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NORTH AMERICA REGIONAL REPORT

Skin Disease Landscape in North America

A Summary of Contributions from the GlobalSkin North America 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 North America, GlobalSkin identified common areas of need shaping the diagnosis, care, treatment, and daily lives of people living with skin diseases in the United States and Canada. Perspectives from Mexico are covered separately in GlobalSkin's Latin America regional report. This work was conducted as part of GlobalSkin's Regional Engagement Workshop Series, a global initiative to understand patient priorities across the 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 North America regional workshop, held on February 23, 2026, and is intended to support GlobalSkin's North American members in identifying advocacy, awareness, and research priorities.

The six areas of need identified in North America are: underfunding and lack of disease registry infrastructure stalling research on skin conditions; training gaps and specialist scarcity causing diagnostic delays; payer restrictions and regulatory barriers preventing treatment access and drug repurposing; siloed systems and social determinants of health driving inequities in access to care; and mental health needs that are overlooked and poorly integrated into skin disease care. 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 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 alopecia areata, atopic dermatitis, eczema, ichthyosis, nail matrix melanoma, palmoplantar keratodermas, pemphigus/pemphigoid, and psoriatic disease, from organizations spanning the United States (US) and Canada. While the challenges described are common across the region, there is considerable variability in healthcare system structure within and across Canadian provinces and US states, meaning these needs manifest differently depending on location and condition.

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 North America 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 North America regional workshop was held on February 23, 2026. Nine of GlobalSkin’s North American members contributed to this report through live interventions and written contributions representing conditions including alopecia areata, atopic dermatitis, eczema, ichthyosis, nail matrix melanoma, palmoplantar keratodermas, pemphigus, and psoriatic disease, from the United States and Canada.

The findings summarized herein provide a regional overview of the North American skin community's priorities and are intended to support GlobalSkin's North American members 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 North America region.

1. Funding cuts and lack of disease registries stall skin disease research
2. Training gaps and specialist scarcity cause diagnostic delays
3. Payer restrictions and regulatory barriers block treatment access and drug repurposing
4. Siloed systems and social determinants of health drive inequities in who can access care
5. Mental health needs overlooked and poorly integrated into skin disease care

1. Funding cuts and lack of disease registries stall skin disease research

Research into skin diseases, and particularly rare skin conditions, is underfunded across North America. Contributors described limited dermatological research, driven by insufficient public investment and a lack of incentives for both academic researchers and industry. The recent reduction in public funding for health research in the United States was raised as an acute and compounding concern, with participants from multiple organizations noting that the cuts have already begun to affect ongoing research programs.

A representative from the psoriasis community described the structural nature of the problem as top-down: when public funding is cut, as has occurred in the US, research across the field is severely affected, not just in industry but also in academic institutions and translational programs. The lack of human and financial resources, combined with a shortage of qualified researchers with expertise in skin diseases, was cited as a critical bottleneck. Participants also questioned the incentives that could drive innovation from a research perspective, given that skin diseases are not treated as critical health priorities.

The absence of robust disease registries was identified as one of the most significant structural barriers to research progress. For rare forms of melanoma, such as nail matrix melanoma, there is no comprehensive data on incidence or natural history, creating a barrier to designing representative clinical trials and establishing clinical guidelines. A representative from the US noted that, without registry data, they are unable even to describe the scope of the problem, let alone address it. Contributors called for registries that document the diagnostic journey, capturing patient pathways, genotype data, and treatment outcomes, and that can be accessed and contributed to internationally. The International Pachyonychia Congenita Research Registry,[1] for example, has changed the landscape for rare skin disorders characterized by painful palmoplantar keratoderma. Operating since 2003, the registry collects consent, information, photos, and even genetic confirmation of diagnosis.

International collaboration was consistently described as both a necessity and a promising path forward in prioritizing skin research. Because the patient populations for many rare skin conditions are small within any single country, achieving meaningful research requires pooling data and resources globally. Participants called for organized research systems focused on dermatology and rare skin conditions, with incentives to drive participation from funders, academic institutions, key opinion leaders, and industry, though participants emphasized not wanting to wait for industry interest before moving forward. A multistakeholder summit, such as the PsoCan Annual Policy Summit,[2] could help align stakeholders on policy and research priorities in skin care. Developing an expert consortium infrastructure, shared online resources, and active engagement with global research initiatives were identified as concrete early steps.

2. Training gaps and specialist scarcity cause diagnostic delays

Across North America, patients living with rare and complex skin conditions face significant barriers in reaching accurate, timely diagnoses. Contributors described a healthcare landscape in which specialist expertise is scarce and geographically concentrated, frontline providers are inadequately trained, and the patient-facing consequence is a long diagnostic process, multiple, uncoordinated

provider consultations, and delayed treatment. A study on patient-reported data cited during the workshop found that patients see an average of five to six different providers and wait approximately ten months before receiving a correct diagnosis.[3]

A representative from Canada described waiting over 12 months for a specialist appointment in many regions, with rural and border communities facing additional barriers. For example, many Canadians are unable to afford to travel to distant specialist centers. Specialist access is not only a rural problem, however. A representative from the ichthyosis community noted that patients become discouraged and sometimes abandon the effort to find knowledgeable care entirely — and that this occurs not just in remote areas. He described learning that a patient was making regular trips from Florida to Connecticut to visit an ichthyosis specialist. In the United States, standard wait times of three to six months for a specialist appointment are common, and even after that wait, patients often see a physician assistant or nurse practitioner rather than a specialist with deep disease-specific knowledge.

The knowledge gaps extend throughout the healthcare workforce. A contributor noted that their organization has identified only one nurse practitioner (NP) in the country actively providing dermatology education for NPs, reflecting the extreme scarcity of educators. Patients are forced to reach out to specialist organizations because local providers are operating on outdated or incomplete information.

Contributors highlighted insufficient training on rare skin conditions in dermatology residency programs, a near-complete absence of rare dermatology education for nurse practitioners and physician assistants, and a notable underrepresentation of rare conditions at major medical conferences. The consequences of this knowledge gap are tangible: a contributor from the US described how some clinicians mistakenly view alopecia areata as a cosmetic issue rather than an autoimmune condition. This misconception results in patients being deprioritized for timely appointments, missed opportunities for early diagnosis, and providers being uninformed about newer treatments, such as JAK inhibitors.

Patient organizations hold significant expertise but remain largely underutilized as educational partners. Several participants described their organizations providing training materials to local providers, maintaining clinical expert networks, and facilitating connections between patients and distant specialists, roles that health systems have not formalized or resourced.

Expansion of telehealth licensing, mobile clinics, affordable genetic testing, and expert mapping and referral networks were all identified as critical tools for closing diagnosis and access gaps. In Canada, a mobile screening model was described that travels into communities to conduct testing, eliminating wait times and extending reach into areas with limited specialist presence. A teledermatology model connecting Ottawa Hospital to patients in Nunavut was described as another example of direct service delivery overcoming geographic barriers. Alongside these access-focused solutions, contributors emphasized the need to build healthcare system capacity through training. Recommendations included integrating rare dermatology content into residency training and better utilizing patient organizations as educational resources for local providers. Contributors emphasized that many promising models exist but are dependent on limited capacity and funding that is typically short-term and project-based, creating a sustainability problem for successful programs.

3. Payer restrictions and regulatory barriers block treatment access and drug repurposing

Patients across North America face barriers to accessing appropriate testing and treatment; these barriers are partly rooted in payer restrictions, formulary exclusions, step therapy requirements, and the high cost of biologics. Contributors described healthcare system structures that routinely require patients to fail on less effective or less appropriate treatments before payers authorize access to the treatment a clinician has recommended. The system, as described, inverts the priorities of clinical care and places the insurer's economic interests in direct tension with patient outcomes.

In Canada, access to and approval of drugs vary significantly by province, creating a patchwork of coverage in which a treatment available in one province may be entirely inaccessible to a patient in another. A representative from Canada emphasized the need for more universal drug access standards across provincial boundaries.

A contributor from the US described an anecdote in which a prescriber ordered a sleep study that was denied as not medically necessary, despite clinical judgment to the contrary. More broadly, he noted that payers in the US represent one of the most entrenched structural problems the community faces, not only restricting access to treatments but also creating barriers to the prescription and reimbursement of generics that have been used clinically for decades. Even treatments with a long history of clinical use can be dropped from insurance formularies, leaving patients without access to medications that had been working for them.

Drug repurposing represents a strategically important opportunity for rare skin conditions, given the high cost and difficulty of de novo drug development. However, participants described structural barriers: multiple manufacturers of a single drug make it unclear which entity should sponsor repurposing research; randomized controlled trial requirements create high cost thresholds that are not recoverable through rare disease markets; and insurers may decline to cover off-label prescriptions even when case-study-level evidence supports their use. There is insufficient profit incentive for large pharmaceutical manufacturers in many rare skin disease indications, with development increasingly falling to smaller companies. Political and financial pressures on large pharma were described as further reducing the appetite for dermatology investment.

Biosimilars were identified as a partial but imperfect solution. While the existence of biosimilars simplifies the regulatory pathway, they are not universally available for all conditions or molecules, and coverage remains inconsistent. Many continue to be treated with conventional therapies, but these are not as effective and are still expensive. The more immediate and widely applicable solution cited was expanding the use of real-world evidence in coverage decisions. Contributors called for greater pressure on payers to recognize real-world evidence, stronger incentives for manufacturers to innovate, and for patient organizations to play a more assertive role in lobbying insurers for formulary and coverage reforms, including affordable, standard genetic testing to support diagnosis.

4. Siloed systems and social determinants of health drive inequities in who can access care

Healthcare systems across North America are structured in ways that fragment care for patients with chronic skin diseases. Contributors described siloed professional relationships, disconnected budgets, and policy frameworks that limit integration of services, leaving patients responsible for navigating between specialists, social services, and financial assistance systems without structured support.

Geographic, economic, and racial inequities shape who is able to access skin disease care across North America, and the compounding effect of these barriers means that the patients with the greatest need often receive the least care. A representative from Canada described Indigenous and Métis communities that have historically been undercounted in health data and underserved in system design. Contributors described patients navigating complex co-payment and drug coverage systems without support, and lower-income patients who cannot access dermocosmetics or medically indicated skincare products because these are sold over the counter and excluded from insurance coverage.

Social determinants of health are generally not incorporated into how healthcare frameworks are designed or how data is collected, meaning that the patients most likely to fall through the gaps, those experiencing income insecurity, housing instability, or geographic remoteness, are also the least likely to be counted in the data that informs resource allocation.

Contributors called for better integration of healthcare and social systems to address growing gaps in access to care, including budget integration and integrated systems of care delivery. A contributor called for data collection to be guided by OCAP (Ownership, Control, Access, and Possession) principles[4] —designed to guide research involving First Nations, Inuit, and Métis communities— to ensure these communities are not further marginalized in health data infrastructure. The Alliance for Healthier Communities[5] in Ontario was mentioned as a promising model for team-based community care to improve access and thus combat inequality. Canada's Connected Care Act[6] and frameworks being developed around social determinants of health, including Ontario's social determinants framework,[7] were cited as promising enablers, but participants noted that these programs have not yet shifted how individual patients navigate the system. Canada has an annual Rural and Remote Medicine Conference[8] that discusses and highlights the needs of these communities and how best to serve their populations. Having people from those rural and remote areas participate in the conversation is vital to finding the best solutions to meet their needs.

5. Mental health needs overlooked and poorly integrated into skin disease care

Across contributions, the psychosocial burden of skin disease emerged as a profoundly underserved dimension of care. Contributors described clinical cultures in which providers focus on the affected part of the body rather than considering how the condition affects the whole person, and healthcare systems in which mental health support is not formally embedded in dermatological care, is rarely reimbursed, and is not treated as a standard component of diagnosis or treatment pathways.

A contributor who works on psoriatic disease policy described the structural dimensions of this fragmentation: both government- and institutional-level budgeting are siloed, such that healthcare budgeting does not follow an integrated model. Canada's Health Act,[9] for example, defines healthcare primarily in terms of medically necessary care. While important, this reinforces separation by excluding broader social and psychological supports from the definition of covered services. Institutionally, she noted that gatekeeping around the scope of practice slows progress toward integrated models of care.

The mental health aspect of skin disease is compounded by the persistent cultural dismissal of skin conditions as cosmetic or superficial. Contributors noted that patients are often told their conditions are cosmetic, are deprioritized in waiting lists, and lack access to the kind of organized disease-specific advocacy networks that exist for higher-profile conditions. A contributor from Canada highlighted that eczema continues to be dismissed as a minor condition of dry skin rather than recognized as a chronic, life-altering disease that affects everything a person does every day. A representative working in the alopecia disease space described the direct harm caused by clinical attitudes that treat alopecia areata as a cosmetic hair issue rather than an autoimmune condition with social, emotional, and psychological consequences. In addition, confusing nomenclature hinders public and patient understanding of how the autoimmune conditions differ from other hair loss conditions. When providers default to minimizing the impact of a condition, even with good intentions, they contribute to patients feeling that their experiences are not legitimate and that they have no grounds for self-advocacy.

This minimization of the condition's severity is not only a clinical failure, but also a policy failure: when conditions are not taken seriously, they do not receive the resources they need, and rural and remote communities bear a disproportionate share of the resulting gap. Patient organizations are attempting to address this gap, but they are doing so with limited resources.

A representative from the pemphigus and pemphigoid community described the challenge of local healthcare providers being poorly equipped to address the psychosocial dimensions of complex conditions, particularly in communities where the nearest specialist is hours away. In Canada, a representative noted that there were very few practicing psychodermaologists nationwide, with only two identified in a recent survey. The contrast between the scale of psychological need and the availability of trained providers reflects a systemic failure to recognize psychological care as part of the core clinical responsibility for this population. She called for more integrated centers where patients can receive both dermatological and mental health care from coordinated teams, and for patient organizations to be supported in improving patient mental health through annual workshops, cognitive behavioral therapy tools, and self-management resources.

Contributors from multiple organizations agreed that mental health considerations should be a standard inclusion in centers of excellence for skin diseases, doctors should be trained to consider mental health as part of their dermatology practice, and they should consider how the conditions affect the patient as a whole. Social prescribing, in which healthcare providers write formal prescriptions for social supports, is emerging as a formalized practice in Canada, with a national Social Prescribing Institute in development. This model demonstrates that integration is achievable; what is required is the policy will and sustained funding to bring integrated models to scale.

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 conditions, are not treated as policy priorities at the national or state/provincial level in North America. Decision-makers view skin conditions as superficial or primarily aesthetic and focus their attention and resources on conditions associated with high mortality or severe disability. The burden of skin disease on quality of life, mental health, economic productivity, and healthcare utilization is poorly captured in existing data and, therefore, systematically underestimated in policy and funding decisions. Additionally, skin conditions are subject to persistent social stigma, reducing patients' ability to self-advocate effectively.

In the United States, recent cuts to public research funding represent an acute and immediate threat, compounding a pre-existing baseline of underinvestment. The result is a research ecosystem that lacks adequate data infrastructure, struggles to incentivize research, and is unable to generate the evidence base needed to make the case to policymakers for greater investment. In Canada, provincial variation in drug access and fragmented budgeting models create structural inequities that patients cannot navigate on their own, and that persist because integrated models of care and policy remain underfunded and lack formal institutional support.

Across both countries, payer systems impose significant access barriers that override clinical judgment and prevent patients from accessing the diagnostic tools and treatments most appropriate for their conditions. The absence of meaningful real-world evidence pathways, combined with step therapy requirements and formulary exclusions, creates conditions in which patients are harmed by the structures of the systems intended to serve them. Reforming these systems requires advocacy aimed at payers and insurers as well as at manufacturers and regulators.

Patient organizations across North America are performing essential functions: training local providers, mapping clinical networks, connecting patients to specialists, and filling in for the data infrastructure that health systems have not built. However, they are doing so without adequate funding, dedicated staff, or formal recognition in governance structures. Compensating and structurally integrating these organizations is not a nice-to-have; it is a prerequisite for any meaningful improvement in care for people living with rare and chronic skin diseases.

Priorities for Policy Action

- Reversal of public research funding cuts affecting skin disease research in the US, and sustained commitment to publicly funded research investment linked to the actual burden of skin diseases, including rare dermatological conditions
- Development of national disease registries that capture patient diagnostic journeys, genotype data, and treatment outcomes, and are designed for international interoperability and collaboration
- Adoption of social determinants of health frameworks in health data collection and program design
- Harmonization of drug access and approval standards across Canadian provinces to eliminate inequities in which a patient's treatment access is determined by provincial regulation rather than clinical need

- Reform of payer systems in the US to recognize real-world evidence in coverage decisions, reduce step therapy barriers, and ensure that clinically recommended treatments are accessible without requiring patients to fail on less appropriate therapies first
- Mandatory inclusion of skin disease content in dermatology residency curricula and in training programs for nurse practitioners and physician assistants, with formal roles for patient organizations as educational partners
- Formal integration of mental health and psychosocial support into clinical care pathways for skin diseases, with reimbursement of psychological care as a covered health service for patients and caregivers
- Investment in telehealth, mobile clinic models, and expert referral networks to address geographic barriers to specialist access, with sustained funding mechanisms to allow promising programs to continue beyond short-term project grants
- Advocacy and public education campaigns to challenge the cultural dismissal of skin conditions as cosmetic issues, increase public and policymaker awareness of disease burden, and support patients in self-advocacy, for example, the *Working it Out* campaign[10]
- Structural funding for patient organizations to employ dedicated staff, sustain programs, and participate meaningfully in research governance, clinical guideline development, and health policy processes

Conclusion

Contributions from patient organization representatives across North America tell a consistent, 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 differences in healthcare system structure between the United States and Canada, similar core problems occur: low political prioritization, insufficient data infrastructure, siloed care, geographic inequity, unrecognized mental health burden, payer-driven access barriers, and inadequate patient participation in research and governance. Patient organizations are performing essential work with extremely limited resources, often without compensation and without a meaningful seat at the tables where decisions about their conditions are made.

While the World Health Assembly Resolution on Skin Diseases[11] represents meaningful international progress, it still needs to be translated into tangible national health strategies. The pathway forward requires coordinated action across clinical, institutional, and national policy levels, including the development of integrated care models, sustained investment in disease registry infrastructure, reform of payer systems that currently harm the patients they are meant to serve, and genuine inclusion of patient organizations as equal partners in governance. Skin health must be recognized as an essential component of overall health, and the patient organizations that represent those living with these conditions must be resourced and respected accordingly.

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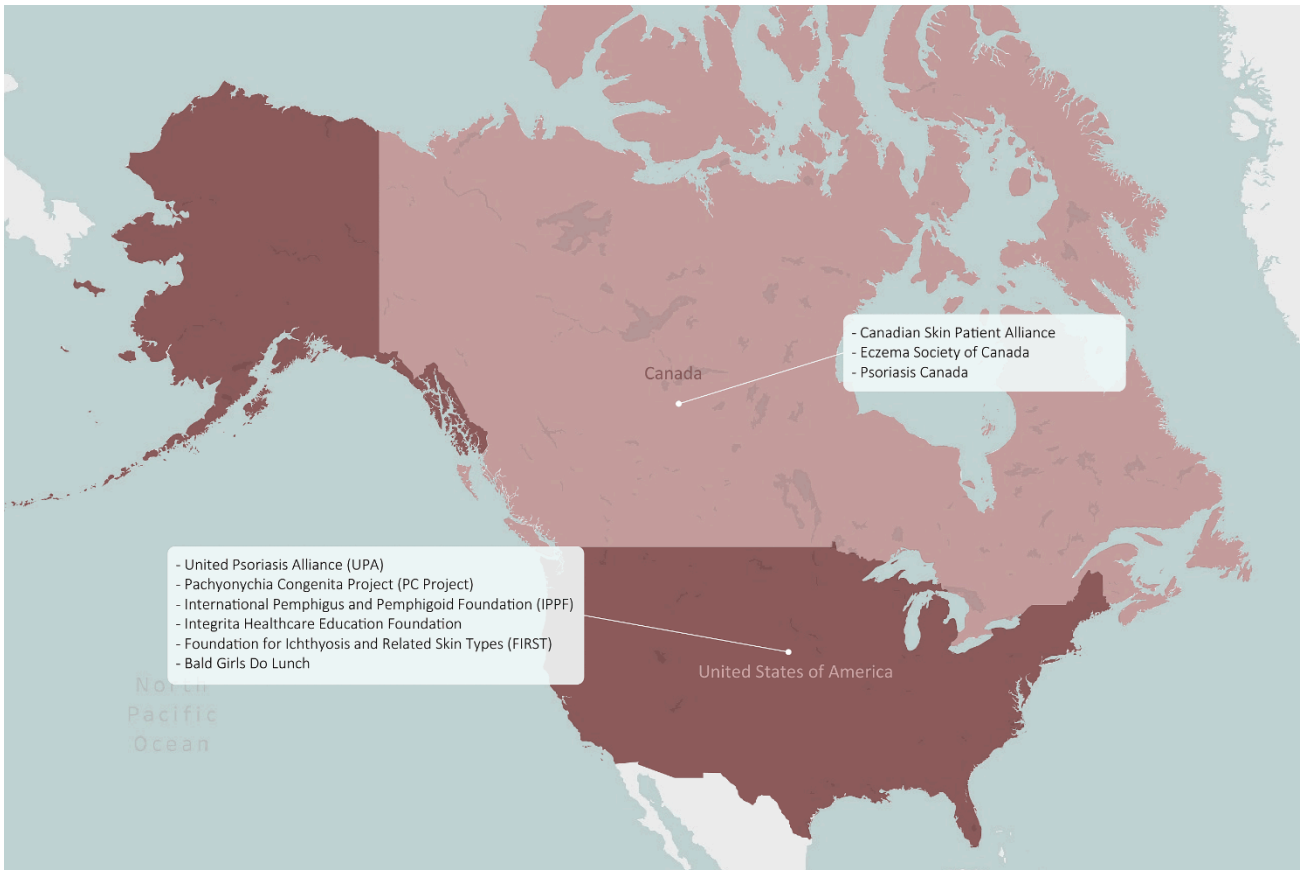
- Bald Girls Do Lunch
- Eczema Society of Canada
- Psoriasis Canada

North America Contributor Map



Geographic distribution of contributing organizations across online and offline engagement.