



IRISH SKIN
FOUNDATION

Supporting people with skin conditions

Strategy 2021-2025



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Foreword

We are delighted to present the Irish Skin Foundation's (ISF) Strategy 2021–2025, which outlines the strategic vision and priorities identified during our recent public consultation on supporting people living with skin conditions in Ireland.

The drafting process for this new Strategy has given the ISF opportunities to take stock of our work over the past 5 years, to consider our future direction, and to put forward plans for our development.

Our strategic pillars reflect the priorities identified by the ISF's Board and the views of over two hundred contributors to our consultation process.

Our plans for support, education and awareness projects aim to bring the ISF's work to the attention of a wider audience. We will develop our educational capacity further and broaden the scope of the resources we have available for people living with different conditions at different stages of life. While our focus will remain on the most common skin conditions, we will continue to leverage the organisation's capacity to support people affected by a wide range of less common skin problems.

Advancing our advocacy work to secure improved and better-resourced public services will remain a key priority for the ISF in the coming years.

The ISF works to increase understanding and public awareness of major skin conditions. Much of our work focuses on up-to-date management and supporting people living with or caring for unpredictable and recurring inflammatory conditions and prevention of skin cancers. We also work to address misconceptions, which can be a source of much distress when left unchallenged. Over the course of this plan, we will work to identify novel and effective ways to inform, engage and support people living with skin conditions, and the wider public.

Lastly, the ISF's work has been made possible by careful resource planning and in maintaining our strong board of charity trustees and committed staff team. We will be reviewing how we resource individual projects, looking at new means to sustain the organisation and continually renewing governance to ensure that patient advocates and healthcare professionals continue to work together to support people with skin conditions.

We would like to thank everyone who contributed to this plan, for taking an interest in the future of the ISF, and the communities with whom we work.



Dr Marina O'Kane
Chairperson



David McMahon
Chief Executive

Introduction

This Strategy is designed to guide our work and to assist us in concentrating on the priority areas which our public consultation has indicated are most important to improving quality of life for people with skin conditions.

The priorities identified represent both a continuation and the further development of our work over the past 5 years. We aim to ensure that our services, supports and resources are of the highest standard and remain demonstrably relevant and fit for purpose.

The ISF must be an effective voice for dermatology patients, people living with inflammatory skin conditions and the wider public at risk of skin cancer. Evidence-based advocacy will be central to influencing public policy for better-resourced healthcare services. While this will be a challenge, the ISF will continue to work collaboratively with other charities, advocates, relevant organisations, professional bodies and state agencies in a responsible and sustainable manner that emphasises positive outcomes for people most impacted by skin disease.

Naturally, this plan assumes the sustainability of funding at current or higher levels. To ensure that necessary resources will be available, on-going efforts to secure existing and new sources of funding will be a key function of the organisation's management over the course of this Strategy.

About the Irish Skin Foundation

The ISF was formed in 2011 when people living with psoriasis and atopic eczema, carers and family, skin-cancer prevention advocates and healthcare professionals working across the community in dermatology, agreed to join forces to improve quality of life for people living with skin conditions in Ireland.

Since that time, the ISF's work has been made possible by the generous support of the City of Dublin Skin and Cancer Hospital Charity, our Foundation Partners and, project-specific donations from advocates and supporters.

Following our public launch in 2013, we moved operations to UCD's Charles Institute of Dermatology and agreed our first Strategic Plan in 2015.



Our focus and work

The ISF is a national charity dedicated to improving quality of life for people living with skin conditions. We promote skin health and the prevention of skin disease by providing support, independent information, engaging in advocacy and raising awareness.

We operate a free Ask-a-Nurse Helpline providing direct, accessible and specialist guidance about skin conditions on an appointment model. Throughout the year we run events, including public information meetings and community outreach. There are many forms of skin disease, which include inflammatory conditions such as eczema, psoriasis and hidradenitis suppurativa (HS); skin cancers, including melanoma, basal and squamous cell carcinomas; autoimmune conditions such as lupus and vitiligo; and hereditary diseases such as ichthyosis.

The impact of skin diseases on quality of life can be far-reaching and profound. Many conditions are chronic in nature with treatment focusing on reducing and controlling symptoms. Rashes, flare-ups, and lesions are often very visible to others. People living with a skin condition not only have to cope with how it affects them personally but also with the reaction of those around them.

In recent years, we have created a trusted suite of independent information on the most common skin conditions for nationwide distribution to GPs and hospitals, hosted meetings for different patient communities around the country and have led awareness campaigns. We have also contributed to research, advocated for better public services and access to new therapies, hosted annual education days to broaden access to first-line dermatology education, and many other health promotion activities in communities and hospitals.



Strategy 2021-2025: preparation and consultation

Between September 2019 and January 2020, we asked people to tell us what kind of organisation they wanted to see, and their views about the pathway to get there. We received answers from:



158 people living with different skin conditions

-  **10** healthcare professionals (6 from within dermatology, 4 from outside dermatology)
-  **1** representative body, education or training provider
-  **1** individual or organisation engaged in dermatology-related research
-  **7** representing the pharmaceutical industry
-  **1** representing the skin-health industry
-  **7** non-self-identifying contributors
-  **4** helpline supporters and Foundation Partners
-  **11** ISF charity trustees

Overall, given the wide range of contributors the responses were remarkably similar. Key take-away points from the consultation were that:

- We continue to provide trustworthy “go-to” information on major skin conditions in print and on-line
- The ISF Ask-a-Nurse Helpline is our most valued service
- We engage more proactively in public-service advocacy
- We work to extend the organisation’s reach and presence

Challenges

Many people living with recurring, unpredictable, and often highly-visible skin conditions experience stigma and self-consciousness, in addition to painful and disruptive physical symptoms.

It is very common to struggle to secure timely care and treatment. Worldwide public-health systems have difficulties in recruiting and retaining specialist staff which contributes to long waiting times for appointments. Irish patients can also face practical difficulties and geographical inequities in accessing even standard treatments like phototherapy. They also encounter extended delays in accessing new therapies which are readily available in the UK, Northern Ireland, and other EU countries.

The ISF's response has been to provide access to specialist, accessible and free guidance from dermatology clinical nurse specialists, to raise the standard of information available to the public in Ireland and build awareness of the serious impact of skin disease.

A key challenge for the organisation will be to stay ahead of developments, ensuring that current and future service users are well-served against a background of increasing demand.

Our commitment to working in partnership with all stakeholders to influence, disseminate, and exchange knowledge, will remain central to our work. Our intention is to lead communications about skin conditions to ensure that they are widely understood to be a serious health challenge.



Skin cancers

Skin cancer rates are expected to more than double by 2045. Complex and life-threatening skin cancers are best managed by hospital-based multi-disciplinary teams. These rising rates of complex cancers, and our ageing population, will put further pressure on hospital services.



Demand for access to innovative treatments

There is growing demand among people living with severe and complex chronic skin conditions for consultant diagnosis, management plans, and access to advanced and life-changing new treatments and therapies which require ongoing hospital-based management.



Sláintecare and primary care management of skin conditions

A very large proportion of people living with chronic skin conditions can access the care they need through their local GP. An increase in the number of GPs, managing more people with chronic conditions, and a public appetite for smooth integration with hospital and wider-community care services, are expected to feature in the delivery of the Sláintecare reform agenda.



The National Treatment Purchase Fund (NTPF)

The NTPF currently spends hundreds of millions of euro buying appointments in the private sector for patients on public waiting lists for diagnosis and treatment. Policy attitudes to the NTPF's approach differ from committing additional funds, to replacing it with another system entirely. Opposing views mitigate against long-term structural investment in public health services.

For people living with chronic conditions, who need access to on-going management, the current NTPF-style system offering one-off appointments (often far from home), will not address their long-term healthcare needs.

ISF Vision, Mission and Values

Many skin conditions are chronic and recurring in nature, often highly visible, and some people may carry the heavy burden of management along with negative past experiences of distress and stigmatisation. Recognising the reality of people's different lived experiences, while emphasising hope for the future, we have set our Vision, Mission and Values accordingly:



Vision

Our vision is for everyone in Ireland to lead healthy lives, as unburdened as possible by skin conditions.



Mission

We are a national charity dedicated to improving quality of life for people living with skin conditions. We promote skin health and the prevention of skin disease by providing support, independent information, by engaging in advocacy and raising awareness.



Values

Compassion, care, integrity, accessibility, respect and empowerment.



Priority areas: 4 strategic pillars

The strategic approach of the ISF has been broken down into 4 priority areas or pillars. Over the coming years, our attention will be on the following four strategic areas:



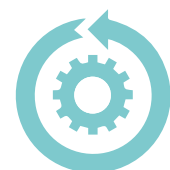
We support with information, education and learning together



We advocate and influence for change

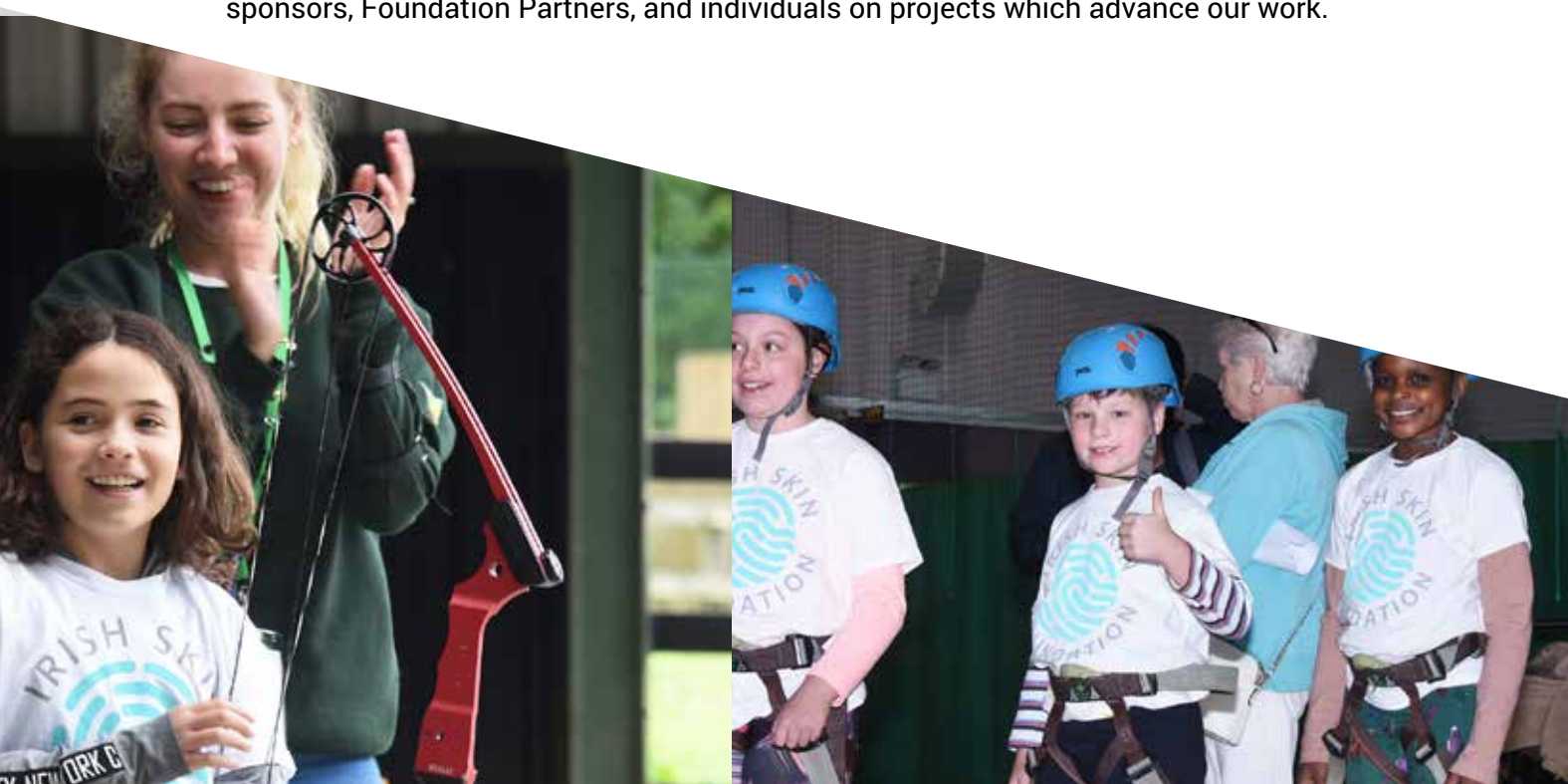


We use research to advance our work



We strengthen organisational capacity and presence

For each strategic area we will outline broad objectives and actions. Much of our strategy will be delivered through projects that are aligned with our objectives. We look forward to working and collaborating with other organisations, bodies, groups, sponsors, Foundation Partners, and individuals on projects which advance our work.



Pillar 1: We support with information, education and learning together

Our first pillar reflects a continuation and expansion of our work to support people with skin conditions. We aim to bring the ISF's existing supports to the attention of more people, to develop peer-led education and to broaden the scope of the resources we have available for people living with different conditions at different stages of life.

Our focus will remain on the most common skin conditions, but we aim to leverage the organisation's capacity to support people affected by a wide range of less common disorders.

Actions under this strategic pillar:

- 1.1 Continue to engage and lead with independent and up-to date digital and print information, created in partnership with people living with diverse skin conditions and expert healthcare professionals and stakeholders.
- 1.2 Sustain and promote our Ask-a-Nurse Helpline which provides specialist, accessible and free access to dermatology clinical nurse specialists to support people living with or managing skin conditions.
- 1.3 Identify novel ways to engage and grow awareness of major skin conditions, their management, the challenges experienced, and misconceptions, among existing and new groups of patients.
- 1.4 Grow our capacity for accessible education, self-management, and group-learning initiatives.
- 1.5 Develop patient and healthcare professional volunteers to participate in our support work.
- 1.6 Grow our capacity to deliver public engagement and awareness meetings offering education and learning opportunities (e.g. SkinSideOut, Dermatology Study Day and various other health promotion events nationwide).



Pillar 2: We advocate and influence for change

Strengthening our advocacy work, to persuade and influence policy and policy makers to address health inequality among patients who have skin disease, is our second strategic priority.

We aim to become a stronger voice advocating for improved and better-resourced public services by advancing evidence-based arguments and by highlighting the voice of patients.

Actions under this strategic pillar:

- 2.1 Develop our organisational capacity to advocate effectively, and to commit to engage with organisations and individuals working to promote the interests of people living with skin conditions.
- 2.2 Ensure that people with skin conditions are prioritised within the public healthcare system.
- 2.3 Engage with the Department of Health, the HSE Dermatology Clinical Programme, Sláintecare, Healthy Ireland and other key agencies to advance the interests of people living with skin conditions.
- 2.4 Consult on, review, and re-issue our 2016 Oireachtas submission on the future of healthcare, to increase understanding of dermatology patient issues at government level.
- 2.5 Continue to work with international organisations which are aligned to our mission (e.g. Global Skin / International Associations of Dermatology Patient Associations (IADPO) and the International Federation of Psoriasis Associations (IFPA)).
- 2.6 Forge stronger links with general practitioners through the Irish College of General Practitioners (ICGP) and with dermatologists through the Irish Association of Dermatologists (IAD).
- 2.7 Continue to advocate for people on an individual basis and on individual issues which arise through the course of our work.



Pillar 3: We use research to advance our work

Like many organisations seeking to improve public health services in Ireland through evidence-based advocacy, we have found that where there is no data it can be difficult to define problems and therefore to frame potential approaches to address them.

Our third strategic priority concerns aligning future research work more closely with the organisation's advocacy agenda, while developing our capacity to engage with new projects as they arise.

Actions under this strategic pillar:

- 3.1 Draft a research strategy on which the ISF will focus our efforts.
- 3.2 Enhance patient advocacy through research and publications.
- 3.3 Develop a Public and Patient Involvement (PPI) strategy.
- 3.4 Facilitate donations for research (e.g. for skin cancer research projects).
- 3.5 Foster relations with researchers in dermatology (e.g. at the Charles Institute for Dermatology and at other centres).



Pillar 4: We strengthen organisational capacity and presence

Lastly, our fourth strategic pillar concerns the future development of the ISF itself. Over the last 5 years we have worked tirelessly to build our staff team, our Board and strong relationships in the sector.

Moreover, the organisation has established a track record of thoughtful, carefully considered, practical services and outputs – delivered on budget, on time and in consultation with individuals and organisations impacted by our work.

Actions under this strategic pillar:

- 4.1 Continue to strengthen our staff team, our board of charity trustees and our governance structures.
- 4.2 Develop and broaden our fundraising capacities, maintain financial sustainability, and review current support programmes (including a review of the Foundation Partnership programme).
- 4.3 Encourage and support our staff, through a culture of continuous professional development, to maintain operations to the highest standards, in line with best practice, and relevant regulatory obligations.
- 4.4 Maintain the relevance and effectiveness of ISF services and outputs through monitoring, evaluation and consultation with stakeholders. To make changes when necessary and to ensure our work serves existing and emerging communities.
- 4.5 Foster greater awareness of the unique work of the ISF among the general public, policymakers and healthcare professionals.
- 4.6 Maintain levels of awareness of skin conditions, their management, the challenges experienced, and common misconceptions.
- 4.7 To choose our future commitments carefully so that our efforts have the greatest impact.



Operational planning and strategic project proposals

This strategic outline is a high-level guide to the overarching approach of the ISF to our work from 2021-25. It should be considered in combination with the ISF's operational plans and with our strategic project proposal process in mind.

For more information, please contact David McMahon, CEO about operational planning and strategic projects at davidmcmahon@irishskin.ie



ISF Board of Trustees



Chairperson: Marina O'Kane



Rupert Barry



Michael Foley



Caroline Irwin



Kenneth McKenzie



Padraig O'Cearbhaill



Sheila Ryan



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Anne-Marie Tobin



Rosemarie Watson



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