, and some added external references, provide the fodder for this White Paper.

How Dermatology Patients Differ from other Patients

Despite its wide prevalence, skin disease and the psycho-social impacts of visible skin conditions are often misunderstood. The public frequently reacts badly to people with rashes and sores believing incorrectly, that the condition may be contagious. In some cultures, skin patients may be asked to leave public swimming facilities, or be subject to staring, while in other cultures, they are shunned and kept out of sight.

While some conditions are now treatable, most skin diseases are still incurable. Embarrassment and shame can be a daily experience for the sufferer – and it will last their lifetime. Understandably, many experience isolation and depression, sometimes resulting in suicide.

Among the general population and healthcare regulators, a broad understanding is lacking regarding the role and function of the skin in the body's overall health. There can be an attitude that “it's just skin,” even though many diseases affecting the skin also result in serious co-morbidities such as arthritis, depression, inflammatory bowel conditions, and cardiovascular diseases. Some skin diseases are deadly.

Key issues facing Dermatology Patients

Access to proper diagnosis and care

The vast number of diseases and variations of conditions create a lack of consistent and current training for specialists and primary care physicians.

The Canadian Skin Patient Alliance, on their medically reviewed site, states that there are more than 3,000 diseases and conditions that affect the skin. Many are extremely rare.ⁱⁱ

The family doctor or general practitioner – the first line of care – is often given little or no training regarding skin disease even though, according to the Annals of Family Medicine, more than 12% of consultations they perform have to do with complaints regarding the skin.ⁱⁱⁱ

Dermatologists are the experts in skin diseases and yet, anecdotally, some acknowledge to patients that even if they could be trained to recognize and treat such a vast number of diseases, they might never come across many of them in their practice. Access to good resource materials and current treatment information is often not available in many parts of the world.

Patient knowledge and access to information

Patients are often unfamiliar with their specific condition or its treatment options. Many have no resources with which to determine if they are being given all the necessary information regarding the benefits and potential side-effects of suggested therapies or have not been made aware of alternative treatments available to them.

Some are uncomfortable questioning a doctor or don't have the "language" with which to have a meaningful conversation regarding their condition and/or its treatment.

Geographical distribution and availability of specialists

Many patient leaders report that the number of dermatologists is too low to meet patient demand and that wait times are too long. In the United States, for example, increasing patient load has not been met by a corresponding increase in doctors, partly because of a federal cap on the number of medical residents who can be trained each year^{iv}. In Canada, not only are there not enough dermatologists for the population, but too few are being trained to replace those who are retiring each year^v.

While the World Health Organization has reported that a growing awareness of skin disease has started a "flurry" of initiatives to increase access to proper care in developing countries, there remains much to be done.^{vi}

Access to care is particularly difficult in rural areas where great distances must be travelled to receive assessment of a condition. Multiple consultations and therefore many long trips may be required and can be very costly to the patient.

Cost of accessing care and treatments

Where government funded healthcare or private insurance is not available, many patients are simply unable to consult with general practitioners or specialists due to the cost.

Even when a doctor is accessible, the cost of new and effective treatments can be prohibitive and are sometimes disallowed under government or private insurance plans which can be slow or reluctant to fund new therapies.

Hidden costs – including travel, over-the-counter supportive treatments and time off work – may also impact a patients' ability to seek or continue treatment with a specialist or doctor.

Societal perceptions

In some societies, there are social stigmas isolating the patient which must be overcome before they will seek help with a condition. Shunned by their community, these societal perceptions can result in a patient being isolated or never seeking treatment. For example, in several African countries, people who have pigmentation or other skin disorders are seen to be a visible sign that their family has been cursed by the gods, so the social cost of skin disease is visited upon the entire family if the skin condition is visible.

The timelines for addressing these problems can vary widely depending not just on the complexity of the issues, but also the geographical challenges within the country.

Empowering Dermatology Patients to get the best possible care

Become an expert

While patients may want to believe that their physician is an expert in their disease, that may not be the case, particularly with respect to more rare conditions. When patients educate themselves with up-to-date information about their condition and their therapy choices, they are less intimidated and more likely to have productive conversations with their healthcare provider.

Participate in the conversation

Patient leaders suggest that patients be encouraged to ask their healthcare providers “why” at each stage of the consultation until they feel comfortable with their understanding of the recommended therapy and participate in shared decision making.

In addition to understanding their treatment, in their paper, “*Non-compliance in Dermatology and its Implications*”, the British Journal of Healthcare Assistants, discusses how patients are more compliant or adherent with their therapies when they have established a relationship with the healthcare provider that encompasses the whole patient experience – including psycho-social issues – not just the symptoms of the specific disease.^{vii}

Depending upon a patient’s education level, socio-economic status, age or other factors, not all patients are capable of completely understanding their disease nor speaking up during medical appointments. In those cases, it’s helpful to find an advocate who can join patients in their consultations and model for them how they can speak up on their own behalf.

Dermatology Patient Organizations (DPOs) empower patients

Provide information resources

A Dermatology Patient Organization (DPO) is often sought out by the patient or family member when a patient first displays symptoms or has been newly diagnosed. While DPOs have a responsibility to encourage patients to seek out professional assessment of their condition, there is a great deal of useful information that they can impart via their websites or through peer contact to help empower the patient. It’s incumbent upon the DPO to ensure that their information is current and accurate.

The following suggestions were discussed during the *GlobalSkin 2017* Conference:

- a. *Establish a global network that can provide information on a local basis*
By bringing the international support community together, resources can be shared by local support organizations to help patients within their communities.
- b. *Establish a help line for patients to speak with mentors – peer to peer*
Talking with someone who has experience with the same symptoms and difficulties can

provide not just information, but can also help to eliminate fear and the sense of isolation.

c. *Teach patients how to live with their disease*

In some cases, the DPO can provide useful coping strategies; e.g. skin camouflage where appropriate, dressing techniques, or how to deal with itching. This can be done online, or via print materials left in physician offices, or through information sessions.

To assist patients in this way, it is important the DPO make both family doctors and dermatologists aware of their services so that patients can be referred to the organization.

d. *Inform patients about their rights to and options for access to care*

In some countries a patient may not need to go through a general practitioner or family doctor to see a specialist, but there may be additional costs to do so. Patients might possibly seek treatment through a hospital which may not charge a fee.

In addition, DPOs can communicate that there may be other healthcare providers that would be helpful for a patient; e.g., family counsellors, psychologists or nursing clinics.

e. *Provide support and information for parents of children with skin conditions*

Parents are often at a loss as to how to advocate for their afflicted child while maintaining balance within the family. The DPO often has this experience or knows of members who have navigated the waters of advocacy for a child. Providing both informational and personal support can be invaluable.

f. *Conduct patient information sessions including doctors, other patients and DPOs*

Consultation with a doctor can be brief and often questions will arise long after the patient has left the office. It can be informative and reassuring to meet with other patients and have an opportunity to ask questions of the experts in a more informal and less hurried environment.

g. *Patient stories*

Sharing the patient story is a means of helping other patients feel like they are not alone. This information can provide support for new patients experiencing symptoms and it presents a face to the disease or skin condition.

These stories can be shared through on-line webinars or in person for those patients who may not have access to the internet or social media.

They can be advertised on DPOs websites and social media, posted in doctors' offices and clinics, and printed in local papers.

h. *Publish best practices*

Patients need to understand the current best practices in the treatment of their disease. In some instances, their knowledge can be a good resource for the doctor as well.

Where available, patient organizations can add links or the actual guidelines to their websites so that patients and family members are better informed when they have their consultation with the doctor.

i. *Communicate with other DPO's*

Networking with other patient organizations provides opportunities for sharing patient support information and experience. The *GlobalSkin2017* Conference was an example of how coming together across disease and geographic borders allows for informed exchange of knowledge and ideas and can reduce duplication of effort and ultimately improves the patient experience.

j. *Help to train family physicians*

The membership of the DPO is sometimes a vast network with access to many first line doctors. The DPO can be in an excellent position to work together with general practitioners to help provide dermatology information about the lived experience of the disease – particularly with respect to rare diseases.

Provide tools for patient empowerment

There is so much information for a patient to read and absorb that it can potentially be overwhelming. DPOs can help to manage and track the effectiveness of treatment in order to maximize the time available with the doctor. These might include fact sheets to be taken to the consultation.

Most especially in the case of rare diseases, it can be helpful to the doctor for the patient to bring current information about the condition and potential therapies.

With respect to the social aspects, unafflicted people are often either uninformed or misinformed about the nature of a skin disease. Patients often don't feel comfortable or able to communicate information about the nature of their illness to people they encounter who might react negatively. The DPO could provide patients with a printable card they can carry to be given to those who may be interested or disturbed by their disease.

Dissemination of information

Information is not useful unless it is in the hands of patient. The DPO has a large role to play in the dissemination of information. These are some suggestions that arose from the discussion at *GlobalSkin 2017*:

- Make information available for patients at the first point of care – primary contact with the primary care physician or nurse practitioner.
- Encourage doctors to offer questionnaires for patient comments which can direct the patient to the DPO for further support.
- Collaborate with doctors to inform patients of on-line tools and workshops or training programs.
- Foster cooperation between hospitals and patient organizations for distribution of literature, posters, information regarding on-line or in-person workshops.
- Provide information that can be distributed through pharmacies.
- Make good use of social media to bring people to the information provided.
- Make materials available to pharmaceutical representatives to distribute to doctors' offices.

Advocacy Role of the Dermatology Patient Organization (DPO)

The word “advocacy” is subject to differing meanings or interpretations and the need for patient advocacy varies greatly internationally from country to country and region to region.

Ways in which DPOs can advocate

Preparation

Defining the needs and building a plan can help the DPO understand what is required to advocate for their patients.

Is there a need for policy change, disease awareness, physician education, public education, or access to dermatologists? Each of these types of advocacy potentially involves a different target audience for whom the message must be tailored.

It's important to know who the decision makers are within the target audience(s). This might involve learning about the public health management structure in the local, regional or national government and how this compares with other countries.

The DPO must find a balance between the urgency of the need and the capacity of the organization. Some advocacy campaigns can be very long. The organization must understand if they are able to sustain a long campaign and what resources are required to make the plan achievable.

Regardless of whether the DPO is advocating for policy changes, access to care or treatments, or funding, it is important to demonstrate the need. It may be necessary to research disease statistics before launching a campaign. Needs may vary by geographical location.

Knowledge of the cultural context of the disease can be crucial to a successful advocacy campaign. If a disease is particularly stigmatized in a culture this can influence the perceptions of health providers, regulators and insurers. It may be necessary to campaign on this perception prior to advancing other advocacy goals.

Taking action

i. Educate

As stated earlier, the general practitioner may have no experience, tools or resources to diagnose and recommend initial or specialized treatment of the disease.

The membership of the DPO is sometimes a vast network with access to many doctors and dermatologists with whom they can work to help provide dermatology information, particularly about rare diseases to general practitioners.

There is an increasing awareness of the benefits of treating patients holistically or multi-disciplinary – nursing, psychology, rheumatology and physicians treating other co-morbidities. Treatment and disease information can also be distributed to these groups.

Most especially in the case of rare illnesses, information can be provided to dermatologists who may never have encountered the disease in their practice.

Pharmaceutical representatives can be a very effective vehicle for distributing information created by the DPO as they are in regular contact with physicians.

Where funding and distribution for an information piece can be arranged with multiple supporting partners, the distribution may be wider and the independence of the DPO is easier to maintain.

It can be helpful to foster cooperation between hospitals and patient organizations for distribution of literature, posters, and information regarding online workshops.

ii. Work towards change

Learn who has the power to influence and make changes.

Meetings with the ultimate decision makers can be hard to arrange and the DPO must be as prepared as possible to maximize the opportunity.

Once it's understood how the health system operates, creating relationships with decision makers and establishing the DPO as the expert at various levels within a governing department can be helpful with advocacy efforts. This is not always easy and, where there is a disinterested party, it can be best to continue to work without them by joining with key stakeholders to make the patient's voice heard. Educate these people with regard to the disease and best practices.

These relationships can be useful in learning what decision makers are looking for from the organization; e.g. first-hand experience, validated data, education.

Once a connection is made, decision makers will need to be educated about not just the need amongst the population but also the patient experience – with and without treatment. Once this takes place, change can begin. However, DPOs should not expect this kind of change (new regulations, approval of treatments or funding opportunities) to happen quickly. Look for reasons to meet more than once with a decision maker; e.g. new statistical data, new treatment information, treatment success stories.

It's important to explain unfamiliar terminology.

Patient stories can be useful in humanizing the information being presented. Where possible, have a patient present at the meeting. Photographs or short videos could also be used if this is not possible.

The Dermatology Patient Organization must decide in advance what is the one thing being asked for and never ask for more than one thing at a time. This decision is a crucial part of advocacy preparation. Some changes, while perhaps not the most important, are easier to accommodate and can happen more quickly than other. These easier “asks” can help establish a working relationship with important contacts.

The DPO should always acknowledge and congratulate decision makers when positive changes are made.

Create and protect credibility

It's imperative that the Dermatology Patient Organization finds and stays current with good information regarding their disease landscape; e.g. number of patients, best practices for treatment. While they must become the “expert”, they must not ever recommend one treatment over another and must make it understood that treatment plans are decisions are made between patients and their doctors.

Equally important, they must remain independent of any of their funding partners. This is best accomplished by working with different companies so that the DPO does not give the appearance of having a conflict of interest. Transparency in this regard is vital to maintaining credibility.

Opportunities for Cooperation

Opportunities to learn from other organizations and combine efforts can also create a louder voice when advocating for change. These would include:

- For many diseases, information regarding the prevalence of a condition may not be available. Exchanging data between organizations, e.g. data from developed countries can be used to help underdeveloped countries.
- DPOs that are more established may have useful information about previous advocacy campaigns. Sharing successes and failures – what worked and what didn't – can inform effective advocacy plans.
- Often, the needs of other patients, regardless of disease area, are similar to those of the dermatology patient. Reaching out to different groups and leaders – not exclusively dermatology organizations – can provide insight into advocacy challenges and sometimes the DPO's voice can be added to theirs where the goals are the same.
- Chances are good that someone somewhere has conducted similar campaigns to those the DPO exploring. Before spending time and money on advocacy materials, it can be useful to open routes for sharing information amongst organizations to prevent "reinventing the wheel".
- While funding available for patient groups is not unlimited and DPOs can sometimes view each other as competitors for financial support, there are many opportunities for collaboration in order to reduce the cost of advocacy campaigns. Leverage each other's talent and expertise.

The Role of the International Alliance of Dermatology Patient Organizations (IADPO)

As an international umbrella organization for all types of skin disease, IADPO can provide an opportunity to connect and facilitate collaboration between DPOs – large and small – around the world for the purpose of sharing information, tools, resources and experience that can be used on a local basis. This can serve to lessen both competition amongst groups and overlap of services.

Global Research on Impact of Dermatological Diseases (GRIDD)

What is GRIDD

In dermatology, to date, there has been no study of the impact of dermatological diseases on a global scale. Some country-specific impact studies have been done for a very small handful of specific conditions. 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.^{viii}

IADPO is undertaking a ground-breaking global patient-initiated research project which is multi-year, multi-site and multi-disease.

Member organizations will share in the development of the questionnaire and, later, will help us survey the patients they serve. With a better understanding about living with any of over 3,000 dermatological conditions worldwide, the goal is to influence changes at the World Health

Organization (WHO) globally and create tools to help member organizations advocate for improved access to treatment and care locally.

Approach

Working with patient leaders, IADPO will create a Global Research of Impact on Patients (GRIP) tool. It will allow patients living with dermatological diseases to co-create questions from their unique perspective for a research instrument that would allow them to fully describe the impact of disease on them and their family members. This tool will be tested and used in the realm of dermatological diseases first, with a view that if successful, it can be expanded to validate Patient-Reported Impact Measures (PRIMs).

Using the patient-derived questions, a unique measurement instrument will be created to survey the impact of disease on patients and their family members. The output will be a Global Report on the Impact of Dermatological Diseases with a breakdown by country, region and disease, allowing stakeholders to present data regionally, locally or globally to decision-makers to support the critical need for policy adjustments to improve care paradigms for dermatological disease patients.

Challenges for GRIDD

As many skin patients tend to live without diagnosis and treatment, recruiting subjects from this vast number of sufferers will be challenging.

Gathering evidence even amongst those receiving treatment may present its own hurdles as skin patients tend to not want to be noticed. Although the number of patients served by a DPO may be large, there may be limited formal engagement. The challenge will be to encourage these people to recognize the importance of making their voices heard and participate in the study.

Conclusion

There are many aspects of dermatological diseases that can make a patient feel overwhelmed and hopeless. Faced with a potentially life-long struggle, patients need resources to empower them with respect to finding care, participating in the decision making around their treatments and, in some cases, educating their doctors about their condition and the best practices around therapy.

The Dermatology Patient Organization is a powerful, central resource for patients to connect with those who understand what they are going through and provide them with the tools and information to help them cope and succeed at finding the best treatment. As patients often experience social trauma and stigmatization, they can benefit from being provided resources and guidance to deal with the psychological and social issues that come with a visible disease.

With careful examination of the needs of the patient population in their region, the Dermatology Patient Organization can identify the target audience for their advocacy campaigns, establish priorities and plan within the capacity of their organization. That capacity can be extended through networking with other Dermatology Patient Organizations taking advantage of their skills and experience. International organizations such as IADPO can play a key role in facilitating collaboration between patient groups.

The GRIDD study being undertaken by IADPO will help to establish a new way of measuring and understanding the dermatology patient experience on a global level. The challenge will be to find patients who are willing to “come out of hiding” to participate.

At all times, the good reputation and credibility of the DPO is important when advocating for change and it’s important to maintain an arm’s length relationship with their funding partners.

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