#### Irish Skin Foundation

# ANNUAL REPORT 2015



### NOREEN

I have had psoriasis since I was young. I didn't realise how much of a rut I was in, in terms of managing it, until a friend of mind gave me the "What you need to know about psoriasis" booklet from the Irish Skin Foundation. Since reading it, I've been able to find better ways to manage and treat my psoriasis.

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Irish Skin Foundation

## FOREWORD BY PROF. EOIN O'BRIEN, EXECUTIVE CHAIRMAN OF THE IRISH SKIN FOUNDATION



I am delighted to present our Annual Report for 2015 and to outline our work and our plans for the future.

### OUR WORK FOR PEOPLE WITH SKIN CONDITIONS

The Irish Skin Foundation was launched publicly in March 2013 after securing initial funding from the City of Dublin Skin & Cancer Hospital Charity (CDSCHC). In 2014 we moved to the Charles Institute for Dermatology in UCD, so as to be more closely aligned with the scientific advances being made in dermatology research. We are unique among similar organisations in Europe in that by merging the Psoriasis Association of Ireland, the Irish Eczema Society and the Melanoma and Skin Cancer Society, each of which is represented on our Board, the organisation now represents and supports people with every form of skin disease in Ireland. Our mission is straightforward – to support in all ways possible patients affected by skin disease in Ireland, and their families and carers.

#### **CHALLENGES**

Significant challenges exist for people with skin conditions. There is often difficulty accessing dermatology services. The recruitment and retention of specialist physicians, the need for more dermatology clinical nurse specialists and lack of facilities and equipment are just three factors affecting services. Waiting lists continue to grow with the result that many centres are inundated leading to unacceptably long waiting times for initial and urgent assessment.

#### SOLUTIONS

The ISF can help to resolve these problems, by advocating on behalf of patients so as to influence policy, resource allocation and to address the geographical inequity which is a feature of dermatological services across the country. The ISF can also provide patients with up-to-date practical information on its website, by being present at national meetings, by publishing booklets for patients, through social media, and by the provision of helpline guidance.

During 2015 the procedures and structures were put in place to establish Councils on Advocacy, Skin Cancer, Psoriasis, and Eczema, the membership of which will include patient representatives and medical experts, both nursing and specialist dermatologists, so as to advise and recommend the best policies and needs for patients with different skin diseases.

During 2015, the foundations for a Skin Disease/ Dermatology Helpline service were put in place by identifying nursing staff with specialist expertise in the management of children and adults with skin diseases, by organizing rosters and training sessions, by providing telephones and the computer and software infrastructure that is necessary for the provision of a helpline service that we anticipate will be much used by patients across the country.

We continued, as in previous years to organize and participate in a number of events that included a Family Fun Day for children with skin conditions, their parents and carers at Barretstown, the National Ploughing Championships, and events to improve awareness and management of psoriasis, eczema and hidradenitis suppurativa, details of which are presented in this report.

#### **RESEARCH and INNOVATION**

The ISF is leading the establishment of the National Registry for Skin Diseases in Ireland, an exciting e-health initiative designed to integrate dermatological care provision, audit and research. This innovative project will be a patient-focused hub that will ensure that technology will connect the different facets of the healthcare system to benefit patients with skin conditions throughout Ireland.

I would like to thank the Chairman and Board of the CDSCH Charity for its continuing support, advice and encouragement for the initiatives being established by the ISF. The support of our Foundation Partners and corporate sponsors was essential in allowing us to maintain present facilities, and importantly, to give us the confidence to plan future initiatives.

I am indebted to my Board for the time and effort its members give to assessing and endorsing ISF policy. Our Executive Committee, which meets monthly, gives invaluable guidance and advice for which I am most grateful. Without the dedicated commitment from a small but loyal staff the activities outlined in this report could not have been achieved. Our thanks also go to our many supporters and volunteers, and I would like make a special expression of thanks to those who have taken their time to volunteer or share their personal experiences of living with skin disease.



### A MESSAGE FROM THE COO

Dermatology patients face many challenges including stigma, poor public understanding and inadequately resourced health services. With the exception of melanoma, skin conditions are often disregarded in the public imagination.

To many people in Ireland, psoriasis is just a rash and eczema is an inconvenient allergic reaction. This lack of public appreciation for the plight of skin patients has significant implications.

Some of these implications involve lack of resources and support. For example, we have only 10 dermatologists for every million people in Ireland – even though it's estimated that at any given time, half of us have a skin condition. According to the National Treatment Purchase Fund, over 13,000 patients wait more than six months to see a dermatologist; over 5,500 wait 12 months or more.

There are other more intangible consequences. Many people with skin disease suffer from self-esteem issues and feelings of embarrassment and rejection. They become masters of concealment, planning wardrobes and activities around the need to keep their condition hidden.

In this report we outline our efforts in 2015 to improve quality of life for people with skin disease, create greater awareness of the reality of skin conditions and to secure improved services.

### THE IRISH SKIN FOUNDATION

The Irish Skin Foundation is a national charity with the purpose of supporting people with skin conditions. We provide information and support, engage in health promotion and disease awareness, engage in advocacy and fund community-based research projects. We are supported from several sources, which include individual donors, the CDSCHC, Foundation Partners and other corporate supporters.

Our mission is to improve the quality of life for people with skin disease, promote skin health and the prevention of skin disease by providing support, advocacy and research and by increasing awareness.

#### **Our Origins**

The ISF was established by the CDSCHC following the sale of the voluntary hospital on Hume Street, which had provided care and treatment to people with skin disease for almost a century from 1911-2006.

We are unique among similar organisations in Europe in that by merging the Psoriasis Association of Ireland, the Irish Eczema Society and the Melanoma and Skin Cancer Society, each of which is represented on our Board, the organisation now represents and supports people with every form of skin disease in Ireland.

#### **Our Work Today**

The ISF provides assistance and encouragement to anyone affected by skin diseases; we do this by:

- Providing disease-specific information on our website
- Offering direct, accessible and specialist guidance
  by phone and e-mail
- Running health promotion and disease awareness campaigns
- Advocating for improved services and positive policy changes
- Funding and engaging in community-based research

#### Our Vision for the Future

Our vision is for equitable and timely access for the people of Ireland to the appropriate information, expertise and treatment, so that everyone with a skin disease may lead a full life, free from stigma and discomfort.

### THE YEAR IN NUMBERS





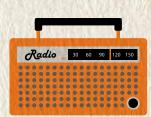
**1,843** visitors to our new HS microsite 365,018

Pages viewed on our website



540,000 people reached through radio interviews on

12 stations





7,038 visits to the Say Something about Psoriasis campaign page and 65,946

campaign video views

**1,840** Eczema Skin Services Packs to pharmacies throughout Ireland



### **RACHEL** (pictured with flowers on her head and with her new friends)

My daughter Rachel (8) has psoriasis. I emailed the ISF Helpline for advice, as Rachel thought that she was the only little girl to have it. The next day I received a reply from Helen who arranged a call from a lovely lady who had psoriasis all of her life, also a call from a nurse, and then Rachel was invited to a fabulous Family Fun Day. She was a different child after it once she understood that she is not alone with her psoriasis. The ISF helped us so much, the articles on Facebook are very helpful, the website has great information. Thank you to all the team for all your help, advice and kindness and thank you for caring.

Alice Poland

### **SKIN DISEASE IN IRELAND**

Over half of the Irish population experience a skin condition each year, resulting in 3.75-6.25 million GP consultations.<sup>2</sup>

Skin diseases cause over 180 deaths each year in Ireland, including 113 deaths due to malignant melanoma. Ireland has one of the highest incidences of skin cancer in the world with nearly 1,000 cases of melanoma<sup>3</sup> and over 9,700 cases of nonmelanoma skin cancers diagnosed each year.<sup>4</sup> By 2040 it is expected that diagnoses of skin cancers will increase by 300%.<sup>5</sup>

Psoriasis is one of the most common skin diseases in Ireland and affects about 73,000 people.<sup>6</sup> Many skin disorders, such as eczema, are increasing in frequency; approximately one in ten children and one in twenty adults have eczema. Quality of life is significantly impaired by skin diseases such as psoriasis, eczema, acne, rosacea and hidradenitis suppurativa (HS), often to an extent that is as great as some life-threatening conditions such as cancer.<sup>7</sup> Dermatology clinics also have the fourth-longest waiting list with 32,000 patients waiting to be seen and routine waiting times of 12-18 months.<sup>8</sup>

During 2015, the ISF raised awareness of HS, a long-term or chronic skin condition that causes painful, inflamed areas typically located around the armpits, groin and buttocks. The condition affects about 1% of the population and as a result of greater awareness dermatology clinics have reported a significant rise in the numbers of patients referred with HS.

Skin disease affects people of all ages and backgrounds. Many people report stigmatisation, a fear of contagion and a failure of others to appreciate the serious health, financial, social and personal impacts of their disease. Everyone with a skin disease deserves to live a full life, free from stigma and discomfort, yet access to the appropriate information, expertise and treatment is not widely available.

Our 2014 Annual Report noted that accurate statistics for skin diseases in Ireland are virtually non-existent. While this remains largely the case, in 2015 the ISF, NUI Galway and Novartis published *The Burden of Psoriasis: Epidemiology, Quality of Life, Comorbidities and Treatment Goals* to address the lack of Irishspecific data about psoriasis.

During 2015, the ISF continued to develop the ISF Integrated National Registry of Skin Disease to address this deficit of accurate information. We aim to improve patient outcomes by positively contributing to evidence-based public policy in dermatology. There are hundreds of skin diseases.

We may talk about them generally under two broad headings:

#### 1. Inflammatory diseases (rashes) including:\*

- acne, eczema, hidradenitis suppurativa (HS), psoriasis, rosacea, and chronic spontaneous urticaria (CSU)
- infections caused by bacteria, viruses, fungi and parasites
- autoimmune conditions including alopecia, lupus, pemphigoid and vitiligo
- hereditary diseases including epidermolysis bullosa (EB) and ichthyosis

#### 2. Skin cancers (lesions):

- basal cell carcinoma (BCC)
- squamous cell carcinoma (SCC)
- melanoma

\*Some conditions may be considered under more than one sub-heading.

In Ireland between 2003-10 an average of 181 people died each year as a result of diseases of the skin and subcutaneous tissue (68) and melanoma (113); figures from the OECD.
 The most common cancer in Ireland is non-melanoma skin cancer; the two main types are basal cell carcinoma (BCC) and squamous cell carcinoma (SCC).

<sup>3.</sup> Non-melanoma: 303% increase in females and 364% in men. Melanoma: 296% in females and 335% in males, figures from the National Cancer Registry Ireland.

<sup>4.</sup> The Burden of Psoriasis: Epidemiology, Quality of Life, Co-morbidities and Treatment Goals, 2015.

<sup>5.</sup> National Cancer Registry Ireland, 2014, estimates that there will be 13,000 females diagnosed and over 20,000 males with skin cancer. This represents an increase of up to 356% in males and up to 234% in females.

<sup>6.</sup> National Treatment Purchase Fund (April 2016), 31,438 outpatient and 508 inpatient/day cases.

### **STRATEGIC REVIEW**

A three year strategic plan was approved by the Board of the ISF in 2015 to guide our efforts and to concentrate energies on a work programme to improve the quality of life for people with skin conditions, provide guidance on skin disease and to promote skin health.

A key element of the review will see the establishment of Councils in order to offer a structure for greater community and stakeholder engagement and to advise the Board of the charity on specific issues.

Our mission is to improve quality of life for people with skin disease, promote skin health and the prevention of skin disease by providing support, advocacy and research and by increasing awareness

#### **Our values**

Integrity, transparency, accountability, strict data protection, community collaboration, respect and empowerment.

#### **Overall goals**

- 1. Improve quality of life for people with skin disease
- Increase the numbers of people accessing professional support to understand their illness
- 3. Enable people with skin disease to alleviate their symptoms by a better understanding of treatment
- 4. Improve knowledge among patients through the provision of accurate information
- 5. Improve the organisation of dermatology services by assisting in gathering accurate disease/ demographic data for the ISF Registry of Skin Diseases
- 6. Influence public policy through effective advocacy
- 7. Foster community-based research in dermatology
- 8. Reduce stigma associated with skin disease

### Our objectives and work programme 2015-18

#### **Nurse Helpline**

The ISF will officially launch our ISF Nurse Helpline in 2016 to provide support to patients by offering equitable access to accurate information and advice.

#### We aim to:

- Improve on current patient supports by providing direct, accessible and specialist nurse advice
- Improve quality of life by providing callers with correct and up-to-date information
- 3. Improve management of skin diseases by providing appropriate guidance

During 2015 the foundations of this new service were laid by identifying nursing staff, investing in telephones, training and computer and software infrastructure. The ISF also became a member of the Helplines Partnership with a view to gaining accreditation for the planned service in 2016-7.

#### Website and health promotion

Maintain the highest standards in information and health promotion materials to provide access to accurate information and guidance.

#### We aim to:

- Inform and educate by providing accurate and up-to-date information on skin diseases
- Encourage community involvement by engaging with patients, producing newsletters, through social media and support groups.

### AMY

The ISF has been really helpful to my daughter Amy over the last couple of years; particularly through the Family Fun Day at Barrettstown. It's a great opportunity for Amy to be herself and participate in activities without fear of what other people think. It's a great boost for her to see other children coping with day-to-day challenges and realising that she is not alone. As parents, we have also picked up useful tips and suggestions from the ISF team.

Jill Pitcher

#### **Dermatology education**

Promote increased dermatology knowledge among those offering skin care advice to the public

#### We aim to:

- Establish an annual Dermatology Study Day for hospital, community, public health and practicebased nurses, pharmacists and others involved in skin care
- Promote the establishment of a university-based diploma course in Ireland for nurses interested in specialising in dermatology

#### Awareness and health promotion campaigns

Establish annual national awareness campaigns around psoriasis, eczema, skin cancer and other diseases; recognising the individual and common challenges experienced by those with each condition

#### We aim to:

- 1
- Increase public understanding about skin diseases
- Dispel prejudices, reducing stigma, isolation and the fear of contagion in our campaigns and materials
- Promote SunSmart behaviours to tackle the rise of skin cancer

#### Advocacy

To establish an advocacy platform seeking better services for people with skin conditions

#### We aim to:

- 1.
- Promote positive change in services accessed by people with skin disease (i.e. improve access to treatment, medical specialists and medications) by effectively advocating on behalf of patients



Have the voice of patients heard by government and policy makers

#### Research

To promote and develop our research role and to bring science to society by supporting communitybased research projects

#### We aim to:

- Continue to support and promote the ISF Integrated National Registry of Skin Disease
- Provide accurate information on rare skin diseases by building our capacity to gather demographic and statistical information on skin disease
- 3. Provide accurate data on the use of phototherapy for conditions such as psoriasis
- Influence the practice of dermatology by the transfer of photographic images as part of an integrated connected health strategy in Ireland

#### **ISF Councils**

To establish Councils within the ISF to encourage greater community engagement, provide insight and structure towards the attainment of common goals

#### We aim to:

- Establish Councils to offer insight, recommendations, expertise and reference to the on-going work of the ISF
- Councils will include those on Advocacy (established in 2015), Eczema, Psoriasis, Skin Cancer and Rosacea.

The ISF Councils will provide valuable perspective and leadership in their respective areas of interest. The Councils may become involved in a range of activities that complement the function of the ISF, such as the supervision/and or preparation of reports and educational materials, fundraising, and organisation of events and meetings.



Karen Keegan, David McMahon, Caroline Irwin, Helen Hadden, Jeannette Brazel & Mark Wheeler at Barretstown Family Fun Day 2015

### A YEAR OF ACTIVITY

2015 was a busy year working to achieve our aims of providing information, raising awareness and advocacy.

#### **Temple Street Children's Hospital**

The ISF called on stakeholders in government and consultant representative bodies to renew efforts to resolve issues caused by the recruitment and retention crisis in specialist branches of medicine, such as dermatology.

#### New restrictions on sunbeds

February saw the introduction of the further restrictions on sunbeds. The ISF welcomed this development but called for an outright ban on sunbeds to end needless and dangerous 'cosmetic' exposure to UVA radiation.

#### Irish Association of Dermatologists

ISF Chairman, Prof Eoin O'Brien presented a review of our

work to the Irish Association of Dermatologists and discussed the challenges and opportunities which exist in providing support for people with skin conditions.

#### Let's talk Psoriasis Support Group - Sligo

The ISF and Selene Daly CNS (Sligo University Hospital) co-hosted a very well attended support meeting, entitled "Let's Talk Psoriasis", in Sligo. Over 80 people attended from throughout the West and North West. The meeting heard from Selene Daly and Dr Tim Anstiss and included a discussion on some of the latest treatments, tips on how to manage your disease while Caroline Irwin shared her own journey with psoriasis.

#### **Burden of Psoriasis Report**

The ISF supported the publication of a key report, with Novartis, exposing the hidden burden and impact of psoriasis in Ireland. The report suggests that more than 73,000 people are affected by psoriasis and that about 9,000 of those have a severe form of the disease.



Launch of the Burden of Psoriasis Report, May 2015

#### International Dermatology Patient Organization Conference (IDPOC)

Our COO attended IDPOC 2015 in Canada, the first ever conference dedicated to patient leaders committed to running support organisations in the area of dermatology. Organisations representing people with eczema, alopecia, psoriasis, skin cancers or rarer skin conditions like pemphigus, epidermolysis bullosa, or HS all attended seminars on how to provide meaningful support.

#### Family Fun Day for Children with Skin Conditions 2015

Our third Family Fun Day for children with skin conditions took place in Barretstown, Co. Kildare on Saturday 29th August and turned out to be another day packed with activities and laughs for all the kids and families.

Each year the ISF is able to help over thirty children and families with skin conditions to enjoy the activities at Barretstown which include arts and crafts, archery, canoeing, fishing, pony trekking and for the very brave, high frame climbing.

#### Eczema Awareness Week 2015 -'Starting from Scratch' guides for adults and children

During Eczema Awareness Week the ISF drew attention to eczema in the media and emphasised the important part that pharmacists have to play in encouraging a good daily care routine of emollient therapy. In partnership with GSK/Stiefel Skin Services Packs were distributed to over 1,800 pharmacists nationwide to promote emollient therapy - the cornerstone of eczema care.



#### First ever campaign about HS (Hidradenitis suppurativa)

In September we launched a new educational resource for people living with a challenging skin condition, HS, which can cause significant pain, anguish and can result in stigma. A new dedicated section on our website, supported by AbbVie, helped increase awareness and shed a light on a poorly understood skin condition. A HS Community support group is now planned.

#### National Ploughing Championships 2015

The National Ploughing Championships routinely draws over 270,000 attendees from all walks of life across Ireland. The ISF took at stand at this event, supported by Leo Pharma, offering one-to-one consultation to dermatology clinical nurse specialists each day. We were visited by over 550 people seeking guidance on skin conditions over the course of the event.

#### Allergy and Free-From Expo 2015

Jeannette Brazel accompanied by dermatology nurses provided oneto-one eczema guidance to adults and children at the RDS Dublin in October.

#### Advocacy

In October the ISF met with Jerry Buttimer T.D., Chairman of the Joint Oireachtas Committee on Health & Children, to seek a hearing before the Committee and to highlight high costs of emollients and dressings for people with eczema.

We also raised serious concerns around delayed diagnosis, inadequate treatment options, centralisation of services in major cities and insufficient access to care for people with psoriasis in Ireland.

#### **Advocacy Council**

Our first Council was formed during 2015 to assist the ISF in the formation of policy and to ensure that all future advocacy work is well grounded in community support and informed by patients, nurses, GPs and consultant dermatologists.

#### World Psoriasis Day 2015 - #SaySomething On-Line Awareness Campaign

The #SaySomething campaign, launched in conjunction with Abbvie, marked World Psoriasis Day in 2015. This year we added Health Snaps (short videos about psoriasis and psoriatic arthritis), an interactive PEST (Psoriasis Epidemiology Screening Tool) to help people with psoriasis identify signs of psoriatic arthritis.

#### IrishSkin.ie - Our Website

The Irish Skin Foundation website has continued to evolve and expand. It hosts all of our information and booklets on skin conditions while providing news and updates on campaigns. There are detailed sections on psoriasis, eczema, skin cancer, HS, and rosacea.

We are continuously improving and developing our website, which is our primary tool for reaching members of the public affected by skin diseases. We will continue to develop more content on health promotion, awareness and advocacy in the coming years.

#### Digital Communication and Social Media

The website has been visited by over 124,357 (up from 43,000 unique users in 2014) and is referenced for common inquiries coming to us via our increasing social media traffic. Our social media reach at the end of 2015 was 2,846 on Facebook (up from 1,600 in 2014) and 951 followers on Twitter (up from 748 in 2014).

#### **Booklets & Publications**

The ISF has published the following resources for people with skin conditions during 2015:

- Eczema Information Leaflet: Taking control of your child's eczema
- Eczema Information Leaflet: Taking control of your eczema (for adults)
  - Hidradenitis Suppurativa Microsite

Pearl, pictured to the left with her Mum and sister Erin, at the annual Family Fun Day in Barrettstown.

Pearl raised awareness and shot a video about her challenges with psoriasis as part of World Psoriasis Day.





### BARRY

Barry McGrath has been living with hidradenitis suppurativa (HS) for almost 30 years. Throughout 2015, Barry has, with the help of the ISF, worked to try and raise awareness and understanding of this condition



### LOUIS

My son has eczema, I contacted the ISF, explained Louis's condition and how uncomfortable he was, especially at night. Your Helpline was very understanding of Louis's condition, informative and gave me really helpful guidance. I'm very grateful to the ISF; Louis's condition has improved so much.

Ciaran Muldowney

## ISF NATIONAL REGISTRY OF SKIN DISEASE

The ISF National Registry of Skin Disease project was established in 2013 to facilitate patients and clinicians to improve the collection and use of data for clinical care provision and research.

The Registry continues to be developed by the ISF Research Fellow, Dr Dmitri Wall, under the guidance of Prof Alan Irvine, Chairman of the ISF Advisory Board, Prof Eoin O'Brien as Chairman of the ISF and with the assistance of Godfrey Fletcher, Business Manager Consultant.

#### **Key Developments during 2015**

#### Network development for registry sub projects

- Atopic Dermatitis: This registry is currently in beta testing at Our Lady's Children's' Hospital Crumlin.
- Phototherapy: This registry is being developed with Dr Anne-Marie Tobin, Clinical Lead of the HSE's Dermatology National Clinical Programme and University Hospital Limerick, and Dr. Sharifa Mohammed(the ISF/Irish Research Council postgraduate grant recipient).
- Epidermolysis Bullosa (EB): Dr Dmitri Wall will act as eHealth lead of a proposed European Reference Network for rare and undiagnosed skin disease. The ISF is developing an Irish EB registry and working with a network of international

EB registries to understand how best to work collaboratively across borders.

Photography: Dr Patrick Ormond is leading this project, with Prof Neil O'Hare (St James Hospital & National Integrated Medical Imaging System), Mr Gregory Johnston (National eReferrals Manager), Mr Anthony Edwards (Clinical Photographer St James Hospital), with the aim of facilitating capture, storage and sharing of high-quality images within established and developing projects in the Irish healthcare system.

#### **Presentations and representation**

During 2015, Dr Wall presented at a number of meetings and represented the ISF Integrated National registry, including: the Global EB CLINET registry meeting in London and at the International Eczema Council the World Congress of Dermatology in Vancouver May 2015 the International Eczema Council. Dr Wall also represents the ISF Integrated Registry in the following fora:

- Health Informatics Society of Ireland (HISI)
- eHealthIreland Council of Clinical Information Officers
   Health Informatics Society of Ireland proposed European Registry Network of Rare and Undiagnosed Skin Disease
- Global EB-CLINET Registry development group,

- Treatment of Severe Atopic Eczema Taskforce
- TCD Health Informatics Alumni Steering
  Committee
- British Association of Dermatologists Dermatology and Genetic Medicine (BADGEM)
- UK Translational Research Network in Dermatology (UK TREND)
- British Association of Dermatologists Health Informatics Sub-Committee (BAD HISC)
- EUPATI (European Patients' Academy on Therapeutic Innovation) platform.

#### **Publications & Policy**

- 'Planning a registry' in Methodological guidelines and recommendations for efficient and rational governance of patient registries D. Wall, A. Irvine, E. O'Brien et al PARENT (Patient REgistries iNiTiative).
- Foreword in Burden of Psoriasis:
  Epidemiology, Quality of Life, Comorbidities and Treatment Goals D. Wall supported by Irish Skin Foundation, Novartis Ireland and the J. E. Cairnes School of Economics at NUI, Galway.
- **ISF Data Protection Policy** D. Wall, primary author.

Dr Dmitri Wall speaking at the Global EB CLINET registry meeting, London, Sept 2015



### **FUTURE COLLABORATIONS & DEVELOPMENTS**

#### **The Charles Institute**

The ISF has worked with Professor Martin Steinhoff, Director of the Charles Institute and Scientific Adviser to the ISF, on a number of successful grant applications, which have resulted in a significant number of scientific communications and publications. The Charles Institute also has four major research projects underway at present:

- Inflammation: psoriasis, rosacea, atopic dermatitis (eczema), itch (pruritus), HS and acne
- Wound healing: epidermolysis bullosa (EB)
- Auto-immune disease: diabetic foot and lower-limb ulcers
- Genetic disorders and cancer: EB and several skin cancers

#### Appointment of Health Promotion Manager

Michelle Dolan, Dermatology CNS, will join the ISF staff in 2016 as Health Promotion Nurse Manager to assist in the delivery of our mission to improve the quality of life for people with skin disease, and to promote skin health and the prevention of skin disease. Michelle is a dermatology CNS and will assist in leading projects including the ISF Helpline, disease awareness campaigns and patient support programmes.

#### New Adult and Parent-Child Psoriasis Resources in 2016

As part of our ongoing health promotion work, the ISF is currently updating and expanding our adult psoriasis booklet **"What you need to know about Psoriasis".** We are planning to distribute 30,000 copies to GPs throughout Ireland in 2016. We are also working on a detailed booklet for parents and children with psoriasis called **"What parent's need to know about Psoriasis"**. The booklet will include a story relating to stigma with points for parents and children who wish to learn more about managing the condition.

#### HS (Hidradenitis Suppurativa)

HS is a long-term skin disease causing painful lesions, boils and deep abscesses in the armpits, groin and upper/inner thighs, between the buttocks and under the breasts. These can lead to devastating breakouts that rupture, causing soft tissue damage and very painful scarring. Our 2015 awareness campaign demonstrated the need for greater support for people with HS; in 2016 we are planning a number of meetings to offer education and encouragement for anyone affected by the disease.

### **FOUNDATION PARTNERS 2015**

We would like to acknowledge with thanks the generosity of our donors and supporters. We are particularly grateful to our Foundation Partners, whose support has been essential to the charity in delivering the programme of public awareness and engagement activities since our public launch in 2013.





PAT BRAZEL



The City of Dublin Skin

NOVARTIS

PHARMACEUTICALS

and Cancer Hospital Charity

### **CORPORATE SUPPORTERS 2015**

We would also like to thank GlaxoSmithKline / Stiefel for sponsorship of our Family Fun Day for Children with skin diseases in 2015 and for working closely with the ISF on the Eczema Services Pack distributed to mark Eczema Awareness Week.

The Irish Skin Foundation would also like to – acknowledge the support of companies in 2015:







### 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.<sup>9</sup> We are also in the process of complying with the ICTR Fundraising Code.<sup>10</sup>

Company Status:	Company Limited by Guarantee without Share Capital; Incorporated 2011
Company Number:	493784
Charity Regulatory Number:	20078706
Company Auditors:	PricewaterhouseCoopers
Governance Code:	On the 'Adoption Journey' to full compliance as a Type B organisation.
Data Protection Policy:	Complete.
ICTR Fundraising Code:	Actively working towards full compliance.
FRS 102:	Adopted in 2015.

### OUR BOARD 2015



#### Patron: Fergus Slattery

Fergus Slattery is a former rugby union player who in representing Ireland earned 61 caps, 18 as Captain. He was a member of the Lions squad in 1971, again in 1974, and was Captain of the most successful Irish touring side ever in 1979. He was a member of the Irish Triple Crown-winning team in 1982. He was inducted into the International Rugby Hall of Fame in 2007. Fergus is now Managing Director of Fergus Slattery Property Investments.



#### Executive Chairman: Eoin O'Brien

Professor O'Brien is a cardiologist and currently Adjunct Professor of Molecular Pharmacology at the UCD Conway Institute of Biomolecular and Biomedical Research. He is a leading authority on the management of high blood pressure. He has written a number of books on the history of medicine including "A Century of Service", which details the history of the City of Dublin Skin and Cancer Hospital.



#### **Jeannette Brazel**

Jeannette Brazel is a parent of a child with severe eczema, and was Chairperson and Co-founder of the Irish Eczema Society, which for many years provided information, education and support to people suffering from or caring for patients with eczema.



#### **Alan Irvine**

Professor Alan Irvine is Professor of Dermatology at Trinity College Dublin and a consultant dermatologist at Our Lady's Children's Hospital Crumlin and St. James's Hospital, Dublin. He has a special interest in children's skin disease, especially difficult eczema, birthmarks and genetic skin disease, and is a principal investigator in The National Children's Research Centre. Alan's Board membership was completed in 2015.



#### **Caroline Irwin**

Caroline Irwin, who suffers from psoriasis, founded the Psoriasis Association of Ireland when she returned to Ireland from living abroad and detected a need for support and information for patients with psoriasis



#### **Fergus McKenna**

Fergus McKenna is a retired Director of Batchelors Foods and former President of the Irish Grocers Benevolent Fund. He lives in Blackrock, Co Dublin with his wife, Kathy. His interests include sport, travel and community welfare.







#### **Matthew O'Brien**

Matthew O'Brien is a retired civil engineer whose working life was largely spent in both the UK and Ireland on the design and supervision of capital schemes in the public health area, and on the management of associated services. He joined the City of Dublin Skin and Cancer Hospital Board in 1999 and was Chairman during the closure and sale of the hospital.

#### Marina O'Kane

Dr. Marina O'Kane is a consultant dermatologist at Beaumont Hospital and James Connolly Memorial Hospital, Dublin. Her areas of interest are severe psoriasis and dermatological surgery. She held positions as president and secretary of the Royal Academy of Medicine in Ireland Dermatology Section and is a member of the HSE Dermatology Clinical Care Programme Advisory Group and HSE National Psoriasis Care Pathway Group.

#### **Patrick Ormond**

Dr. Patrick Ormond is a consultant dermatological and Mohs micrographic surgeon at St James's Hospital, Dublin. He set up the only Centre for Mohs Micrographic Surgery in the public health service in Ireland, and is also Chairman of the skin cancer expert group for the National Cancer Control Programme.



#### **Conor Sparks**

Conor Sparks is the Board's legal representative and Managing Partner of Gerrard L McGowan, Solicitors in North Dublin. He is experienced in all areas of litigation, also practising in the area of Wills and Estate Planing, taxation and dispute resolution. He is a member of the Dublin Solicitors Bar Association, a Commissioner for Oaths and a Notary Public.



#### **Mark Wheeler**

Dr. Mark Wheeler is the Board's GP representative and a GP in North Dublin. Dr Wheeler has a special interest in dermatology in primary care and specialises in diseases of the skin. He is a member of the Primary Care Dermatology Society of Ireland.



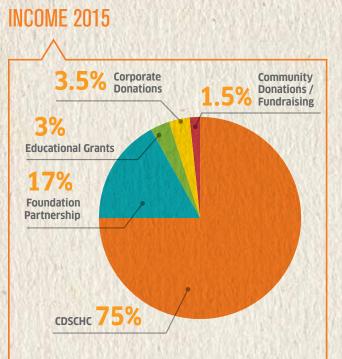
#### **Brian Kirby**

Consultant dermatologist at St. Vincent's Hospital, Dublin.

### **FINANCES / STATEMENT OF ACCOUNTS**

The Irish Skin Foundation is grateful for the support of the CDSCHC for the majority of our core funding. We also greatly appreciate the continued support provided by our Foundation Partners and other corporate sponsors. We are not currently in receipt of state funding or significant donations from the public.

In the coming years we must become self-sustaining by diversifying our income sources and engaging in fundraising. In 2015 the Irish Skin Foundation had an income of €540,637 and operating costs of €502,764. Salaries Costs During 2015 staff costs and salaries were €222,020 or 39% of overall operating costs.



### **OPERATING COSTS 2015**



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October 2016

Irish Skin Foundation

