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



Chairman, Professor Eoin O'Brien

I am delighted to present our Annual Report for 2016 and to outline our work and our plans for the future.

I am pleased to present the Annual Report of the Irish Skin Foundation (ISF) for 2016 in which I outline briefly our achievements during the year.

People with skin diseases are faced with many problems, which include difficulty accessing dermatology services, too few dermatologists and general practitioners with a broad interest in skin disease, and the need for more dermatology nurse specialists. Because of these deficiencies, waiting lists continue to grow and specialist centres are inundated leading to unacceptably long waiting times for initial and urgent assessment.

The ISF helps to relieve some of the distress that these issues cause by advocating on behalf of patients to influence policy, resource allocation and to address the geographical inequity which is a feature of dermatological services across the country. The ISF assists patients with skin disease to obtain relevant guidance by providing up-to-date practical information on its website, by being present at national meetings. by publishing booklets for patients, through social media, and, very importantly, by the provision of an ISF Helpline.

During 2016, the ISF Helpline service was launched to provide guidance and support to hundreds of callers, the ISF extended the events programme nationwide including events for children and others to improve awareness and management of psoriasis, eczema and hidradenitis suppurativa (HS).

The ISF continues to lead 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 City of Dublin Skin and Cancer Hospital Charity (CDSCHC) for its continuing financial 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. My Executive Committee, which meets monthly, gave me 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 specially to thank those patients and their families who have volunteered their time, or shared their personal experiences of living with skin disease.



Executive Chairman

A MESSAGE FROM THE COO

COO, David McMahon

Before reflecting on 2016 I would first like to express my sincere thanks to our Board, office team, volunteers and supporters for their continued hard work and commitment.

Over the course of the year, the ISF team pushed ahead to implement our 2015-18 strategy. This included launching our ISF Helpline which provides free specialist guidance to people affected by all kinds of skin conditions, publishing our new website www.irishskin.ie and expanding our programme of events to include nationwide meetings for people with psoriasis, eczema and HS.

2016 also saw us hold our first Dermatology Study Day for nurses and pharmacists, make our first submission to government on behalf of dermatology patients, launch several new booklets (on adult psoriasis, childhood psoriasis and eczema), and organise awareness campaigns about HS, eczema and psoriasis.

Behind all of this work, lies a deep need for up-to-date, evidence-based and accessible information, resources and support for people living with, or caring for, someone with a skin condition, throughout Ireland.

In this report we outline our efforts in 2016 to improve quality of life for people with skin disease, to create greater awareness of the often difficult reality of living with a skin condition and to secure improved services.

THE IRISH SKIN FOUNDATION

The ISF is a national charity dedicated to improving quality of life for people with all kinds of skin conditions.

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

We operate a free helpline providing direct, accessible and specialist guidance about skin conditions. Throughout the year we run events, including public information meetings.

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

We are supported from several sources, which include individual donors, the CDSCHC¹, Foundation Partners and other corporate supporters.

Our Origins

The ISF was established by the CDSCHC, following the closure 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 skin related patient 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 many forms of skin disease in Ireland.

Our Vision for the Future

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

1. The City of Dublin Skin and Cancer Hospital Charity.

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THE YEAR IN NUMBERS







182,060

Pages viewed on our website



810,000 people reached through radio interviews



people were assisted by the ISF Helpline



7,000 visits to the

Say Something about Psoriasis campaign page and

66,000 ca

campaign video views

40,000

What you need to know about Psoriasis booklets in GPs surgeries and hospitals throughout Ireland



10,000

What you need to know about Eczema booklets in hospitals throughout Ireland





STEPH & PEARL TIER

My daughter Pearl thinks the world of the Irish Skin Foundation and the work that they do. Her first experience of them was when she was invited to their Annual Family Fun Day at Barretstown, where she met other kids the same age with psoriasis, facing the same challenges as her. Since then we have followed the ISF on Facebook and used their Helpline when we needed advice. Pearl was so thrilled when she read the ISF's new booklet telling 'Aoife's story of living with psoriasis' because she felt it told her story and that it would help other children like her.

SKIN DISEASE IN IRELAND

At least one third of the population is affected by a skin condition and between **15-20%** of GP consultations specifically relate to the skin. This represents between **3.5** and **4.7** million GP consultations in Ireland each year.

Skin diseases can be very distressing and cause over **180** deaths each year in Ireland, including **113** deaths due to malignant melanoma. Conditions like psoriasis, eczema, acne, rosacea and hidradenitis suppurativa (HS) significantly impair quality of life, often to an extent that is as great as some lifethreatening conditions such as cancer.

Psoriasis is one of the most common skin diseases in Ireland and affects about **73,000** people. It is estimated that more than **9,000** of those suffer with severe psoriasis and the condition is associated with a number of comorbidities e.g. psoriatic arthritis, diabetes and cardio-vascular disease.

Atopic eczema is another common skin condition that most often begins in childhood, affecting up to **1-in-5** children and **1-in-12** adults. Itch, disrupted sleep and social embarrassment due to the visibility of the condition can have substantial effects on the psychological wellbeing of people with eczema and psoriasis.

Lesser known conditions like Hidradenitis Suppurativa (HS), a long-term inflammatory skin disease of the hair follicle, characterised by recurrent, nodules, 'boil-like' lumps or abscesses that can occur in the armpits, groin, perianal area, buttocks or under the breasts, can be extremely difficult to live with and be the cause great suffering.

Dermatology clinics also have the fifth-longest waiting list with **32,574** patients waiting to be seen and routine waiting times of **12-18** months.

Skin disease affects people of all ages and backgrounds. Many people report stigmatisation often based on a mistaken 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 appropriate information, expertise and treatment is not widely available.



Presenting a donation at Eczema Expert: Advice for Life, L-R Derek and Lee Carey, Helen Hadden (ISF) and Lisa Carey.

THE CAREY FAMILY

When my wife and myself and our son Lee attended the 'Eczema Expert' event we found it a very informative day with plenty of people on hand to point us in the right direction on how to deal with Lee's skin. We found the ISF staff very helpful. We got to hear experts speak and ordinary people like ourselves whose children have skin problems. It was great to know we were not on our own and to hear people give little tips that we might not have thought about trying.

The ISF helped us a lot. Thank you again.



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STRATEGY IMPLEMENTATION DURING 2016

Our 2015 annual report laid out our three year strategic plan for the organisation to guide our efforts and to concentrate energies on a work programme to improve quality of life for people with skin conditions, provide guidance on skin disease and to promote skin health.

ISF Helpline

The ISF launched our Helpline in March 2016 to provide support to patients by offering access to accurate information and guidance.

Website and health promotion

Our new website was launched in September 2016 to deliver evidence-based, up-to-date information about skin conditions which has input from Irish patients, dermatology nurses and consultant dermatologists.

Dermatology education

Our first Dermatology Study Day for nurses and pharmacists was successfully held in April 2016 to increase the dermatological knowledge base of those offering first-line skin care advice to the public.

Awareness, events and health promotion campaigns

During 2016 we extended our programme of events and meetings. These included a HS Community Meeting, Eczema Expert: Advice for Life and nationwide Psoriasis Roundtable Meetings. Meetings such as these play an important role in addressing isolation; building community and helping people make potentially life-changing decisions about their own healthcare. We were delighted to partner once again with AbbVie who supported the HS Community Meeting, and the #SaySomething psoriasis campaign (now in its third year), also partnering with La Roche Posay during Eczema Awareness Week and Novartis who partnered with us on the Psoriasis Roundtable Meetings.

Advocacy

The ISF made our first submission to Government in 2016 in which we represented the interests of people living with skin disease, to the newly formed Joint Oireachtas Committee on the Future of Healthcare. This Committee has been tasked with framing an all-party approach to the strategic planning of our health services over the next decade

ISF Councils

During 2016 Advocacy and Psoriasis Councils were established to encourage greater community engagement, and to provide insight and structure towards the attainment of common goals. In the years ahead, 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 input into reports, educational materials, fundraising, and organisation of events.

NICOLA FARRINGTON

I found the Irish Skin Foundation Facebook page after I was diagnosed with HS. It mentioned a Helpline and the first time in my life I was able to openly ask questions to somebody who understood. I spoke to a very friendly and extremely helpful nurse - it was a relief to find support. The ISF raise awareness for me and my fellow suffers. They are doing amazing work and I commend them fully for the hard work they do. Contacting the Helpline helped me come to terms with my condition and to share my story with others and I am forever grateful. It is an important and vital service they provide and it has made a positive change for the better for me. I would 100% recommend it to others..

A YEAR OF ACTIVITIES

2016 was a busy year, working to achieve our aims of providing information, raising awareness and advocacy.

Hidradenitis Suppurativa (HS) Community Meeting

On 30th January, the ISF and the 'Hidradenitis Suppurativa Ireland' Facebook Support group, held the first ever Hidradenitis Suppurativa (HS) Community Meeting for people with HS, their families and supporters. HS is a chronic skin condition and can be both physically and mentally distressing to live with; it affects about 1% of the population. The meeting was addressed by Barry McGrath (HS patient advocate) and Dr Anne-Marie Tobin and was supported by AbbVie.

Psoriasis Council

ISF Board Members, Prof. Brian Kirby and Caroline Irwin chaired the first meeting of the Psoriasis Council providing input on advocacy issues, information booklets for adults and children with psoriasis and the psychological impact of the disease, amongst other issues.

Opening of the ISF Helpline

While the ISF has been assisting people with skin conditions with information and resources since 2013, more resources were clearly needed to meet demand. In March, a dedicated Helpline was formally launched offering guidance from specialist dermatology nurses on a person-to-person appointment basis (call-back model).

General Election 2016

During the run-up to the General Election the ISF encouraged people with eczema and psoriasis to contact or question election candidates on a number of subjects that affect people living with skin conditions, including the

recognition of psoriasis as a longterm illness, the cost of treatments used to manage eczema and local dermatology services.

ISF Dermatology Study Day

The ISF held its first Dermatology Study Day in April in the Ashling Hotel, Dublin. The programme, with six speakers, was aimed at health care professionals with an interest in dermatology and was very well received with over 80 delegates in attendance from all branches of nursing, pharmacy, general practice and even dentistry.



Visit from Australian Ambassador

The ISF's Chairman Prof. Eoin O'Brien was pleased to welcome Dr. Ruth Adler, the Australian Ambassador to Ireland and her husband and dermatologist, Dr. Conrad Goonerage, to discuss sun-protection awareness, skin cancer and dermatology-related problems, common to Ireland and Australia.

Submission to Oireachtas Committee & Advocacy Council

The Future of Healthcare Committee hopes to address the severe pressures on the Irish health service, unacceptable waiting times for public patients. and poor outcomes relative to cost - all issues that affect the dermatology services needed by people with psoriasis, eczema, skin cancer. HS and other skin diseases. The ISF, with the support of members of the Advocacy Council. made our first submission to government to advocate on behalf of people with skin conditions. making 5 main recommendations.

Family Fun Day for Children with Skin Conditions

Each year the ISF invites 30 families who have a child challenged with a skin condition to take part in this fun filled day.

Families travelled from all over the country to participate in a range of activities from arts and crafts, to archery, canoeing, fishing, pony riding, crazy golf and the high ropes course. The Fun Day makes a lasting difference to a child who has felt isolated and alone with their skin condition when they meet other children facing similar challenges to themselves. The ISF is very grateful to GSK / Stiefel for their continued support of the Family Fun Day.

New Website Launched – www.irishskin.ie

With the development of new resources, booklets and the Helpline, we launched a new website in September to improve how we communicate with the public and to provide an easily accessible hub for information and awareness campaigns.



Eczema Awareness Week and Eczema Expert: Advice for Life

During Eczema Awareness Week in September we hosted a weeklong programme of events to raise awareness about eczema. which is estimated to affect up to 1 in 5 children and 1 in 12 adults in Ireland. The week concluded with a free public event entitled Eczema Expert: Advice for Life, to give people advice on how to live a comfortable life with eczema. Guest speakers included Dr Grainne O'Regan, Consultant Paediatric Dermatologist, Ms Annamma Raju, Clinical Nurse Specialist, Tallaght Hospital, and patient advocate Ms Jeannette Brazel. We would like to thank La Roche Posay for their support of the meeting.

ISF Helpline @ the National Ploughing Championships

The ISF brought the largest nurse team yet to our stand at the National Ploughing Championships in Tullamore where we met over 800 people and offered information and support for a range of skin conditions. Of the more than 1,500 exhibitor stands in Tullamore, the ISF stand was profiled as one of only nine 'Top picks' by the Irish Farmers Journal. We would like to thank LEO Pharma for their ongoing support.

#SaySomething about Psoriasis Campaign

For the third year, and to mark World Psoriasis Day, the #SaySomething Campaign this year focused on some of the challenges and stigma that people with psoriasis can encounter in their daily lives. A new microsite provided a hub, where people with psoriasis could access a range of resources, such as practical advice from psychologist Dr Kate Russo who, in a thought-provoking video, offered tips on how to confidently deal with other people's attitudes to your skin. We would like to thank AbbVie for their continued support of this campaign.

Nationwide Psoriasis Roundtable Meetings

In November, the ISF held a series of roundtable meetings for people living with psoriasis - each attended by up to 50 people in Waterford, Galway, Limerick and Athlone. We would like to thank the local consultant dermatologists and dermatology nurse specialists for their expert assistance at the meetings, along with motivational, health and fitness speakers. We are also grateful to Novartis for their support.

Booklets & Publications in 2016

The ISF published the following resources for people with skin conditions during 2016:

- What you need to know about Psoriasis (revised edition)
- What you need to know about your child's Psoriasis

 What you need to know about Eczema





AGNIESZKA WARCIAK

My name is Agnieszka. My son Joseph suffers from eczema since birth. Unfortunately he flared up so badly last year he needed two hospital admissions. The Irish Skin Foundation helped me a lot - firstly to understand more about his condition, secondly I got the opportunity to talk to someone who understands what we are going through.

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ISF HELPLINE

About one third of the Irish population experiences a skin condition each year, yet access to the appropriate information, expertise and treatment is not widely available.

The ISF Helpline provides free, direct, accessible and specialist guidance about skin conditions, delivered by dermatology nurse specialists, on a person-to-person appointment basis.

Following the launch of the Helpline in March 2016, we provided assistance to 684 people with a wide range of inquiries about skin diseases of all kinds, but also in respect of health entitlements, dermatology services, advocacy and general support.

Typically, our nurses spend 30 minutes with an individual caller, once an appointment is made, and will follow up by e-mail or with additional calls where necessary.

During the Helpline's first year of operation, 24% of callers have contacted us about psoriasis. 20% about eczema: however approximately 33% of callers have no formal diagnosis when they first make contact with us.

This last third of callers tend not to have attended a GP (often citing the cost of consultations as a barrier or their long-held feelings of resignation regarding chronic or "embarrassing" conditions) and/or engage in a wide variety of self-treatment behaviours, in many cases for extended periods of time with little effect and frequently at great personal expense.

The ISF Helpline was supported by AbbVie. LEO Pharma. Novartis and Pfizer in 2016.











NATIONAL REGISTRY FOR SKIN DISEASES

The Irish Skin Foundation Registry continues to be developed by the ISF Research Fellow Dmitri Wall. under the guidance of Prof. Alan Irvine, Chairman of the ISF Advisory Board, and with the assistance of Godfrey Fletcher, Business Manager.

Work by the National & International Skin Registry Solutions CLG (NISR) group and their collaborators has recently led to Our Lady's Children's Hospital Crumlin being designated by the Department of Health as a centre of excellence for rare skin disease in Ireland: one of just 3 centres in Ireland so designated across all medical disciplines and sub-disciplines.

The main activities of 2016 have focussed on the development of registry software for the following:

- **Atopic Dermatitis:** Software testing will commence in both Our Lady's Children's Hospital and St James's Hospital once approval is received from the respective IT Departments.
- **Phototherapy:** Data is being extracted from long-term phototherapy databases that belonged to AMNCH and University Hospital Limerick. Dr Anne-Marie Tobin, who is leading this project,

has issued an invitation to the dermatology community to re-form a national phototherapy users group.

Epidermolysis Bullosa: Collaboration with a network of European EB registries, has led to the proposal of a European EB consensus dataset. The product, currently being developed by NISR in association with OpenApp, is developed as both a stand-alone registry and as a means of connecting existing registries.

THANK YOU TO FUNDRAISERS

The ISF is very grateful for the support of donors and fundraisers who support our work. In particular, we would like to thank Jack Breen who completed a Sky Dive, as well as Lee Carey and family.

FOUNDATION PARTNERS

In particular the ISF would like to thank our Foundation Partners for their ongoing support of the charity.









CORPORATE SUPPORTERS

We would like to thank GSK/Steifel for their continuing sponsorship of our Family Fun Day for Children with skin conditions in 2016





We were pleased to partner with La Roche Posay to raise awareness of the challenges of eczema during Eczema Awareness Week, for their assistance with our first Eczema Expert: Advice for Life meeting and for their support in developing our What you need to know about Eczema booklet.

We would like to acknowledge and thank Elave and Bioderma for their support.





The Irish Skin Foundation would also like to acknowledge the support of the following companies in 2016:











































URIAGE

GOVERNANCE

The Irish Skin Foundation is committed to maintaining the highest standards of corporate governance. To provide transparency and ensure we reach the highest standard we have signed up to The Governance Code for Community and Voluntary Organisations in Ireland and are on the 'Adoption Journey' to compliance with the code.² We are also compliant with the ICTR Fundraising Code.³

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: Fully compliant.

FRS 102: Adopted in 2015.

OUR BOARD OF TRUSTEES



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.



Chairman: Eoin O'Brien

Professor O'Brien is a cardiologist and currently Professor of Molecular Pharmacology at the UCD Conway Institute of Biomolecular and Biomedical Research. He is a leading authority in the field of cardiology and especially the pharmacology of blood pressure lowering. He has written a number of books on the history of medicine and recently authored "A Century of Service", which details the history of the City of Dublin Skin and Cancer Hospital.

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Please see www.governancecode.ie

^{3.} Please see www.ictr.ie



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. Jeannette left the ISF Board during 2016 after five years' service.



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.

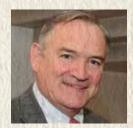
Marina O'Kane

Dr. Marina O'Kane is a consultant dermatologist at Beaumont Hospital and Connolly 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. Patrick left the ISF Board during 2016 after five years' service; Dr Rupert Barry has been nominated to take his place.





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 Planning, 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. Mark left the ISF Board during 2016 after five years' service; the Irish College of General Practitioners is in the process of nominating a candidate.



Brian Kirby

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

FINANCES / STATEMENT OF ACCOUNTS

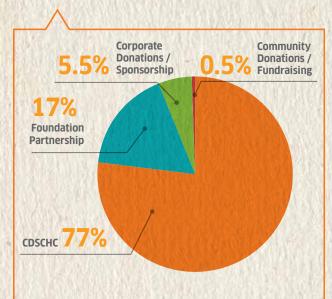
The ISF is grateful for the continued support of the CDSCHC for the greater part of our core funding. We are also very appreciative of the continued support provided by our Foundation Partners and other corporate sponsors. The ISF continues to operate without state funding or significant donations from 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 2016 the Irish Skin Foundation had an income of €684,133 and expenditure of €696,646.

Salary Costs

During 2016 staff costs and salaries were €267,494 or 38% of overall expenditure.

INCOME 2016



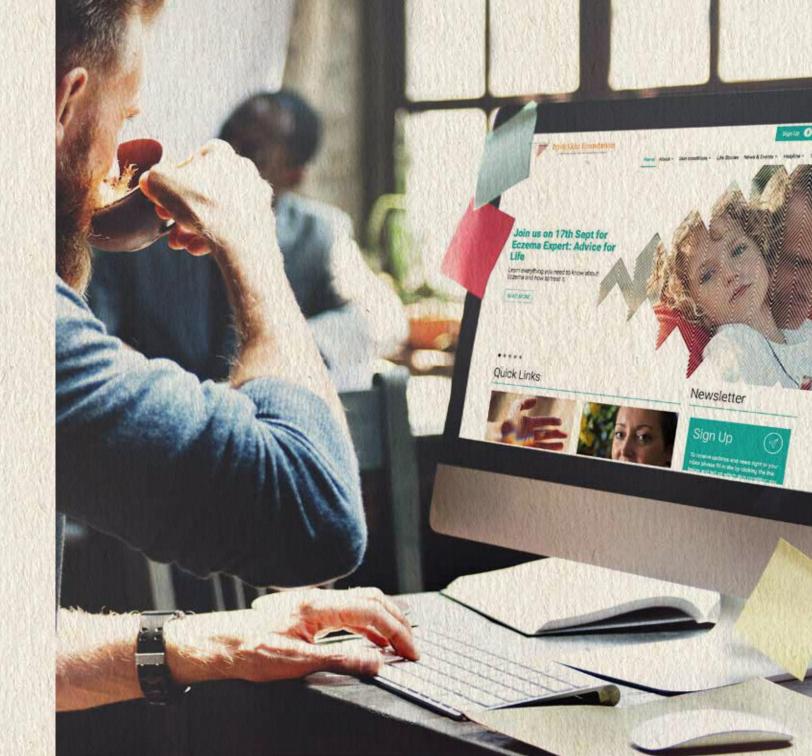
EXPENDITURE 2016





TADGH DOLAN

Psoriasis has changed my life. For the longest time, I viewed that change as negative. Luckily, with resources like the Irish Skin Foundation, I'm now more positive about my Psoriasis and know there is a wealth of people waiting to help.







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September 2017

