



**IRISH SKIN
FOUNDATION**

Supporting people with skin conditions

ISF ANNUAL REPORT 2019



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A Message from our Chairperson

As Chairperson of the Irish Skin Foundation (ISF) and on behalf of our Board of Trustees, it gives me great pleasure to present our 2019 Annual Report.

As a founding Trustee, I have been privileged to watch our Board, working groups and in-house team grow and evolve together since 2012. Together we have created networks and collaborations with patients, dermatologists, nurses, industry partners and researchers throughout Ireland and globally.

It is undoubtedly challenging for people living with a skin condition in Ireland. 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. Key areas of focus for the ISF have been to provide access to free specialist guidance from dermatology clinical nurse specialists, 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 both in dermatology and in healthcare systems, ensuring that current and future service users are well-served against a background of increasing demand.

In 2019, we worked hard to highlight the hidden burden of eczema with the launch of our 'Living with Atopic Eczema Survey' results; we also provided valuable educational opportunities for people affected by skin disorders with our health promotion events and first-of-its-kind skin health event, SkinSideOut; and we collaborated with key stakeholders on the campaigns, projects and events which you will read about in our report below.

None of our work would be possible without generous funding and support from the City of Dublin Skin and Cancer Hospital Charity (CDSCHC). I am also indebted to our Board Members who give generously of their free time and skills to oversee ISF strategy and governance and ensure that everything we do is driven by as diverse a set of stakeholder interests as possible.

I would like to thank our Foundation Partners for their contribution to our Ask-a-Nurse Helpline and public awareness campaigns, and our sponsors who have generously supported our events and initiatives throughout the year. Finally, I applaud our CEO and small but incredibly hard-working staff team - who always seem to deliver twice as much as I expect! I am inspired on a daily basis by their work ethic and compassion.



Dr Marina O'Kane
Chairperson

A Message from our CEO

In Ireland, living with a skin condition can be costly and may profoundly affect quality of life and psychological well-being. Approximately 54% of the population is affected by skin disease every year and between 15-20% of GP consultations specifically relate to the skin. Our work aims to improve quality of life for people and their families affected by skin disease.

The Ask- a-Nurse Helpline which offers free, specialist guidance for individuals continues to be a core part of the work the ISF does to support people affected by skin conditions. In 2019, 650 people contacted our Helpline looking for one-to-one guidance from a dematology clinical nurse specialist on how to manage a skin condition for themselves or a loved one. Approximately 75% of those that contact our Helpline have a diagnosis and are looking for more information on how to manage their condition, but it is important to note that a quarter (25%) of all those that contact the Helpline do not have a diagnosis and have found us through an online search when looking for information about their symptoms, continuing to demonstrate to us, the need for such a service.

In 2019, we continued to provide the most up-to-date information and advice for people affected by skin conditions through the launch of new and updated resources, such as our Acne Information Page, Managing Scalp Psoriasis Leaflet, and Melanoma Skin Cancer Leaflet.

The ISF was proud to be part of the working group responsible for developing Ireland's first National Skin Cancer Prevention Plan which is part of the National Cancer Strategy 2017-2026. We were also pleased to make a patient organisation submission to the National Centre for Pharmacoeconomics (NCPE) in relation to a new therapy for atopic eczema and to advocate for wider access for patients to a potentially 'life changing' new drug.

I would like to express my sincere thanks to our Chairperson, Board of Trustees, dedicated ISF team, volunteers and supporters for their continued commitment, willingness to give up free time and their hard work in supporting the organisation and the people it exists to help. We are very grateful for the continued support of the CDSCHC, our Foundation Partners, Corporate Sponsors and all those who help us to fulfil our mission.



David McMahon
Chief Executive

About the Irish Skin Foundation

The ISF is a national charity dedicated to improving the quality of life of people living with or caring for skin conditions and disorders.

We operate a free Ask-a-Nurse Helpline service, providing direct, accessible and specialist guidance. Throughout the year we run events, including public information, health promotion and education meetings. The ISF is also involved in advocacy and policy work, helping people affected by skin conditions to navigate services, influencing public policy and raising awareness of different conditions throughout the year.



Skin conditions and disorders

There are many forms of skin disease, which include inflammatory conditions, such as eczema and psoriasis; skin cancers, including melanoma, basal and squamous cell carcinomas; autoimmune conditions, such as lupus and vitiligo; and hereditary diseases. The impact of skin diseases on quality of life can be far-reaching and profound.

Many skin conditions are chronic in nature, with treatment focusing on reducing and managing symptoms. Rashes, flare-ups and lesions are often very visible to others. Consequently, someone living with a skin condition may not only have to cope with how it affects them personally, but potentially also with the reaction of those around them.



Our Origins

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 CDSCH, 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 Vision & Mission

Our vision is for everyone in Ireland to lead healthy lives, as unburdened as possible by skin conditions. Our mission is to promote skin health and the prevention of skin disease by providing support, independent information, engaging in advocacy and raising awareness.

2019 at a Glance



650 people contacted the Ask-a-Nurse Helpline, which is supported by our Foundation Partners



500+ registrations for SkinSideOut



50+ Healthcare Professionals attended our fourth annual Dermatology Study Day



Launch of New Resources

- Acne Information Page
- Scalp Psoriasis Leaflet
- Melanoma Skin Cancer Leaflet
- Findings from our 'Living with Atopic Eczema Survey' in which 454 people with moderate to-severe eczema participated
- *Ask How I Feel* campaign to encourage people with psoriasis to give consideration to being more open about the emotional, psychological & psychosocial experience of living with psoriasis



ISF submission to **NCEP** for 'life-changing' new therapy for atopic eczema



ISF Health **Promotion Team** outreach at colleges, hospitals and organisations throughout the year



Partnered on the launch of Ireland's first National Skin Cancer **Prevention Plan 2019 – 2022**



Public consultation on the **ISF Strategy** for 2020-2025

Our Activities in 2019

Health Promotion Outreach

The ISF Health Promotion Team participated in wide range of events during the year, giving talks, and providing information and guidance to people affected by skin conditions at several third-level institutions, hospitals and organisations.

Health Fairs, Sun Awareness Events and 'Skin Health' Talks



The team attended a number of Health Fairs including at Dundalk and Athlone Institute of Technologies, and St. Vincent's University Hospital, Dublin, providing a wonderful opportunity to meet with students, staff and visitors to provide information about a variety of skin conditions and general skin health.



Participation in sun awareness events included those held by the Mater Hospital, Dublin, Our Lady of Lourdes Hospital, Drogheda, University College Dublin (UCD) Get Sun Smarter, and again at the fourth annual UCD festival, to provide information about protecting skin from natural and artificial ultraviolet radiation.



It was also a pleasure to meet with the attendees of the University of the Third Age in An Cosán, in Jobstown, Dublin, to give a talk on 'Skin Health and Common Skin Conditions'. The team were also invited by the Central Bank, to two of their locations to provide talks on sun protection and two inflammatory skin conditions, psoriasis and eczema.





“Really impressed with service, from initial contact to return call from Carmel the nurse. Staff were incredibly supportive and informative. This was the first time in my psoriasis journey that I felt supported. Many thanks.”

Maureen Reynolds

Dermatology Study Day

On Saturday 6th April, we hosted our fourth annual Dermatology Study Day in the Ashling Hotel, Dublin. The programme was aimed at healthcare professionals with an interest in dermatology. Attendees came from across the health disciplines i.e. nursing, pharmacy and general practice.

The objective of the study day was to provide healthcare professionals with an opportunity to enhance their current knowledge when encountering patients with dermatological conditions in the community. Continuing Professional Development (CPD) points were awarded for attendees.

Our comprehensive programme for the day included talks on alopecia; common paediatric skin conditions; rosacea; burns and abrasions; hidradenitis suppurativa (HS); and skin cancer.

Attendees had the opportunity to visit exhibitor stands, learn about products on the market for various skin conditions and avail of free samples.

We were delighted with the very positive feedback we received from attendees, deeming the day to be a success.

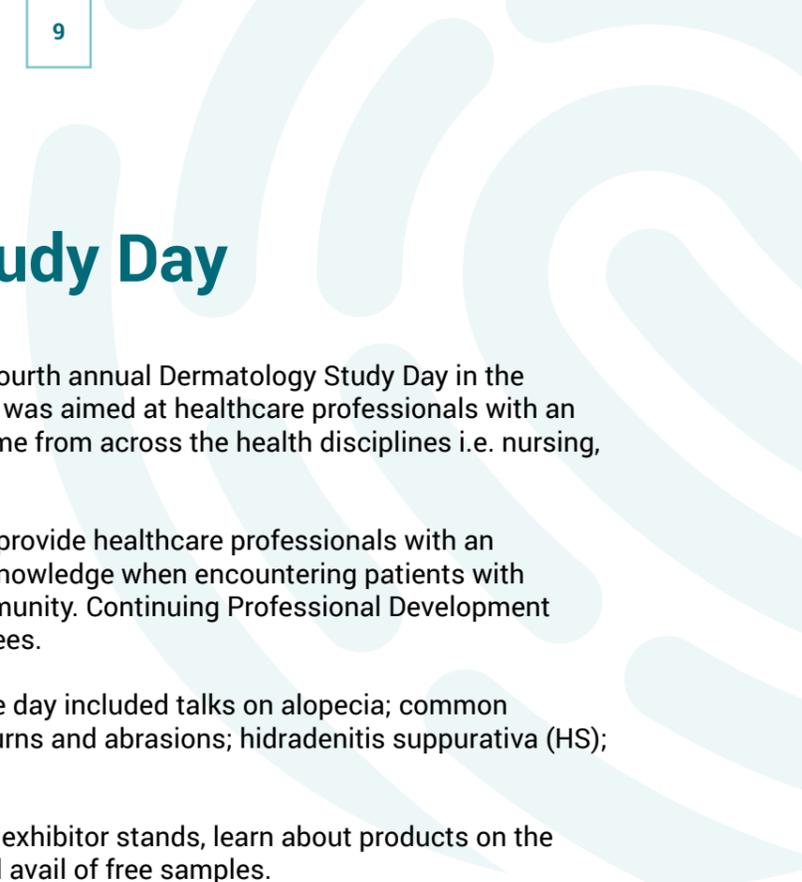
Saturday 6th April 2019
Ashling hotel, Parkgate street, Dublin 8

**ISF DERMATOLOGY
STUDY DAY 2019**

For nurses and pharmacists providing first-line
management of skin conditions /disease.
BOOK TODAY!



**IRISH SKIN
FOUNDATION**
Supporting people with skin disorders



UCD Get Sun Smarter: Second Annual Sun Awareness Event to Prevent 'Killer Tans'

On 9th and 10th April, we co-hosted the second annual **'UCD Get Sun Smarter'** event in collaboration with the Charles Institute for Dermatology, Systems Biology Ireland and the Irish Cancer Society.

At the two-day sun awareness event, the ISF provided students, staff and members of the public with guidance on how to stay safe in the sun and the dangers of occasional, intense, sun exposure, as well as information on other skin conditions. The Irish Cancer Society brought along a skin scanner/UV Light Box, which gave visitors to the stand an indication of the sun damage to their face. Systems Biology Ireland provided a microscopic demonstration of what skin cancer looks like up-close.

Sunscreen samples donated by brands supporting the ISF and the event, were available to visitors to the stands, along with melanoma information leaflets and information on how to protect and inspect their skin.

On day two of the event Consultant Dermatologist, Dr Patrick Ormond gave an excellent talk on **'Killer Tan: The Sun and Your Skin'**.

The event garnered much media attention with advance notice of the activities published in the Irish Times, and radio interviews secured across national and regional radio stations about the importance of sun safety, whether at home or abroad. National radio broadcaster, Today FM, attended the event to record interviews with Professor Desmond Tobin, Director, Charles Institute of Dermatology; and David McMahon, CEO, ISF. They also captured the student reactions to the sun damage they had seen on their face from the UV Light Box.



GlobalSkin 2019 Conference

In June, the International Alliance of Dermatology Patient Organizations (IADPO), also known as GlobalSkin, brought over 120 skin patient group leaders from 35 countries together in Milan, Italy for three unique events: the RareDERM Forum, the Atopic Eczema Forum and the GlobalSkin 2019 Conference.

The RareDERM Forum and Atopic Eczema Forum each spanned two days and took place prior to the GlobalSkin 2019 Conference. Nearly 40 delegates from 13 countries represented rare and uncommon dermatological disease patient group leaders, while 25 delegates from 21 countries represented the atopic eczema community.

Participants benefited from formal learning sessions, strategic thinking and connecting with other patient leaders and dermatology stakeholders.

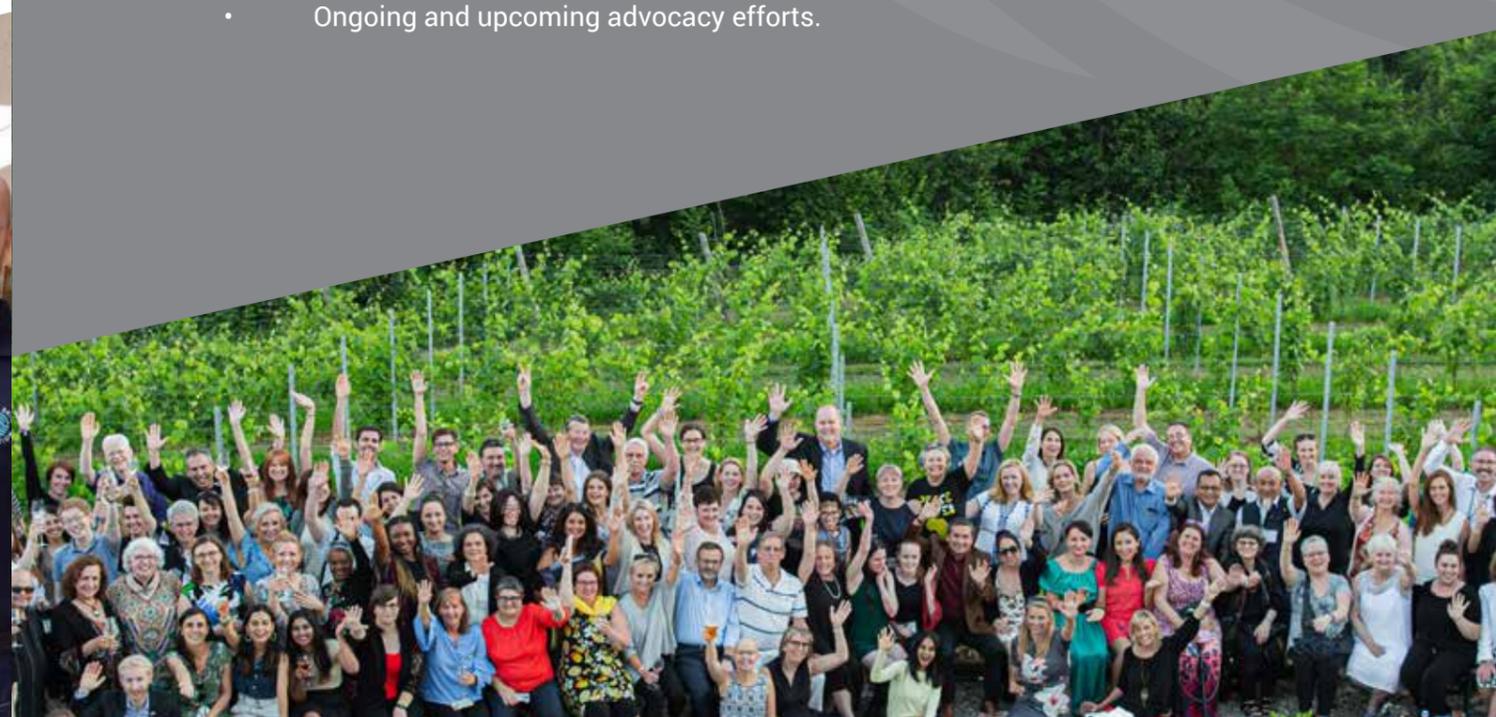
IFPA Annual Members Meeting

In July, the International Federation of Psoriasis Associations (IFPA) brought over 90 participants, including psoriasis association representatives, IFPA partners and the IFPA Board and Secretariat, together in Barcelona, Spain, for the annual members meeting to convene and exchange ideas.

IFPA is a non-profit organisation comprised of national and regional psoriasis association members from around the world. IFPA gives psoriasis associations a global voice to campaign on behalf of people who have psoriasis and psoriatic arthritis.

The meeting was divided into four key focus areas:

- IFPA's new journey and capacity development
- Science and communications initiatives
- Preparations for World Psoriasis Day
- Ongoing and upcoming advocacy efforts.



UCD Festival

On Saturday, 8th June, the UCD campus was transformed for the 4th annual UCD Festival.

The event is now a firm fixture on the family festival calendar and aims to showcase the innovation, creativity and research that takes place on campus every day with a host of stands, exhibitions and indoor and outdoor activities to enjoy each year.

The Irish Skin Foundation were delighted to take part in the festival for the first year by joining with the Charles Institute of Dermatology and Systems Biology Ireland to create a booth for 'Melanoma and Skin Protection Awareness'.

Visitors to the booth received our new and updated Melanoma Skin Cancer leaflets, guidance on how to protect their skin from sun damage at home or abroad and learned more about the dangers of occasional, intense, sun exposure and how they can reduce their risk of skin cancer.

People also had the chance on the day to check their faces' previous history of sun exposure through a UV light box / skin scanner operated by our Health Promotion Team. We provided visitors to the stand with free sunscreen samples for different skin types – normal / combination; dry / sensitive; and specially formulated for kids.

Systems Biology Ireland showed people an up-close demonstration of the differences between healthy cells and melanoma cells through a microscopic demonstration.

At the event we had hundreds of visitors to the stand to discuss sun safety, ways to reduce risk of skin cancer and check their face in the UV light box. People living with chronic inflammatory skin conditions visited the ISF stand to get guidance on skin conditions such as psoriasis, eczema, acne, rosacea and HS. The event was hugely successful, and we were delighted to be involved!



Family Fun Day at Barretstown

Every September as a new school year commences, we have an extra special event on our calendar at the ISF. We search far and wide for 30 children who are having a challenging time with a skin condition and bring them and their families to Barretstown for a day full of exciting family fun and adventure!

Each child is nominated by their paediatric dermatology nurse to ensure that those who have had the toughest time have an opportunity to experience a day at Barretstown, a children's charity that offers free, medically endorsed camps and programmes designed for children and their families living with serious illness.

At Barretstown families meet other children and parents facing similar challenges and can feel a sense of support and connection in a therapeutic environment where the focus is on fun for the entire family.

On 7th September, the ISF brought families from all over the country together to experience plenty of exciting activities to include arts and crafts, archery, canoeing, fishing, pony trekking and for the bravest amongst us, rock wall climbing! Dermatology nurses from Crumlin and Temple St. volunteered their time to come along and offer guidance to parents who had questions to ask about how to manage their child's skin condition.

Here are some of our favourite comments from the day:

Did you enjoy the day? *'It was a day filled with fun and excitement'*

What did you enjoy the most? *'The kindness, the smiles, absolutely everything!'*

'A great day out to take your mind off things'

'Our kids loved learning how to fish – a new skill. I'd say fishing rods will be on the Christmas list for Santa this year!'

What did you enjoy the least? *'Going home!'*

Any other comment? *'It was so much more than we all expected.'*

We have all had such a wonderful day together.

Opportunities to try new things together, to forget about everything else for a day and just have fun'.



Ploughing Championships

The National Ploughing Championships, Europe's largest outdoor event, took place on 17th-19th September in Ballintrane, Fenagh, Co. Carlow.

The county lived up to its reputation as the sunny south-east, offering blue skies and sunshine for the entire 3-day event, bringing record-breaking attendance figures of 297,000 people, all eager to enjoy a great day out!

For those keen to protect their skin from those strong UV rays and those with an interest in a particular skin disorder such as psoriasis, eczema, acne, rosacea and many more, our 'Ask a Nurse' Helpline team was on hand to offer guidance and information on a one-to-one, individual basis.

As always, our expert team comprised dermatology Advanced Nurse Practitioners and Clinical Nurse Specialists and their vast knowledge was in much demand by members of the public concerned about their skin.

The ISF promoted key sun safe behaviours to members of the farming community, outdoor workers and other visitors, and provided information on how to protect and inspect their skin.

We also provided visitors with an array of information leaflets providing trusted information on a range of common skin conditions, free sunscreen samples to help with sun protection during the long day ahead, and a variety of emollient samples from our brand sponsors to take home and try on their skin.

The ISF has been a proud participant at the National Ploughing Championships for the past 7 years.

"I rang enquiring about how to see a dermatologist for a skin condition I have had for over a year. I gave some details and a nurse rang me back that evening. She gave me very good advice on caring for the skin. I subsequently visited a GP who has an interest in skin conditions. Between the nurse's and GP's advice I bought some products and it appears to be clearing up. Keep up the good work on the Helpline. I really appreciated the call back from the nurse and advice given."

Peter Delaney



SkinSideOut: First of-its-Kind Skin Health Event

The ISF wanted to create a full-day public event which could provide people living with or caring for someone with a skin condition, with the opportunity to learn more about how to manage all aspects of their condition to include physical, psychological and psychosocial challenges.

On 16th November, we hosted SkinSideOut in the Science Gallery, Trinity College Dublin consisting of five talks and panel discussions covering six topics – eczema; psoriasis; acne and rosacea; the ingredients in skin care products; and skin cancer prevention.

Attendees had the opportunity to speak with skin care brand representatives, learn about the different product ranges, and avail of free samples. Each attendee received a gift bag of select skin care products, worth upwards of €50 to take home.

Over 500 registered for the talks, with panel discussions on eczema and psoriasis fully subscribed in advance!

Following each talk the ISF Ask-a-Nurse Helpline nurses were on hand to provide free, up-to-date guidance to attendees on skin conditions and attendees were also invited to mingle in a dedicated space for tea/coffee and snacks to share peer-to-peer experiences and support one another.



Living with Atopic Eczema

The 'Living with Atopic Eczema' panel discussion featured Virgin Media Presenter, Claire Brock, Moderator; Dr Maeve McAleer, Consultant Dermatologist; Paul Herriot, Patient Advocate; Glenn Kenneally, Patient Advocate. The panel explored the findings from the 'Living with Atopic Eczema Survey' and the key challenges faced by people living in Ireland with this common skin condition.



Exploring Acne and Rosacea

Dr Síona Ní Raghallaigh, Consultant Dermatologist spoke about the different types of acne and treatments available for this common skin condition affecting approximately 85% of the teenage population. Dr Ní Raghallaigh also explored rosacea, known as, "The Curse of the Celts"; the causes, symptoms, sub-types and treatments.

Psoriasis on Your Mind?

The panel discussion featuring Claire Brock, Moderator; Prof Brian Kirby, Consultant Dermatologist; Caroline Irwin, Patient Advocate; Dr Eddie Murphy, Clinical Psychologist focused on the emotional and psychological toll psoriasis can have on people and how to manage this aspect of the condition, so that it does not impair quality of life.

What's Really in Your Face Cream?

Prof Anne-Marie Tobin, Consultant Dermatologist, explained the differences between pharmaceuticals, cosmetics and cosmeceuticals, the ingredients that make up our creams and ointments, and what these components actually do.

Preventing Skin Cancer in Ireland

This discussion between David McMahon, Moderator; Kate O'Flaherty, Healthy Ireland; Prof Anne-Marie Tobin, Consultant Dermatologist; Kevin O'Hagan, Irish Cancer Society; Kay Curtin, Patient Advocate provided an overview of the aims of the Department of Health, Healthy Ireland and National Cancer Control Programme's (NCCP) recently launched National Skin Cancer Prevention Plan 2019 – 2022 and what steps we can take to ensure we achieve these aims.



Advocacy

ISF Proud to be Part of Working Group to Develop Ireland's First National Skin Cancer Prevention Plan

Minister for Health, Simon Harris TD and Minister of State for Health Promotion, Catherine Byrne TD launched the first National Skin Cancer Prevention Plan 2019 – 2022 for Ireland.

The plan was developed by the Department of Health in conjunction with the National Cancer Control Programme (NCCP) and key stakeholders. These included other Government Departments and national organisations representing priority groups, including the Irish Cancer Society, Marie Keating Foundation, ISF and Breakthrough Cancer Research.

The three year plan is aimed at tackling the most common type of cancer in Ireland. Over 11,000 cases of skin cancer are diagnosed each year and the number of cases is projected to more than double by 2045.

The plan focuses on the fact that most skin cancers can be prevented. It addresses awareness of skin cancer prevention and has identified the priority groups as children, outdoor workers, those who participate in outdoor leisure activities and sunbed users.



Dupilumab (Dupixent) Submission to the National Centre for Pharmacoeconomics (NCPE)

In July 2019 the ISF made a submission to the NCPE in relation to a new therapy for atopic dermatitis (also known as atopic eczema) and to advocate for wider access for patients to a potentially 'life changing' new drug.

In 2017, the European Medicines Agency approved a drug called Dupilumab (Dupixent) for the treatment of moderate-to-severe atopic eczema in adult patients who are candidates for systemic therapy. This new drug is administered by injection under the skin.

Dupilumab is a targeted therapy believed to work by blocking the actions of two key proteins [interleukin-4 (IL 4) and interleukin-13 (IL 13)] involved in the inflammatory response, which plays a part in the development of atopic dermatitis.

The submission drafted by the ISF included patient testimonials and life stories, providing unique and powerful perspectives about the day-to-day burden of living with atopic eczema, along with recent findings from the ISF 'Living with Atopic Eczema Survey' and published literature and research.

This new biologic, if it becomes available, would extend the range of treatments available for patients with atopic eczema, and potentially herald the beginning of a new era of life-changing treatments for this distressing condition.

Living with Atopic Eczema Survey

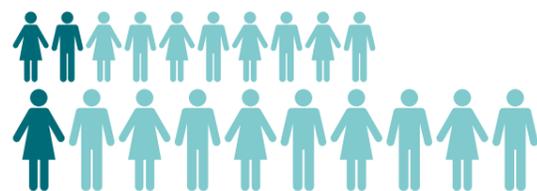
To mark the second annual World Atopic Eczema Day and reveal the hidden burden of living with atopic eczema, the ISF released the key findings from our '**Living with Atopic Eczema Survey**' to which 454 people living with eczema or caring for someone with eczema responded between September 2018 – April 2019. Preliminary findings from the survey were also presented at the Irish Association of Dermatologists (IAD) annual conference.

The findings show the pronounced negative impacts that atopic eczema can have on quality of life, including sleep disruption, absences from school, as well avoidance of exercise and social activities. A major symptom of atopic eczema is intense itch, which is commonly reported to disrupt sleep, with findings revealing that the overwhelming majority of children (86%) and adults (84%) living with the condition experience ongoing sleep disturbance.

Additionally, more than a quarter (26%) of carers of children with eczema say their child missed 1-2 days of school per month due to their condition, with over a third (34%) of children and two-thirds (65%) of adults admitting to avoiding exercise, activities and sport. More than half (52%) of adults surveyed avoid social activities altogether.

The survey findings also reveal that the cost of eczema treatments and doctor's appointments needed to manage the condition can be a significant financial burden, with 42% of carers of children and 49% of adults reporting the need to cut back on household expenses due to the cost of managing atopic eczema. The figures show one quarter spend at least €2,300 annually on doctor's fees, over-the-counter products and prescription treatments.

The Burden of Atopic Eczema: Key Domains of Impact



Atopic eczema (AE) affects as many as **one in five children** and **one in ten adults**¹

The major symptom is **unbearable itch**¹



86% of children, and 84% of adults reported interrupted/loss of sleep²



AE can affect **attendance** at work^{3,4}, **performance** at work³, **sick leave** and potentially, **job choice**⁵



26% of carers reported that their child had been absent from school **1-2 days per month**²

42% of carers of **children, and 49%** of **adults**, reported cutting back on household expenditure because of the cost of managing AE²



43% of **adults** reported that AE contributed to **depression** in the last two years²



64% of **adults, and 34%** of **carers of children**, reported that AE contributed to **avoidance of exercise**²

AE **negatively impacts** on an individual's **quality of life**, as well as that of the wider family³



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Equity of Access for Dermatology Patients

In May, the ISF called for research into the effects that a household's distance from specialist dermatology services is having on patients living with chronic inflammatory skin disorders such as psoriasis, atopic eczema and hidradenitis suppurativa.

Access and utilisation of health services is multi-faceted but often influenced by cultural, behavioural and financial factors. One critical variable is thought to be the distance of the patient's household from a specialist clinic. The phenomenon of decreasing health care utilisation with increasing distance lived from a facility is often called the "distance-decay effect".

If research were to suggest that the current model for delivering services may be weighted too far in favour of hubs based in major cities, then service provision may be failing to deliver equity of access for thousands of children and adults living with skin conditions in many parts of Ireland.

The ISF will continue to advocate for more equitable and convenient specialist access for patients to services. Outreach clinics in peripheral hospitals support local networks of GPs, providing care closer to home for patients, and onsite dermatology consultations for inpatients. Certain peripheral hospitals already provide phototherapy services, but more can be done to make this widely available.

Hospital-based dermatology typically delivers a wide range of specialist services which can include phototherapy, patch testing, minor surgery, photodynamic therapy, nurse-led treatment clinics and clinical research.

World Psoriasis Day 2019

On World Psoriasis Day (29th October), the ISF joined with IFPA and 55 member organisations globally to raise awareness about psoriasis and the complex emotional toll that this common skin condition can inflict, which is estimated to affect at least 73,000 people in Ireland.

Along with the physical burden of psoriasis, the often-visible nature of the disease means people living with the condition may have to cope with the reactions of others to the appearance of their skin. This can impact negatively on quality of life, self-esteem, social and personal relationships, which can then take an emotional, psychological and psychosocial toll on people with psoriasis.



Psoriasis on Your Mind?

Psoriasis on Your Mind? was part of a series of panel discussions and talks given by expert medical speakers and patient advocates, which took place at SkinSideOut, the ISF's skin health information event at the Science Gallery.

Dr Eddie Murphy is also part of the 'Ask How I Feel' psoriasis awareness campaign, which focuses on looking at psoriasis from the inside out and urges people not to suffer in silence, but encourages people around you – friends, family and healthcare professionals – to #AskHowIFeel.

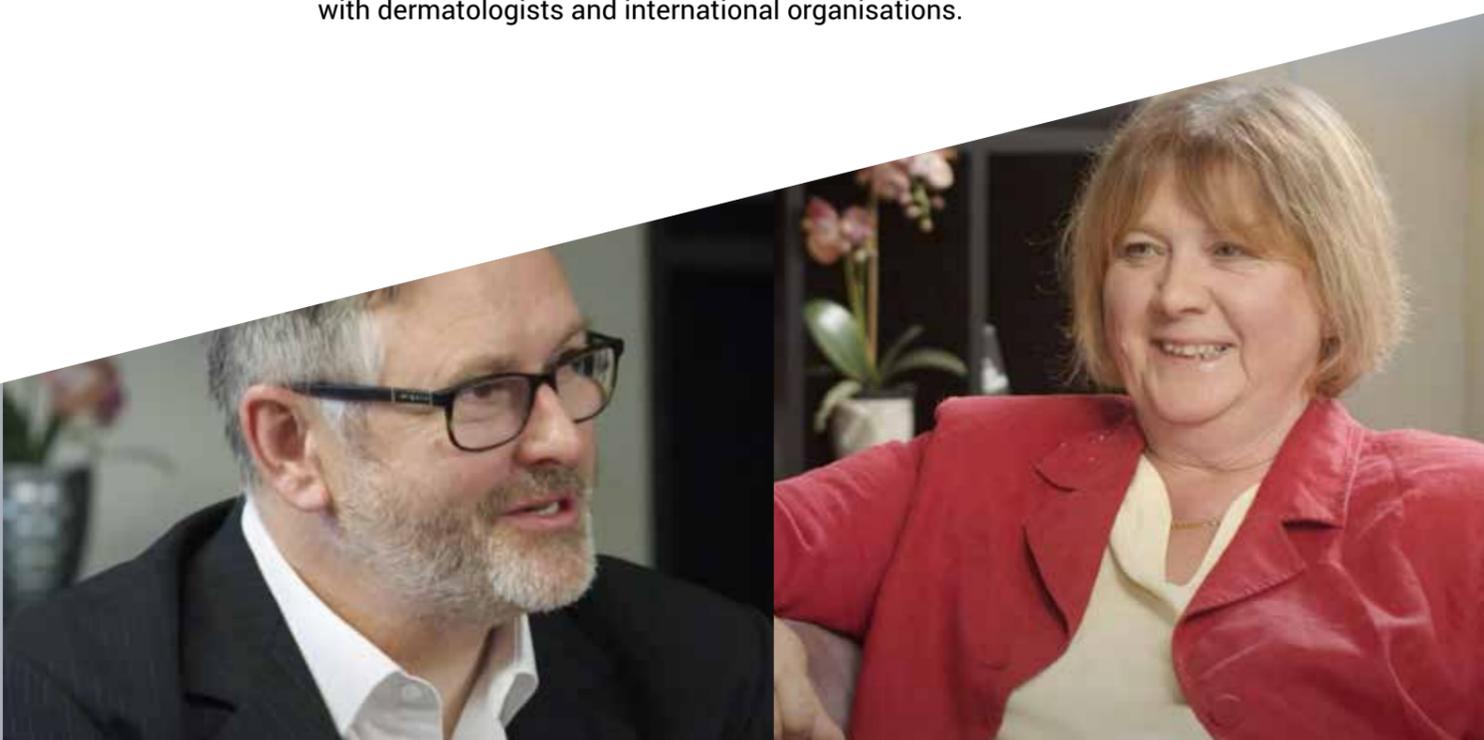


Global Psoriasis Atlas

New prevalence data released from the Global Psoriasis Atlas (GPA) on World Psoriasis Day 2019, estimated more than 72,000 people are affected by psoriasis in Ireland. The GPA is a collaboration between three leading international organisations in world dermatology: IFPA; International League of Dermatological Societies; and International Psoriasis Council.

One of the key aims of the GPA is to provide information about the worldwide epidemiology of psoriasis. The GPA will be updated annually, in collaboration with dermatologists and international organisations.

ISF Services & Resources



Ask-A-Nurse Helpline

The Ask-a-Nurse Helpline provides free, direct, accessible and specialist guidance about skin conditions, delivered by dermatology clinical nurse specialists, on a person-to-person call on an agreed day and time. We handle queries on a wide range of topics from acne, eczema, psoriasis, hidradenitis suppurativa, rosacea and many more common and more complex, rare conditions.

In 2019, 650 individuals contacted the Ask-a-Nurse Helpline in relation to how to manage a skin condition and/or how to access dermatology services as wait lists for secondary care continue to increase.

For its first 3 years, our Helpline consistently returned a user satisfaction rating of 90% or higher. To better understand their outcomes, and to continue to meet the needs of those who contact us we moved to a more data driven validation tool in autumn 2019.

Developed in association with consultant dermatologists Prof. Brian Kirby and Prof. Anne-Marie Tobin, we use the survey to evaluate our service under defined criteria - our starting point being whether or not the service user already had a confirmed diagnosis at the time of contacting us. This more detailed survey follows up with patients 4-8 weeks after their Helpline interaction to enquire whether their condition has improved and what steps they have taken since reaching out to us. This data allows us to statistically determine to what degree we have a positive impact on service users, both for those with/without a diagnosis when they first contact us.

In autumn 2019 over two thirds of people assisted by the Ask-a-Nurse Helpline self-reported that their condition had either 'Much Improved' or 'Somewhat Improved' after speaking with our nurse. Of those that had no diagnosis on contacting us, half (50%) visited a GP after speaking to a nurse and half of those (50%) subsequently received a diagnosis. These service users are encouraged to contact us again should they have any further queries.

The Ask-a-Nurse Helpline was supported by AbbVie, LEO Pharma, Novartis, Pfizer, Sanofi, Celgene and UCB in 2019.



“Fantastic service, much needed due to lengthy waiting lists. Advise and recommendations re my daughter’s psoriasis are clear, helpful and crucial. Thank you for your support and medical direction.”

Gráinne Wall

#Ask-How-I-Feel Psoriasis Campaign

As part of the #AskHowIFeel psoriasis awareness campaign in November, Novartis and the Irish Skin Foundation (ISF) launched a dedicated resource, AskHowIFeel.ie, housing new support and advice videos for people living with the skin condition.

The campaign is designed to encourage those living with psoriasis to seek support from others and to have more open conversations about how the condition impacts their lives not just physically, but emotionally.

The resources include videos that feature patient advocate Caroline Irwin in conversation with Dr Eddie Murphy, Clinical Psychologist, Adjunct Associate Professor, UCD School of Psychology and #AskHowIFeel campaign ambassador, looking at psoriasis from the inside out. Video contributions were also made by ISF CEO David McMahon; ISF Chairperson and consultant dermatologist at Beaumont Hospital and Connolly Hospital; Dr. Marina O'Kane; and ISF Board Member and GP, Dr Catherine Wilkinson.

The informative and candid videos focus on several topics including discussing the common challenges people living with psoriasis face, pathways to support, and the importance of working with your healthcare professional, particularly your GP.

Melanoma Skin Cancer Leaflet

Skin cancer is the most common cancer in Ireland with upwards of 11,000 cases diagnosed each year. If current trends continue, this number is projected to more than double by 2045.

The ISF's new Melanoma Skin Cancer leaflet has been prepared in consultation with people affected by melanoma, dermatology nurses and consultant dermatologists, and aims to help members of the public to identify changes in their skin which could indicate the presence of a melanoma. The leaflet is available in the information resources section of our website.

The leaflet is endorsed by the National Cancer Control Programme (NCCP), Healthy Ireland and the Irish Association of Dermatologists (IAD) and was published to coincide with the launch of Ireland's first National Skin Cancer Prevention Plan in May 2019.



Joni Clarke

"The Helpline proved invaluable when trying to deal with my baby's eczema. The lady on the phone (Helen) went out of her way to arrange a nurse to call us even though one was not due to make calls that day. The advice was great as the nurse works by day in a paediatric dermatology setting while our own GP has limited knowledge in this area. It is this focused knowledge and the eagerness to help that made our experience with ISF so valuable. It really was so helpful. With GP lack of specific and up to date knowledge and waiting lists for specialists so long, the service is badly needed. Many thanks to Helen and the nurses."

Acne Information Page

In March the ISF launched its new Acne Information Page, developed in conjunction with GPs and dermatologists, who treat this common skin condition on a daily basis. The resource aims to provide the public with accurate information on the signs, symptoms, causes and treatments for acne.

Acne is the 8th most common disease in the world. It affects more than 645 million people, around 9.4% of the global population, and can affect 85% of teenagers and young adults.

This common inflammatory skin condition, typically occurs during the teenage years, frequently around 12-14 years of age, and peaks around 16-17 years in females, and 17-19 years in males. Sometimes acne can persist, or even appear for the first time in adulthood.

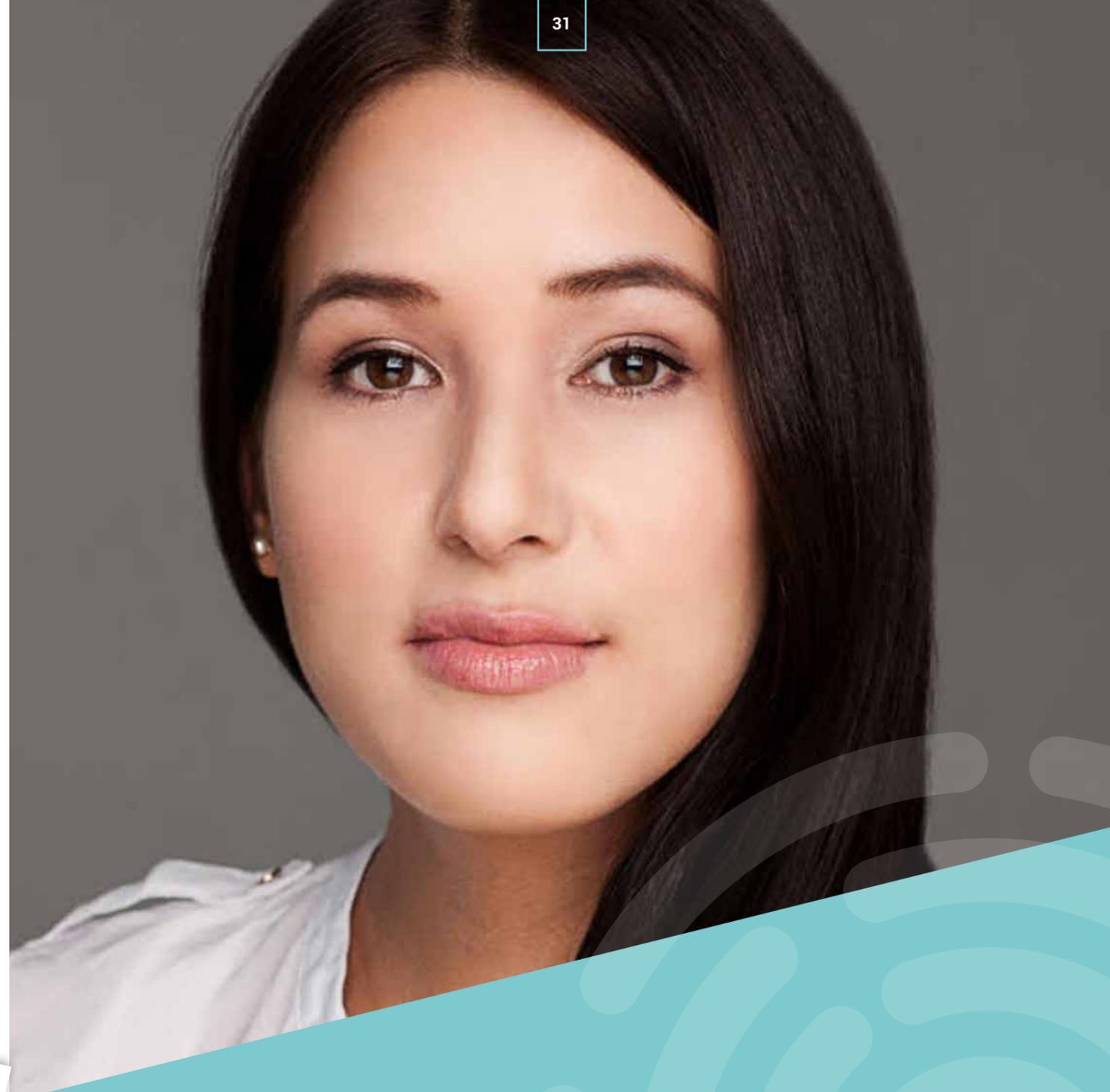
Managing Scalp Psoriasis Leaflet

To address one of the most frequently asked questions to the Ask-a-Nurse Helpline, the ISF published a 'Managing Scalp Psoriasis' leaflet providing detailed guidance on how to manage and treat this presentation of psoriasis.

The scalp is one of the most common sites to be affected by psoriasis, and sometimes is the only area of involvement, with almost 80% of people affected at some point in their lives.

Rosacea Information Page

In November 2019, the Rosacea Information Page on the ISF website was updated to provide visitors with the most up-to-date information and guidance for this common skin condition.



Elena Suryo

"The website and Helpline is an excellent source of information and support. They went out of their way to help me, an expat, to guide me through the complexities of the Irish health care system in regards to my medical needs."

Research

Women with Psoriasis or Psoriatic Arthritis Survey Call

In September, in conjunction with IFPA and EUROPSO, and in collaboration with UCB, the ISF posted a call on the website for women, aged 18-45, living with psoriasis or psoriatic arthritis to take part in a survey to understand what living with psoriatic illness is really like. The results will contribute the development of new solutions for people living with psoriasis or psoriatic arthritis and will raise awareness of the impact of the condition on women in particular.

Research call for people living with Eczema or HS

The ISF posted a call on our website for patient participants for two research studies at St Vincent's University Hospital in September. The focus of the first research study was on adult eczema/atopic dermatitis, compared with normal skin/skin unaffected by eczema to gain a greater understanding of the mechanisms of this skin disease. The focus of the second research study was for hidradenitis suppurativa.



Research Call for HS Everyday Wound Care User Study

In November, on behalf of the Clinical Research Platform the ISF called for people living with HS to test a wound dressing product specifically designed for use in that condition.

ISF Strategy 2020-2025

In December we began developing the ISF's strategy for 2020-2025. The strategy will guide the future work of the ISF. We sought opinions and feedback from the public and key stakeholders, to inform and shape the strategy.

Psoriasis 2020

Following the success of the **'Living with Atopic Eczema Survey'** conducted in 2018-2019, the ISF plans to conduct research on psoriasis and discover the true challenges of living with this common skin condition.



Fundraising, Governance & Finances

Thank you to Our Fundraisers!

The ISF is very grateful for the support of donors and fundraisers who support our work.

In particular, we would like to thank Paul Keating for the considerable sum raised in memory of a dear friend and ISF supporter, Conor Heffernan for his nightclub fundraiser and to Bernie & Peter Rice of the Melanoma Trust, all of whom were thoughtful and generous in their donations.

Foundation Partners

We would like to acknowledge with thanks the generosity of our Foundation Partners, who sponsor the ISF Ask-a-Nurse Helpline and our continuous work throughout the year to support people with skin conditions.



Corporate Sponsors and Supporters

We would like to thank GSK/Stiefel for their continuing sponsorship of our Family Fun Day for Children with skin conditions in 2019.



We would like to thank all the organisations and brands that supported our first event of its kind, SkinSideOut. Without their help and support the event would not have been such a major success.



The Irish Skin Foundation would also like to acknowledge the support of the following companies in 2019:



Governance

The Irish Skin Foundation is committed to maintaining the highest standards of corporate governance. To provide transparency and ensure we reach the standards expected we have signed up to the organisation 'Type B' strand of The Governance Code for Community and Voluntary Organisations in Ireland and are on the 'Adoption Journey' to compliance with the code.

Company Status:	Company Limited by Guarantee without Share Capital; Incorporated 2011
Company Number:	493784
Charity Regulatory Number:	20078706
Revenue (Charities Unit) (CHY)	19949
Company Auditors:	PricewaterhouseCoopers
Governance Code:	Full compliance as a Type B organisation
Data Protection Policy:	Complete
FRS 102:	Adopted in 2015

ISF Board of Trustees



Chairperson: *Marina O'Kane*



Rupert Barry



Michael Foley



Caroline Irwin



Kenneth McKenzie



Padraig O'Cearbhaill



Sheila Ryan



Paul Herriott



Anne-Marie Tobin



Rosemarie Watson



Catherine Wilkinson



Jennifer Wilson O'Raghallaigh

Finances / Statement of accounts

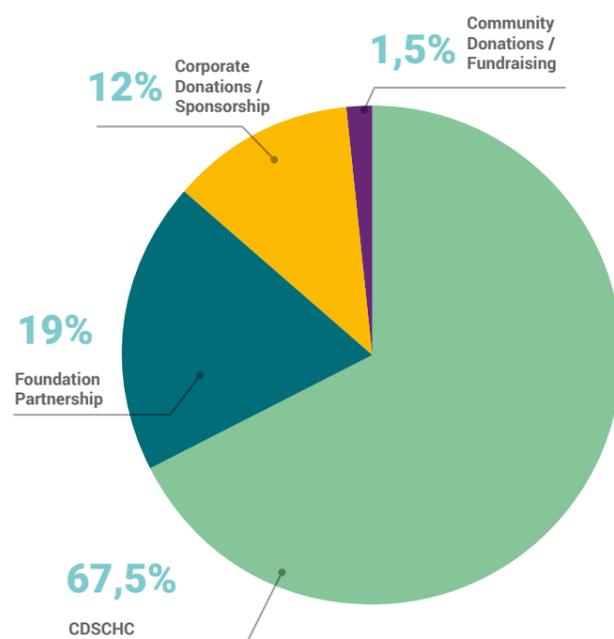
The ISF is grateful for the continued support of the CDSCHC for our core funding. We are also very appreciative of the continued support provided by our Foundation Partners and other corporate sponsors. The ISF continues to operate without state funding or significant donations from the public.

While the core funding greatly assists the organisation in pursuing our goals and objectives, the ISF has been very successful in fundraising to either partly-fund, or entirely cover the costs of the ISF Helpline, events, and health promotion programmes. In 2019 the ISF's income was **€720,884**, while expenditure was **€667,356**.

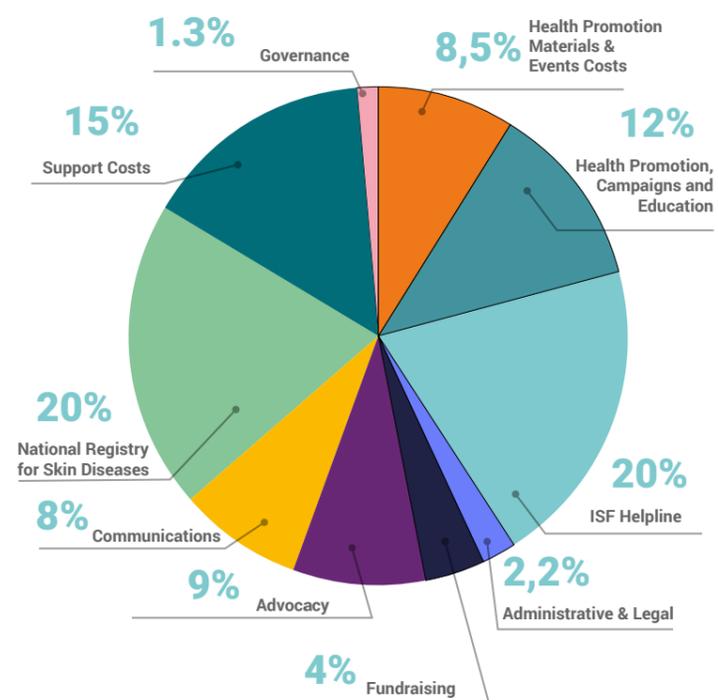
Salary Costs

2019 staff costs and salaries amounted to **€369,250** or 55% of overall expenditure.

Income 2019



Expenditure 2018





IRISH SKIN FOUNDATION

Supporting people with skin conditions

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