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Organizations

GLOBALSKIN EUROPE REGIONAL REPORT



Skin Disease Landscape in Europe

A Summary of Contributions from the GlobalSkin Europe Regional Workshop

GlobalSkin, the International Alliance of Dermatology Patient Organizations, along with its 350+ Members, is dedicated to improving the lives of people living with skin conditions worldwide. Through contributions from representatives of skin patient organizations across Europe, GlobalSkin identified common areas of need shaping the diagnosis, care, treatment, and daily lives of people living with skin diseases in the region. This work was conducted as part of GlobalSkin's Regional Engagement Workshop Series, a global initiative to understand patient priorities across all six World Health Organization (WHO) regions and to support the community's input into the development of the WHO Global Action Plan on Skin Diseases, along with member advocacy efforts for implementation of the Skin Diseases Resolution. This report presents the findings from the European regional workshop, held on February 19, 2026, and is intended to support GlobalSkin's European members in identifying advocacy, awareness, and research priorities.

The six areas of need identified in Europe are: low political prioritization and underinvestment; insufficient research, data infrastructure, and evidence of burden; disparate access barriers and workforce challenges; fragmented systems and a lack of multidisciplinary, coordinated care; under-recognized mental health and quality-of-life impacts; and a need for patient empowerment and education. These areas are deeply interrelated and largely stem from a persistent tendency to regard skin diseases as cosmetic or non-serious conditions, rather than as complex, chronic, and often systemic disorders that significantly affect patients, families, and health systems. Policy implications of these six themes are discussed, along with the suggested actions participants identified as the region's most pressing priorities.

The contributors to this report served as proxies for their broader skin patient communities, representing conditions including albinism, atopic dermatitis, congenital melanocytic nevi, cutis laxa, epidermolysis bullosa, ichthyosis, lupus, psoriasis, and vitiligo, from countries including Croatia, France, Greece, Ireland, the Netherlands, Serbia, Spain, Turkey, and the UK. While the challenges described are common across the region, there is considerable variability in political support, healthcare system structure, and patient organization capacity, meaning these needs manifest differently across countries and conditions.

Across contributions globally, a consistent finding emerged: there is a need for greater recognition of the burden of skin diseases at both the individual and societal levels. Increased awareness would lead to resource allocation, the creation of dedicated policy frameworks, proportional research investment, a stronger and better-trained workforce, equitable access to care and innovation, and greater empowerment for patients and their families. Without this recognition, the cycle of underinvestment and under-prioritization continues. This report aims to make that burden visible and to translate the lived experiences of people across Europe into actionable priorities for policymakers, researchers, health systems, and the dermatology community.

Methodology

In 2026, GlobalSkin conducted an exploration of the needs of people living with skin conditions by engaging directly with its members across all regions. Participants reflected a wide range of experiences and perspectives, serving as proxies for their broader communities. The engagement aimed to understand patients' priorities, identify regional differences, and map the strengths and gaps in the health system for the prevention, diagnosis, treatment, and long-term management of skin conditions.

Information was gathered through the Regional Engagement Workshop Series, which included two-hour virtual regional meetings, interactive prioritization of needs, interviews, and offline/post-workshop written contributions. Discussions were structured around topics including data collection, data sharing, research, affordability and accessibility of care, local healthcare, innovative service models, patient empowerment, and social awareness. Insights from these sessions were documented and reviewed to identify common themes, regional variations, and priority areas for action. Workshops were organized for the following regions: Africa, Asia Pacific, Eastern Mediterranean, Europe, Latin America, and North America. The European regional workshop was held on February 19, 2026. Nineteen of GlobalSkin's European members contributed to this report through live interventions and written contributions representing conditions including albinism, atopic dermatitis, congenital melanocytic nevi, cutis laxa, epidermolysis bullosa, ichthyosis, lupus, psoriasis, and vitiligo, from countries including Croatia, France, Greece, Ireland, the Netherlands, Serbia, Spain, Turkey, and the UK.

The findings summarized herein provide a regional overview of the European skin community's priorities and are intended to support GlobalSkin's members in Europe in identifying advocacy, awareness, and research priorities, as well as supporting national, regional, and global policy advocacy efforts, such as consultations into the development of the World Health Organization Global Action Plan on Skin Diseases.

Results

The following six themes were identified as the key areas of need across skin disease communities in the European region.

1. Limited understanding of true burden leads to low political prioritization and underinvestment
2. Insufficient research and data infrastructure result in limited evidence of burden
3. Disparate access barriers and workforce challenges present across Europe
4. Care suffers from fragmented systems and lack of multidisciplinary, coordinated care
5. Mental health and quality of life under-recognized in care and resource prioritization
6. Patient empowerment and education needed to equip patients to improve care

1. Limited understanding of true burden leads to low political prioritization and underinvestment

Participants across countries described a failure by governments and health systems to treat skin diseases as serious public health priorities, driving chronic underfunding of services, research, and workforce development. Similarly, rare dermatological conditions are often overlooked and underfunded, especially where they are not life-threatening. Despite the World Health Organization recognizing skin conditions as among the most impactful disorders globally in terms of disability,¹ this has not translated into proportional political attention, inclusion into national health strategies, or investment.

Patient organizations across the region described difficulties sustaining engagement with the government. A representative from Turkey described how high turnover among government officials means relationships built over years must be reestablished repeatedly, placing the burden of continuity entirely on patient organizations. In Serbia, a contributor described meeting with the Health Ministry for the first time in many years, noting that patient organizations are often taken seriously only when they can offer electoral relevance. In Croatia, patient organizations have experienced a complete breakdown in government communication, with meeting requests going unanswered and national plans allowed to lapse. In Slovenia, patients were described as routinely excluded from policy discussions about the conditions that most affect them. A contributor described conducting national patient-led research that was subsequently dismissed by government authorities and noted that patients and their representatives are not taken seriously and are expected to work without compensation.

Despite the documented psychosocial and economic burden of skin conditions,² the lack of robust evidence on the burden of skin disease remains a challenge: without compelling data on economic costs and societal consequences, it is difficult to make the case to policymakers who, in turn, prioritize conditions they can more readily measure. Available evidence suggests that public investment in chronic skin disease care can generate measurable societal returns over time;³ skin health spending should be positioned as a long-term investment rather than a short-term cost.

2. Insufficient research and data infrastructure result in limited evidence of burden

A consistent concern across contributions was the lack of reliable, comprehensive data on the prevalence, burden, and outcomes of skin diseases. Participants described fragmented and incomplete data ecosystems, as well as significant barriers to data sharing. Research focuses on biomedical and clinical aspects, with insufficient attention to prevention, psychosocial impact, and integrating patient-reported perspectives into research and planning. Lack of data affects treatment access; for example, potential treatments for epidermolysis bullosa are not covered if there is no clinical trial data to support their use in this indication. Skin manifestations in lupus have historically been overlooked even within lupus-specific surveys and research, and the pace of change in recognition and treatment remains slow.

In Turkey, a representative raised concerns that there is no accurate national count of people living with albinism. Since 2010, government institutions have begun registering people through disability reports; however, registration remains incomplete because not everyone obtains a disability report or registers with the online healthcare system.

In the Netherlands, a contributor described data systems as relatively well developed across primary care, hospital care, and disease-specific registries, but noted that these systems remain fragmented and that integration of patient-reported outcomes (PROMs) and patient-reported experience measures (PREMs) into routine care is still limited. As a result, the broader burden of skin diseases, including psychosocial impact, is frequently underrepresented in planning, policy, and research.

Cross-border data sharing faces structural barriers, including privacy legislation, intellectual property concerns, and institutional competition. A representative from France reinforced that competition between institutions prevents effective data pooling. Existing legislation requires extensive documentation and approvals for cross-border data sharing, particularly for biopsies and genetic analyses. The European Health Data Space initiative⁴ was noted as a promising development, but standardization and compliance processes remain slow.

Other contributors emphasized the importance of patient associations actively building their own scientific databases and supporting research. One example is the Global Vitiligo Atlas,⁵ which went beyond patient testimonials to collect scientific data to support research. Another example is participation in the European Rare Disease Research Alliance.⁶ Participating in clinical research design was seen as important; participants highlighted that trial sites are often located far from target populations, and restricted support from patient organizations in recruitment creates access barriers that must be proactively addressed with patient input.

The active development of scientific capacity within patient communities was highlighted as a key priority, including the establishment of formal scientific committees, systematic collection of scientific literature, participation in clinical research design, and the integration of patient representatives into scientific writing teams.

Participants called for alignment of data standards at the national and EU levels; strengthening collaboration between existing data initiatives; structured integration of PROMs and PREMs into routine care; formal patient organization roles in data collection and governance; development of integrated data ecosystems combining clinical, patient-reported, and quality-of-life data; and support for patient associations in building professional reputation.

3. Disparate access barriers and workforce challenges present across Europe

Access to dermatological care and innovation is far from standard across Europe. In Greece, patients in remote areas and on smaller islands must independently arrange and fund their own transport to reach specialist care, a cost the health system does not cover. Proposals for tele dermatology solutions have been consistently rejected as too expensive or experimental, leaving patients without viable alternatives. In Spain, despite free healthcare and accessible interdisciplinary care, waiting times for dermatologist appointments in some regions can exceed a year, and access to innovative treatments varies significantly by hospital as institutions procure their medicines independently. In Serbia, dermatologists are described as well-trained but operating under extreme time pressure, leaving no space for the broader psychosocial dimensions of complex chronic conditions. The approved treatment list for atopic dermatitis, which had not been updated for several years at the time of the workshop, significantly limits access to biologics and newer therapies, placing patients at a material disadvantage relative to peers in better-resourced countries. In Turkey, state hospital dermatology appointments involve considerable waiting times, and a sunscreen reimbursement scheme that covers only a portion of

actual costs is burdened by a complex claims process that discourages uptake. In the UK and Ireland, specialist expertise in rare skin conditions is concentrated in capital cities, requiring costly travel for patients elsewhere, and long waiting lists with a postcode lottery system. One representative described a case in which a patient's ichthyosis diagnosis was corrected from vulgaris to X-linked only after persistent self-advocacy for genetic testing, which the healthcare professional did not know was an option for diagnosis. In the Netherlands, dermatological care is generally well organized, yet patients face variability in waiting times and reimbursement rates for products used for daily skin management. Prescription and non-prescription skin management items can be expensive and are becoming increasingly burdensome amid the cost-of-living crisis. Many dermocosmetics that could serve as medicines are sold over the counter and, therefore, not eligible for insurance coverage. This similarly extends to sunscreen regulation and coverage.

A looming shortage of dermatologists across Europe was raised as an urgent concern. Large numbers of dermatologists in several countries are approaching retirement age, and without corrective action, the deficit may take well over a decade to resolve. The trend toward aesthetic dermatology, driven by higher income potential, is drawing qualified specialists away from clinical practice, and too few medical students are entering the field. Geographic disparities further deepen inequity, with rural and underserved areas experiencing greater shortages of trained dermatologists and limited teledermatology options. In France, the French Society of Dermatology organized a program that traveled from town to town to recruit members and improve access to care. Participants called for research into recruitment barriers, expanded training pipelines, and stronger recognition of dermatology as a serious medical specialty.

Primary care knowledge gaps amplify access problems across countries. In the Netherlands, general practitioners were reported to have limited dermatology training, severe time constraints during consultations, and a lack of decision-support tools, resulting in underdiagnosis and delayed referrals. In the UK, most children with eczema are treated in primary care. These providers are cautious in their prescribing practices, leading to a misalignment between disease severity and treatment strength, e.g., moderate to severe eczema treated with a low-strength, mild topical steroid. One idea to overcome these barriers is digital care and task shifting; for example, in the UK, nurse-led eczema clinics provide telephone support and self-management for children under five, reducing barriers to access⁷.

Across countries, participants called for greater investment in digital care tools and accessible teledermatology consultations, expanded professional education in dermatology, including for rare dermatological conditions, increased access to and awareness of treatments for disease management, and strengthened referral pathways between primary and specialist care.

4. Care suffers from fragmented systems and lack of multidisciplinary, coordinated care

The absence of coordinated multidisciplinary care was among the most widely raised concerns across the workshop. Participants from nearly every country described systems in which patients must navigate between siloed specialists without structured teamwork, shared records, or support for care coordination.

A representative from Greece described the situation faced by patients with complex skin conditions who also experience related systemic manifestations: they must independently locate and coordinate between multiple specialists, with no case worker or coordinating function to assist.

Different specialists may give contradictory treatment instructions, leaving patients to resolve these conflicts themselves. This reflects a structural culture of medical individualism among specialists that is neither required nor incentivized to change. Greater systematic collaboration between dermatology and other specialties is essential, given that many skin conditions involve multiple organ systems.

A representative from a lupus patient organization highlighted that skin manifestations in lupus are frequently treated by dermatologists and rheumatologists who operate independently, without coordinated treatment plans. Additionally, others noted the complete absence of a systematic referral process between dermatology, ophthalmology, and psychology for people with albinism, and raised the situation of caregivers as a similarly neglected dimension of care.

Participants highlighted that decision-makers and the general public widely regard skin conditions as minor issues, assuming they affect only the skin and will resolve on their own, directly contributing to the absence of multidisciplinary care frameworks. A representative from the congenital melanocytic nevi community highlighted a systemic pattern in which care for rare conditions is still frequently minimized as a cosmetic issue rather than recognized as a complex disorder requiring lifelong multidisciplinary follow-up and called for shared decision-making models and health literacy-sensitive counseling.

A representative from France emphasized that the European Reference Networks (ERNs)⁸ were tasked with developing international clinical guidelines but have not delivered, with a few exceptions,⁹ due to understaffing and a lack of project management capacity. The ERNs represent the most significant existing European infrastructure for coordinated care of rare dermatology conditions, but have developed slowly, having been layered onto existing healthcare structures without additional human resources. Participants noted that effective network coordination requires dedicated professional project management support; currently, leadership is composed of clinicians who are often overworked and lack the management expertise to run the network.

Where multidisciplinary care models do exist, such as in specialist French hospital units and reference centers in Barcelona (Hospital Sant Joan de Déu¹⁰ for pediatrics and Hospital Clínic¹¹ for adults), they could serve as models worth scaling. Participants recommended integrated care models and clinical guidelines that look beyond treatment to prevention and other essential supportive services; structural requirements for cross-disciplinary collaboration; formal multidisciplinary care pathways for skin diseases with dedicated care coordination roles; strengthened referral pathways between pediatric and adult care; and investment in ERN governance and project management capacity.

5. Mental health and quality of life under-recognized in care and resource prioritization

Participants described a systemic failure to recognize and adequately address the psychological, emotional, and social burden of skin diseases, from individual clinical consultations to national policy frameworks. Contributors emphasized that stress functions as both a trigger and a consequence of skin disease, and that collaboration between psychologists and dermatologists should be a standard feature of care rather than an exception.

Atopic eczema was described as being routinely dismissed as a minor condition by decision-makers and the wider public, with its far-reaching impacts on mental health, social life, employment, and daily functioning remaining largely invisible, directly limiting investment in holistic care.

A contributor from Spain noted that despite strong evidence that visible skin conditions are associated with stigma, anxiety, depression, and reduced quality of life, psychological support is not systematically integrated into dermatology services.¹²

Participants called for routine integration of quality-of-life and mental health screening into care pathways, formal collaboration between dermatologists and psychologists, recognition of psychological care as an essential reimbursable service, including for caregivers, and research funding that explicitly includes psychosocial and economic burden as outcomes.

6. Patient empowerment and education needed to equip patients to improve care

Participants called for substantially improved patient education, self-management support, and meaningful patient inclusion in decision-making at every level. Patient organizations recognize the need to train patients to make the most of their time during doctor visits, given the limited consultation time. Heightened psychosocial sensitivity, shared decision-making models, transparent risk communication, and health literacy-sensitive counseling were emphasized as essential, particularly when risk reduction is not proportional to the physical and psychological burden of extensive procedures, e.g., in the preventive surgical removal of nevi. Successful models in rare conditions demonstrate that co-produced care plans, patient-held digital records, and virtual multidisciplinary consultations can improve outcomes and patient satisfaction.¹³

A representative from France highlighted the development of therapeutic patient education (TPE) programs¹⁴ for rare and chronic conditions as a model worth sharing, noting that these programs equip patients to manage their conditions more actively in daily life, a function clinicians cannot fulfill within short consultation windows.

In the Netherlands, the availability of patient information was reported to be improving; however, not all information is equally accessible, particularly for individuals with lower health literacy. Co-creation of materials at accessible reading levels, with patients engaged as active partners, was recommended.

In Spain, it was similarly emphasized that access to information alone is insufficient if that information is not understandable, actionable, and tailored to patients' realities. Partnerships among patients, clinicians, researchers, educators, and policymakers were identified as essential for co-creating culturally accessible educational materials and decision-support tools.

A representative from Greece made a broader argument for public health education on skin conditions, so that people can recognize symptoms and seek care earlier, shifting the first point of reliable information away from already-overstretched clinical appointments.

In the Netherlands, awareness and social acceptance were identified as core areas for healthcare improvement, with particular emphasis on the challenge of changing attitudes among the general population, which may feel little connection to conditions it does not personally experience.

Participants proposed educating children on skin health as part of the standard health curriculum to improve awareness and acceptance. Other ideas include collaborating with the media and building multistakeholder partnerships to continue and scale awareness campaigns, such as Fundación Piel Sana's campaign¹⁵ from the Spanish Dermatology Society.

The sustainability of patient advocacy efforts was also raised as a fundamental concern: much advocacy work is carried out without compensation, even as responsibilities become increasingly complex. Even where programs are published and validated, they frequently go unimplemented

due to funding gaps or insufficient expertise in program development. Multiple participants called for compensation structures that value patient representatives' time and for structural funding that allows patient organizations to employ dedicated staff. A representative from the Netherlands noted that even a single paid staff member makes a significant functional difference to an organization's effectiveness and called for support in developing similar organizations in countries where patient advocacy infrastructure remains limited. Participants recommended funding and scaling TPE programs with quality standards; co-creating health literacy, self-management education, and decision-support materials with patients; structured and compensated roles for patient representatives in research and policy processes; and sustained funding mechanisms for patient organizations.

Policy Landscape and Recommended Actions

All six thematic areas reflect a common set of interconnected policy gaps. Skin diseases, particularly rare, chronic, or non-life-threatening, are not treated as policy priorities at the national or regional level. Decision-makers view skin conditions as superficial or primarily aesthetic and focus instead on conditions associated with high mortality or severe disability. The burden of skin disease on quality of life, mental health, and economic productivity is poorly captured in the evidence base and therefore systematically underestimated.

While the World Health Assembly Resolution on Skin Diseases¹⁶ represents meaningful international progress, it still needs to be translated into tangible national health strategies. Representatives called for skin diseases to be explicitly included in national rare disease policies and non-communicable disease frameworks, with binding clinical pathways and formal patient representation in governance. Shifting the policy framing toward economic logic is essential: evidence that investment in chronic skin disease care yields measurable societal returns must be communicated more effectively to government audiences.

European frameworks, including ERNs and the European Health Data Space Regulation, have significant but underutilized potential to drive harmonization and accountability. ERNs must be properly resourced to deliver the multicenter research and international guidelines that remain part of their original mandate. Patient organizations must be systematically involved in policy design and guideline development as equal partners, not as an afterthought.

Priorities for Policy Action

- Explicit integration of skin diseases, including rare conditions, into national health strategies and rare disease frameworks
- Strategic communication of economic return-on-investment evidence to government audiences to reframe skin health spending as long-term public value
- Proportional, publicly funded research investment linked to the actual burden of skin diseases, with research agendas that include preventive care and economic, psychosocial, and quality-of-life dimensions
- Coordinated national registries and strengthened data infrastructure aligned with data standards at the national and EU level to facilitate sharing across local and regional associations, facilitate collaboration between existing data initiatives, and enable country-specific analyses

- Investment in ERN governance and project management capacity, with a clear requirement to deliver timely international clinical guidelines with clinical pathways that reduce regional variation
- Expanded dermatologist training pipelines, with incentives for clinical and rare disease specialization over aesthetic practice
- Establishment of integrated, multidisciplinary care models through service gap mapping, piloting of coordinated care teams, standardizing protocols, and establishing patient advisory boards to co-design care models
- Investment in culturally accessible teledermatology and digital care tools, particularly for rural and remote populations
- Gradual integration of PROMs and PREMs into routine care and research
- Recognition of medically indicated psychological care as an essential, reimbursable health service for people living with skin diseases and their caregivers
- Multilevel awareness campaigns, including integration into school education and development of patient-friendly education and care tools
- Exploring formal roles for patient organizations in data collection and representation in ERNs, clinical guideline development groups, and national health policy bodies
- Structural funding for patient participation across these platforms and for patient organizations to employ dedicated staff, sustain activities, and participate meaningfully in research, education, and governance

Conclusion

Contributions from patient organization representatives across the European region tell a consistent and urgent story: skin diseases remain significantly underrecognized, underfunded, and poorly served by fragmented health systems. This reflects systemic policy failures, insufficient evidence, and a persistent cultural tendency to frame skin conditions as cosmetic rather than serious and life-affecting.

Despite variation across countries, the same core problems recur: low political prioritization, insufficient data, siloed care, geographic inequity, unrecognized mental health burden, and inadequate patient participation. Patient organizations are doing essential work with limited resources, often without compensation and without a genuine seat at the tables where decisions are made.

The pathway forward requires coordinated action across clinical, institutional, national, and European policy levels, including the development of binding care pathways, integrated multidisciplinary models, investment in the dermatology workforce, proportional research funding, and meaningful patient inclusion in governance. Skin health must be recognized as an essential component of overall health and human dignity, with patient organizations as equal partners in achieving that goal.

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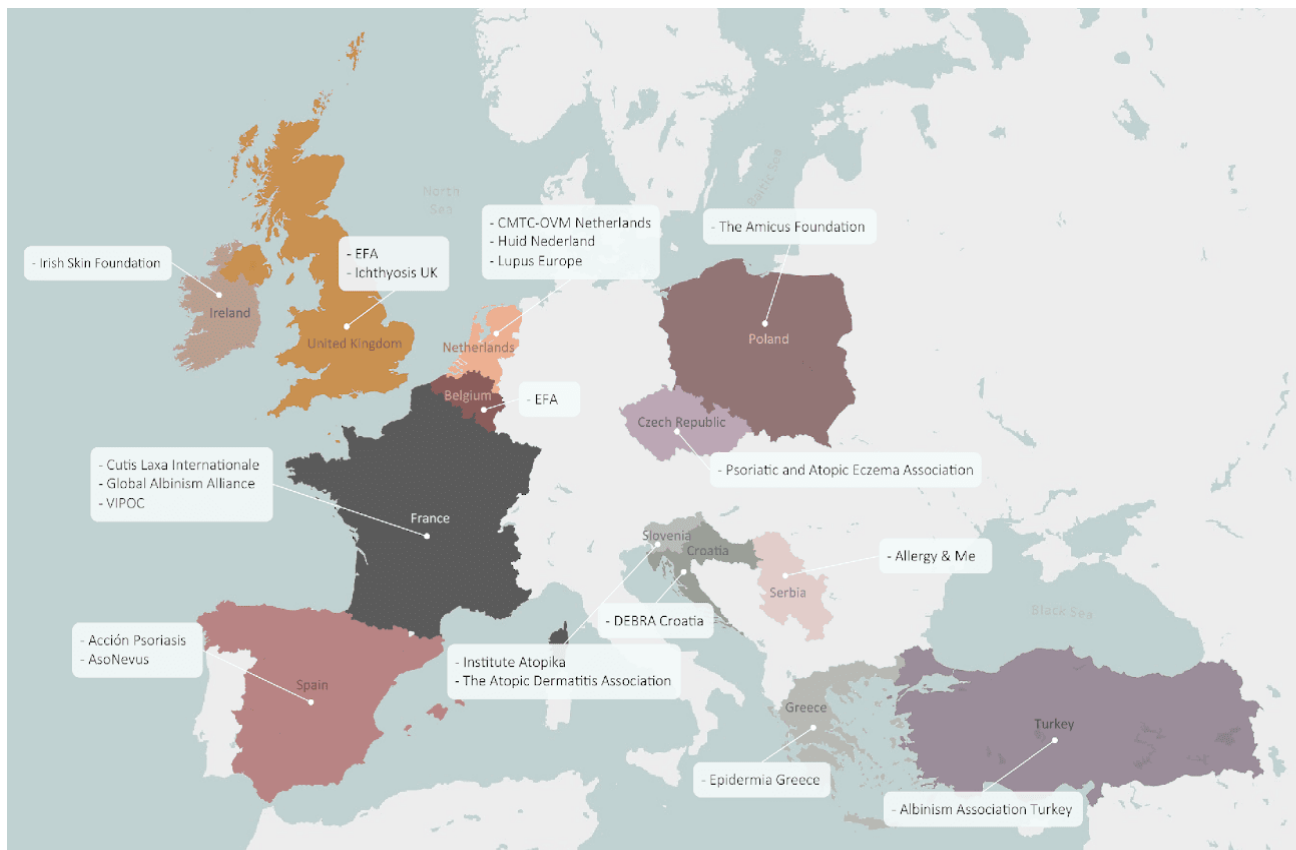
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Europe Contributor Map



Geographic distribution of contributing organizations across online and offline engagement.