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International Alliance of
Dermatology Patient
Organizations

IADPO European Community

Landscape analysis for EuropaDERM



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Introduction and Overview

In 2020, the International Alliance of Dermatology Patient Organizations (IADPO), known also as GlobalSkin, announced the establishment of EuropaDERM: enhanced cooperation platform of its European members. The initial objective of EuropaDERM is to allow European members to achieve their advocacy objectives in a collaborative and coordinated way.

In order to design EuropaDERM in compliance with European patients' needs and priorities, IADPO conducted semi-structured interviews with its European members. Current document is a summary analysis of IADPO's European members' key challenges, strengths, advocacy capacities, policy priorities, as well as their vision for the EuropaDERM initiative. It summarizes 26 interviews conducted with European patient leaders in November and December of 2020 representing atopic eczema, psoriasis and rare diseases.

Members' Key Strengths, Successes, and Challenges

IADPO European members constitute a **heterogeneous** patient community. They are different in structure, resources and operational style. Patient organization (PO) culture is also divergent across European countries: the opportunity for the PO to have a say in health policy differs from one country to another. In the Netherlands, the Ministry of Health considers that “patient organizations are the third party in health”. In France, collaboration has been regulated by law, both at the state and the regional levels. In Germany, patients are recognized as actors in the field of health (Akrich, 2008). In Eastern Europe, patient organizations are at the formative stage in contrast to Western Europe where they are strong actors. Yet, they are all striving for similar objectives: to make better the lives of patients.

Principal focus of the community's activity is **raising awareness** about specific skin conditions. This includes awareness-raising activities within the patient community and in society, consequently increasing patients' preparedness to address specific challenges caused by skin conditions and make public spaces friendly for skin and allergy patients. Patient organizations in Europe often raise awareness about specific diseases in **innovative** and modern ways – using art, audio-visual content, digital campaigns, etc.

Since skin conditions impact the **quality of patients' lives** and those of their families, this is the main focus for patient organizations. They require, in general, a coordinated or **holistic approach** to skin diseases by specialists and other health care providers. According to patient leaders, mental and psychosocial impact should be taken into

consideration by practitioners, who often consider the skin diseases as solely cosmetic problems.

Misperceptions about skin diseases can result in discrimination and stigma towards patients by society, and as a result, many patients, in particular those with severe conditions, feel isolated and abandoned. Therefore, **affordable access** to psychological services is one of the priorities for patient organizations.

In some cases, patient organizations advocate for **access to specific treatments and to affordable medicines**. Lack of training among practitioners may result in **delays in diagnosis** of diseases. This situation is even more serious with rare diseases, the diagnosis of which can take up to 15 years. There are also considerable delays between booking an appointment and actual consultation. Furthermore, the COVID-19 pandemic is causing delays in treatment and skin patients were not prepared for such a situation.

However, many patient organizations work in cooperation with specialists and practitioners, as well as researchers – some on an individual basis, while others collaborate on an institutional basis. Some of them are very active in contributing to scientific research on medical dermatology.

Members' Capacity and Involvement in Advocacy

Considering that skin diseases represent an economic and social **burden** not only for patients and also for societies and healthcare systems, most patient organizations are involved in **advocacy** activities on a national level. Working with public institutions, such as national health authorities, is a common tendency among patient organizations. This competence has evolved over the years, positioning patient organizations as key influencers of national health policies.

Advocacy work with public institutions is carried out by IADPO European members, which includes the following examples:

- *Allergy UK* works with institutions responsible for public education to make schools better places for allergic pupils. The charity also advocates for better food labelling (Precautionary Allergy Labelling) with relevant public bodies.
- *Lupus Europe* members advocate with public institutions for access to specific treatment covered by social security.

- *AADA (Spain)* holds regular meetings with the Spanish Health Ministry to raise awareness of atopic eczema, to secure extra public resources for the disease and to improve health services.

- *Malta Eczema Society* works with the Health Ministry to make their Social Security Act favourable for atopic eczema patients.

- *Atopika (Slovenia)* presents research results to the government to stimulate action.

- *Allergija I Ja (Serbia)* works with the Serbian Ministry of Health to make medicines free through social insurance. While this association works with the Serbian Institute of Mother and Child on advising practitioners on allergies, their advocacy activities with the Serbian Ministry of Environment aim to improve air quality. Finally, the association cooperates with the Serbian Ministry of Education to prevent discrimination in kindergartens and schools against children with allergies.

- *British Association of Skin Camouflage* collaborates with British Medicines and Healthcare products Regulatory Agency on approval of certain medical products.

Some associations do not work directly with public institutions, but through patient federations. IADPO member, the European Federation of Allergy and Airways Diseases Patients' Association (EFA), carries out advocacy activities targeting the European Union institution on behalf of its member organizations.

Members' European Policy Priorities

Patient leaders deplore the fact that there is **no political advocacy** focused specifically on dermatology at the European level. Medical dermatology seems to be absent from the political debates, both at the national and European levels. Cancer and cardiovascular diseases, and most recently COVID-19, are dominating public debates, leaving little space for dermatological diseases.

Moreover, there is lack of a spotlight on rare skin diseases at the European level. A European rare skin diseases body is necessary, according to patient representatives of rare dermatological diseases.

Among IADPO European members' representatives, many are patient advocates at the European Patient Advocacy Group (ePAG). They represent rare skin diseases in the European Reference Networks, as well as the interests of the wider patient community. Furthermore, some patient representatives are actively engaged in scientific committees and working parties of the European Medicines Agency. In

addition, some members of the European patient community are active in scientific research focused on dermatology. People representing dermatological diseases in European bodies constitute an important resource for the European community of GlobalSkin and cooperation among them could be enhanced.

There are noticeable regional **disparities** in healthcare: those disparities occur within countries and Europe-wide. These are not only differences in access to healthcare and unmet healthcare needs, but also in health-related behaviours and conditions exacerbated by socio-economic differences. Furthermore, these disparities make patients residing in remote regions even more vulnerable. Health inequalities have been acknowledged by the EU and the Organization for Economic Cooperation and Development (OECD), and according to these organizations, a multi-vector action and strong political will is needed to address the issue.

The biggest challenge for patient organizations is related to **funding**. Since the number of patients increase every year, the financial burden increases proportionally. Therefore, patient organizations need to be regularly informed about potential funding opportunities at the European level.

Finally, language barriers are one of the main obstacles for communication and close cooperation among European patient organizations across the continent.

Recommendations on Capacity Initiatives, Policy Priorities and Potential Avenues for Advocacy

The majority of patient leaders provided the feedback that **EuropaDERM** is a timely and necessary initiative. A European body representing dermatology patient organizations with strategic and long-term vision is needed. According to patient organizations, a range of responsibilities should be assigned to this body.

-Building Momentum

EuropaDERM should develop a consistent reputation and set of objectives. A pan-European initiative should gain solid legitimacy in Europe. With the COVID-19 crisis and new institutional framework, the EU's interest in health is increasing. For example, the European Commission has announced the creation of the new European Health Union and has recognized that there is a need to reinforce the European Centre for Disease Control and Prevention as well as the European Medicines Agency. The Commission has also announced that a Health Emergency Response Authority (HERA) will be proposed at the end of 2021. Maintaining this **momentum** is therefore very important. Patient representatives should have a strong voice, should be

taken seriously and should be trusted partners of European institutions (for public consultations, etc.). An interest group in dermatology should be created in the EU parliament (similar to one that currently exists on Allergy and Asthma).

Principal advocacy activities (particularly with the EU institutions, Council of Europe and World Health Organization) need to aim at bringing medical dermatology to the **political agenda**. Also, the EU needs to have a policy plan towards patient organizations. EU **policy priorities** – namely EU Beating Cancer Plan, Horizon Europe, Pharmaceutical Strategy for Europe, as well as Artificial Intelligence – need to create a friendly environment for dermatology patients. When designing and implementing these policies, patients' needs and concerns must be at the forefront.

Representation should be ensured for **underrepresented** skin conditions. Representation in the **European Medicines Agency** and the **European Reference Network** could be done through the coordinated work of patient advocates and advisers, related to IADPO.

- Fostering a European Movement

The question of regional disparities is an issue and needs to be tackled through strong European policies. Improving cross-border healthcare needs to be addressed, not only by the European and international institutions, bodies and agencies, but also by stakeholders from academia, non-governmental organizations, the healthcare community and industry.

However, a renewed debate on medical dermatology needs to embrace the entire **European continent**, and not only the EU. The initiative should leave no one behind. The European dermatological patient community members consider the withdrawal of the United Kingdom from the EU as a big loss. British patient organizations represent enormous expertise and experience. Therefore, the impact of Brexit on health policies must be minimized. Along with the European approach, regionalization is also important to take into account, as some diseases are regionally spread.

- Focus on Various Policy Areas

Beyond exclusively health-related policies, various policy areas, from research to social policies, must also be scrutinized.

More advocacy efforts should be made towards **investing in research** in medical dermatology (through Horizon Europe, among others). Voices need to be raised for increased inclusion of patient representatives in scientific research both in steering and designing. Given its prevalence, dermatology is essential to the European

research agenda. There is a need for European **guidelines** for dermatology patients and practitioners.

The **psychosocial and economic dimensions** of medical dermatology need better focus by the European bodies. Stigma, discrimination at work and job losses related to dermatological conditions are significant systemic issues, particularly for those patients with severe cases. Therefore, decision and policy makers need to prioritize the social protection of the dermatology patients.

- EuropaDERM Principles

The EuropaDERM initiative should foster cooperation among patient organizations. Networking and collaboration among patient representatives should be promoted to ensure **better information flow** among European patient organizations, which need to share best practices and learning from each other's experiences. A platform of shared data could be useful for further data-driven initiatives. Furthermore, **enhanced cooperation** between similar patient organizations across Europe is needed. Cross-border patient cooperation in Nordic countries provides an excellent example.

EuropaDERM needs to adopt a **patient-centred approach**, and patient engagement should be encouraged. However, fostering any disease-specific identity is cautioned and is best avoided. Activities need to be focused on advocating for all dermatology patients and not pitting them against others, nor creating new lines of division.

- EuropaDERM Actions

EuropaDERM ideally is a response to the lack of resources among European patient organizations. Facilitating funding opportunities for patient organizations, helping them with translations and other tasks are expected actions of assistance.

To empower local organizations to boost their capabilities, EuropaDERM needs to support them through seminars, networking, and sharing expertise through **capacity-building**. This includes and should not be limited to providing advocacy toolkits supported by improved data and reporting on dermatological diseases in Europe. It also includes providing opportunities for patient organizations to have their say in Brussels and at the national level.

Finally, EuropaDERM is expected to help to support **artistic initiatives** of patient organizations. These types of initiatives are already among the flagship activities of some IADPO members such as Atopika (Slovenia) and AADA (Spain).

Conclusion

This document summarizes the vision shared by approximately one-third of IADPO's European members and reveals many factors to be taken into consideration when advancing the EuropaDERM initiative.

Despite operational distinctiveness and resource disparity, all the patient organizations are aligned on a patient-centred objective. Over the years, they have developed capacity to advocate for particular issues, or to influence domestic policies impacting patients' lives. These competences need to be reinforced by various means, particularly through sharing practices and capacity-building measures.

Extra resources are needed to operate at the continental level. This seems essential, since patient leaders consider that medical dermatology does not get the attention it deserves at the political level. The input and influence of dermatology patient representatives will provide essential information in steering many health issues, which fall within the European policies.

European patient organizations would therefore need local coordination in Europe to carry out such activities. The EuropaDERM initiative is a natural collaboration allowing patient organizations to succeed in this endeavour. Synergies created through the interaction of patient groups can position EuropaDERM as a united voice of dermatology patient organizations across Europe representing millions of vulnerable people.

Appendix

The following patient organizations participated in interviews:

1. Allergy UK (United Kingdom)
2. AMICUS Fundacja Łuszczycy i ŁZS (Poland)
3. Asociación de Afectados por la Dermatitis Atópica - AADA (Spain)
4. Association française de Vitiligo (France)
5. Atopika (Slovenia)
6. Atopikerna (Sweden)
7. British Association of Skin Camouflage (United Kingdom)
8. CMTC-OVM (Netherlands)
9. Debra (Croatia)
10. Debra (Belgium)
11. Društvo Atopijski Dermatitis (Slovenia)
12. Dutch Association for People with Atopic Dermatitis – VMCE (Netherlands)
13. Eczema Outreach Support (United Kingdom)
14. European Federation of Allergy and Airways Diseases Patients Associations - EFA (Belgium)
15. Genespoir (France)
16. Hidradenitis Patienten Vereniging (Netherlands)
17. Irish Skin Foundation (Ireland)
18. Lichen Sclerosus Foreningen (Denmark)
19. Lupus Europe (United Kingdom)
20. Malta Eczema Society (Malta)
21. Naevus Global (Netherlands)
22. National Association for the Assistance and Support for Persons with Allergies, Celiac and Other Autoimmune Disorders (Serbia)
23. PEM Friends (United Kingdom)
24. Skin and Allergic Diseases – Interregional (Russia)
25. The Patients' Association HS (Denmark)
26. Vereniging voor Ichthyosis Netwerken (Netherlands)

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