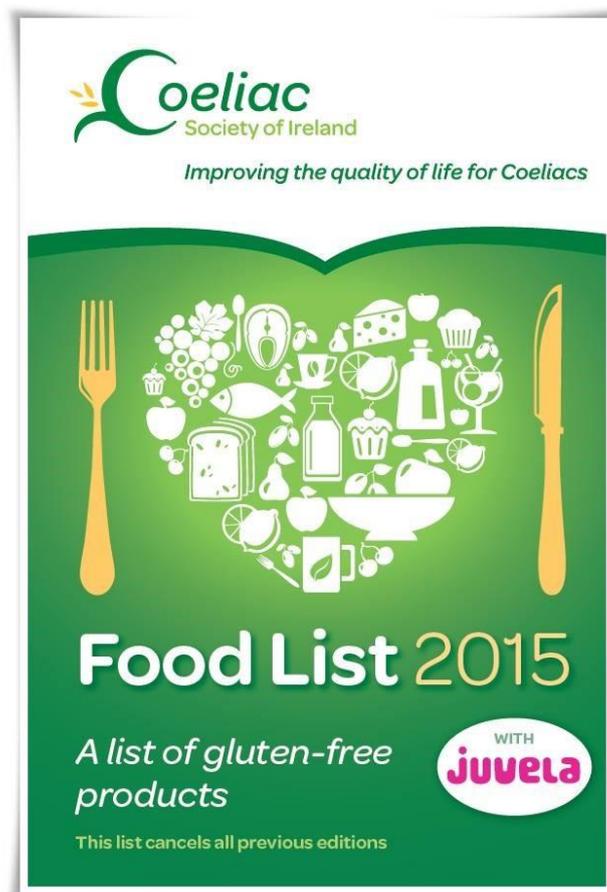




Strategic Plan 2015 – 2018



Executive Summary

This strategic plan sets the societies direction and primary goals for 2015 to 2018:

- To deliver a range of products and service, that enhance the quality of life, for people who require a gluten-free diet for medical reasons
- Increase awareness of coeliac disease
- Increase the profile of the coeliac society of Ireland amongst our key stake holder groups
- Develop a marketing strategy that strengthens the Coeliac Society of Ireland brand
- Develop a clear research strategy
- Strengthen the charities capacity to ensure the appropriate resources in key roles are in place to deliver the core strategy
- Ensure Coeliac Society of Ireland has a clear funding strategy that has both short and medium term funding secured and identified to sustain the core strategy
- Continue to strengthen the focus on governance and regulation, aiming to put Coeliac Society of Ireland at the fore in influencing regulation.



Who we are

Coeliac Society of Ireland is the National registered charity (CHY7484). The Society is the only authoritative source of support and advice for people with coeliac disease and dermatitis herpetiformis in Ireland. We are the trusted source of expertise on coeliac living.

Coeliac disease is an autoimmune disease. The person has a life time incurable reaction to gluten, a protein food in wheat, barley, and rye. Gluten is found in up to 30% of foods in the supermarket. The only medicine is a strict gluten-free diet for life. Upon diagnosis, avoiding gluten can be quite challenging, particularly when eating out of home.

Since 1970, the Coeliac Society of Ireland has provided information and support to people who have coeliac disease throughout Ireland. The charity also raises wider public awareness of the disease. Through our information and support, we help people with coeliac disease to live life to the full.

Mission

Our mission is to improve awareness, detection and management of coeliac disease and related conditions requiring a gluten free diet for medical reasons

Vision

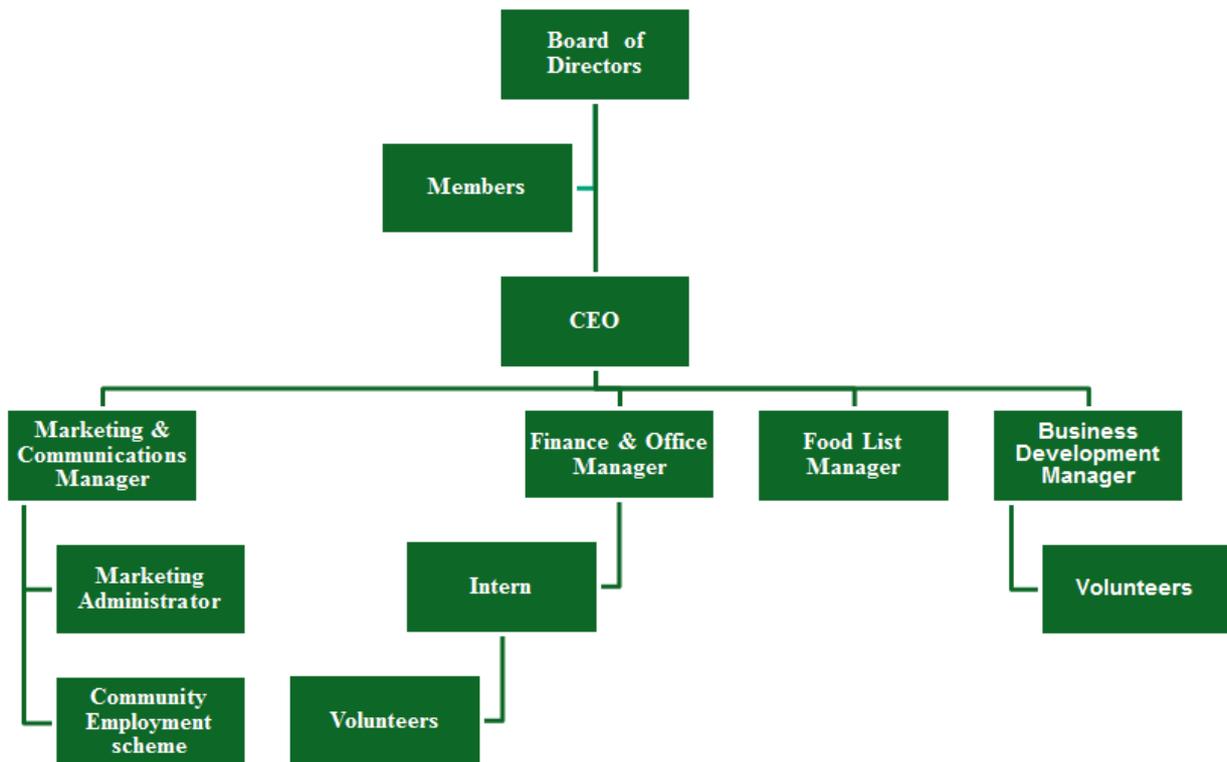
Our vision is to improve the quality of life for people with coeliac disease and other who benefit from a gluten free diet for medical reasons



Aims of the Society

- To provide for the promotion of health, by promoting, safeguarding and protecting the interests of the members of the community, who require a gluten-free diet, for medical reasons
- To advance public education and raise awareness of the nature of coeliac disease, its symptoms, its treatment and the difficulties faced by approximately 1% of the Irish population estimated to be coeliac.
- To improve the quality of life for coeliacs, those with DH (dermatitis herpetiformis) or gluten intolerance and those who must adhere for medical reasons to a strict gluten-free diet for life.
- To ensure that all coeliacs have the dietary and medical information and peer support to live life to the full with their disease.
- To help those on a gluten-free diet for medical reasons to make the transition from a normal diet through support and information.
- To provide information about the suitability of certain manufactured products for a gluten-free diet.
- To present the concerns of coeliacs on a national level through meetings with an array of relevant bodies
- To present the concerns of coeliacs at a European level by being an active member of the European Association of Coeliac Societies (AOECS). AOECS has observer status at the Codex Alimentarius Commission that sets International food standards.
- To keep the members and coeliac community up to date with new developments in medical research on coeliac disease and any changes in legislation in areas such as food labelling.
- To raise awareness of the disease within relevant industries e.g. catering and hospitality industry.

Organisational Structure



The Board

The board of directors consists of eleven voluntary directors. Demographic diversity is within the board. The directors come from regions across Ireland. A range of professional skills are represented; identified to enhance the charities strategic and operational capabilities. The majority of the directors have personal or professional experience of coeliac disease.

The voluntary board of directors are responsible for the charities strategic vision and is accountable to the members at the Annual General Meeting. They provide long term focus for the society with powers and responsibilities clearly set out in the Articles and Memorandum of Association (last updated March 2013). The CEO manages all operational aspects of the charities work.

Honorary President of the society is Professor Nicholas Kennedy. Professor Kennedy is a medical academic at Trinity College Dublin (since 1984) with particular interest in nutrition and in coeliac disease. He runs the multi-disciplinary outpatient clinic at St James's Hospital (Dublin) for patients with coeliac disease (since 1995). He provides medical advice to the society.

The Staff

There are 6 full time paid staff members of the Coeliac Society. Administrative support is provided by 4 community employment staff, interns via job-bridge and relevant college programmes and also by trained volunteers.

Sinéad Stone, clinical nutritionist provides dietary advice to the society in relation to gluten free products and healthy eating.

Community support

There are presently 14 community based support groups around Ireland. Dedicated volunteers provide their time and personal experience of coeliac disease, to deliver community services such as local events. These events help to raise awareness and also help us to reach vulnerable and isolated people with coeliac disease in their communities. This is an invaluable part of our services, reaching people when they are newly diagnosed, liaising with anxious parents as they learn to cope with their child's diagnosis and also assisting those already diagnosed to maintain their diet, to prevent associated diseases such as osteoporosis and diabetes type 1.

Funding

The Society is 77% self-funded. Funds are generated through membership fees, events, the sale of merchandise, and charitable donations. We are grateful for 23% funding from the HSE. Operating income during 2013 was €356,768, with costs of €367,911.

Coeliac Society of Ireland's Work

We provide:

- Information on coeliac disease and dermatitis herpetiformis
- Information on gluten-free food
- Opportunities for members to meet and to share experiences
- A campaigning voice for coeliacs to the government, health professionals, the food and hospitality industry and the general public.

The Society has over 6,000 members of all ages who have joined us from all over Ireland. Members are not just limited to coeliacs. Membership also includes:

- Those on gluten-free diets for related conditions and other health reasons
- Family members
- Health professionals (GPs, hospital physicians, health nurses, dieticians, pharmacists)
- Those involved in gluten-free businesses (manufacturers, retailers and hospitality including restaurants, cafés, caterers)
- Those involved in gluten-free food provision (hospitals and care homes, schools, work canteens).

Information:

- All new members receive an information pack produced by the Coeliac Society containing the following:
 - Annual food list book: the only comprehensive list of gluten-free products in Ireland
 - Coeliac Ireland: Coeliac magazine distributed twice yearly
 - Coeliac Handbook: general medical information on coeliac disease and other related conditions
 - Information leaflets: including information on Osteoporosis
 - Information tailored for children
- Cookery books titled '*Gluten Free All-Sorts*' and also '*Coeliac Cuisine*' with hundreds of tried and tested tasty recipes for coeliacs and information on suitable non-contaminated natural flours for gluten free cooking.
- Catering & foodservice manual to assist those working in the catering and hospitality industry to understand, source and prepare suitable foods the gluten free diet.
- Restaurant List of over 600 venues throughout Ireland, who are preparing foods without gluten containing ingredients. This is a unique list created by recommendations received by Coeliac Society of Ireland members.

- Travel Information: *'Eating Out'* language cards. The cards are available in a variety of languages. We also provide information on the availability of gluten-free products in other countries.
- Seasonal gluten-free goodie lists for Christmas, Easter and Halloween. These times of year are food centric.
- News and information through www.coeliac.ie plus a monthly *'Coeliac News Online'* email

Services:

- Email and phone support for members and all those who benefit from a gluten free diet and have an interest in coeliac disease.
- Provide a link between members and manufacturers of gluten free products
- Work closely with food industry to improve existing and provide new gluten free products on the Irish market and distribution to food stores.
- Advice for new companies introducing GF products into the Irish market in areas of sourcing of ingredients, labelling, cross contamination issues, product testing etc.
- Catering & Foodservice Manual to assist those working in the catering and hospitality industries in coping with the gluten free diet.
- Events at national and branch level, including cookery demonstrations, presentations by medical experts and Food Fairs

Beneficiaries of our services

Coeliac Society of Ireland serves people with:

- Coeliac Disease
- Dermatitis Herpetiformis
- Those who have been medically diagnosed to benefit from a Gluten Free Diet

The gluten free diet may be recommended for the following situations:

- Non-coeliac Gluten Intolerance (NCGI)
- Wheat Intolerance
- Osteoporosis
- Lupus
- Autism
- Multiple Sclerosis

Requests for information from the Coeliac Society are made by:

Parents and families of those affected

Industry and food providers:

Catering and Hospitality: Chefs, waiting staff in hotels and restaurants, hospital catering staff

Supermarkets

Primary and Secondary Schools

School Training Colleges

Food and Drink Producers

Medical Personnel: Primary care and hospital based

General practitioners

Hospitals

Dietitian

Community Care Workers

Pharmacists

Dentists

Nurses

Nursing home staff

Values

Coeliac Society of Ireland is a charity founded by people with coeliac disease, for people with coeliac disease. This ethos remains. We work passionately to improve quality of life for all people affected by coeliac disease in Ireland.

Diagnosis

We aspire that a guideline for the diagnosis and management of coeliac be created and implemented in Ireland. This would result in increased recognition of symptoms by frontline medical professionals, leading to quicker diagnosis and improved patient care, after diagnosis.

Shopping made easier

We aspire for wider range, availability, improved pricing and labelling of gluten free produce. This would result in improved nutrition and improved adherence to a gluten-free diet and reduction in preventable associated diseases.

Eating out

Gluten free options being readily available on every menu – the mainstream rather than the exception.

Background

Considerable environmental change has occurred since the development of Coeliac Society of Ireland's strategic plan 2009 - 2014:

- Increased regulation of the charitable sector with the adoption of the Governance code and implementation of a Charity Regulator
- Changes to company law
- Economic downturn, reducing both state investment to charities but also the contributions from corporate and private donors
- Increased competition for funding from within our sector through state and foundation sources
- Legislative change directly affected supports to coeliacs, such as the cessation of supports under the general medical card scheme (October 2012) and new entrants to the diet supplement (February 2014). What about the DCSS?
- Positive legislative change such as the extension to declare food allergens on pre-packed foods to include non-pre-packed food (December 2014)
- People adopting a gluten-free diet without diagnosis, which in part maybe due to the difficult and protracted journey many of our members have experienced to gain a definitive diagnosis or negatively celebrity diet culture leading to misinformation regarding coeliac disease
- Increased information about coeliac living online, many with unreliable sources
- Increased gluten-free product supply by large retailers, while price and availability in non-urban areas continues to be a challenge

In light of the considerable environmental changes taking place, Coeliac Society of Ireland's board and CEO elected to develop a three year strategic plan.

The 2009 - 2014 plan set out five primary goals:

1. enhancement of product and services
2. improved communications
3. greater awareness of coeliac disease
4. increased administration efficiency within our operations
5. identifying and developing funding sources

Considerable inroads and achievements were made across all areas of the strategy.

Working to best practise standards, the board began adoption of the Governance Code for charitable organisations and took a leadership position in moving to managing the strategic direction of the charity. In November 2012, the charity's first CEO was appointed, which has served to enhance the pace and efficiency at which the strategic plan could be implemented effectively.

Our goals for product and service enhancement, improved communication of our work's benefit, greater disease awareness, efficiency and sustainability still remain. The 2015 - 2018 Strategy builds upon the achievements made in 2009 - 2014, while also enhancing our ability to be more pro-active in our approach and prepared for environmental change.

Developing this Strategy: An inclusive process

The board began developing this Strategy in March 2014. Following a dedicated planning day by board members, a facilitated half day meeting was then held with staff in May 2014. Inputs were sought from members through our Autumn magazine. All feedback was collated. A further one day facilitated board meeting took place in January 2015 to finalise the three year strategy.

Strategic Goals

Goal 1

To deliver a range of products and service, that enhance the quality of life, for people who require a gluten-free diet for medical reasons

- Increase and Improve our insights from members
- Database enhancement
- Further our relationship with AO ECS member countries, learning from their experience
- Pro-active marketing of the Society and the benefits of our work
- Improve our communications both internally and externally
- Increase awareness of our brand
- Re-develop our website
- Increase digital capabilities
- Work collaboratively with the HSE to strengthen our relationship
- Increase our community supports
- Diversify our membership for relevant audiences
- Develop retention products for existing members
- Distribute disease self management techniques literature to members

Goal 2

Increase awareness of coeliac disease and increase the profile of the coeliac society of Ireland amongst our key stake holder groups

- Progress our advocacy work
- Develop a media relations plan
- Develop communications plans to coincide with annual events e.g. Awareness week
- Existing products: upgrade
- Develop content plans for social media
- Develop annual communications plans for key stake holder groups

Goal 3

Develop a marketing strategy that strengthens the Coeliac Society of Ireland brand

- Identify key markets and produce plans to communicate with each market
- Develop membership recruitment and retention plans, to achieve growth
- Increase our use of focus groups
- Increase of engagement via social media
- Increase our promotion of the benefits of membership
- Continue to develop our relationships with corporate partners
- Revise membership offering with a focus on enhancing membership experience
- Develop internal communications plan to synchronise our processes and service delivery

Goal 4

Develop a clear research strategy

- Set out Coeliac Society of Ireland's approach to research

Goal 5

Strengthen the charities capacity to ensure the appropriate resources in key roles are in place to deliver the core strategy

- Policy and procedure review and development
- Develop a succession planning strategy
- Workforce planning
- Introduce service quality appraisal
- Improve IT and telephony
- Provide training in telephone techniques, communications and IT
- Improve helpline services
- Create an implementation plan for support group development

Goal 6

Ensure Coeliac Society of Ireland has a clear funding strategy that has both short and medium term funding secured and identified to sustain the core strategy

- Enhance our relationship with core funders
- Devise and implement new products for key stakeholder groups
- Commission research with AO ECS countries

Goal 7

Continue to strengthen the focus on governance and regulation, aiming to put Coeliac Society of Ireland at the fore in influencing regulation.

- Review policies, procedures and reporting mechanisms to ensure compliance with all relevant legal and regulatory requirements
- Ensure board, committees, staff and volunteer understand their role, responsibilities and legal duties for decision making
- Achieve SORP compliance

Thank-you

To our members - your continued and invaluable support enables our work

To our staff - for going the extra mile to implement our vision and to serve our members daily

To our volunteers - for being the community face of Coeliac Society of Ireland and providing vital community services

Front-line medical professionals - for directing patients to our service upon diagnosis

Gluten-free manufacturing companies - for your innovation on behalf of our community

Gluten-free food providers - for listening attentively to the needs of coeliacs, for sourcing, preparing and continuing to innovative in food preparation while abiding by legislation

Health Services Executive - for your collaborative and partnership approach to work on behalf of all people affected by coeliac disease

State and representative bodies - Food Safety Authority, Safefood, Restaurant Association of Ireland, Hotel Federation of Ireland, for collaborative working to deliver improved information, awareness and services for coeliacs

Carmichael Centre for Voluntary Groups - Coeliac Societies home; an inspiring charity village from which to operate