

## Coeliac UK Strategy - the next 10 years

### 1. Your growing community

- 1.1 More people than ever before are being diagnosed with coeliac disease and dermatitis herpetiformis (DH). For many of you the journey to diagnosis has been tough and getting the diagnosis is a relief. For others, coping with a lifelong gluten-free diet is a daily struggle.
- 1.2 Coeliac UK has been here to support you for the last 40 years: providing advice and a sympathetic ear, funding research to improve your long-term options and, increasingly, campaigning for better healthcare and more food options for real change in your everyday life.

### 2. What we have done...

- 2.1 In 2010 we completed the latest of our long term plans. The plan was ambitious. We wanted to:
  - improve our support for you with more and better quality services
  - increase the numbers diagnosed by 50% and the adoption of high healthcare standards throughout the UK
  - target manufacturers to increase the range of foods which are gluten-free
  - improve awareness and expertise in gluten-free catering
  - provide resources for high quality research
  - and deliver value for money as a Charity.

#### 2.2 And much has been achieved...

We estimate the numbers of people diagnosed with coeliac disease increased by 44% between 2007 and 2009 – not far short of the ambitious target we set ourselves. Our development of an evidence base to support the need for national guidance on coeliac disease, finally delivered the NICE guideline on recognition and diagnosis of coeliac disease in 2009.

- 2.3 We can all see more, and better, products hitting the supermarkets' shelves in recent years. Between 2004 and 2009, the value of the gluten-free market in the UK doubled to £93 million. It is forecast to grow again to £152 million by 2014, second only to the US market. What's more the UK

- market appears particularly innovative. More new products have been launched in the last three years in the UK than anywhere else in Europe. In 2009 135 new products were launched in the UK while its nearest competitor, Spain, launched 98. We believe that the vibrancy of the UK market is due in some part to the work of the Charity, working to drive up diagnosis to produce more consumers and working with the industry to make the business case for investment.
- 2.4 Tackling the catering sector has proved a particular challenge. The sector is diverse and very fragmented, making it difficult to influence. Nevertheless, the Charity has established constructive partnerships with all the main representative bodies creating awareness and improvement in some areas. For example in the last two years, the Charity has worked with the Institute of Hospitality, the British Hospitality Association, the Craft Guild of Chefs and major catering companies such as 3663 and Sodexo. In 2010 we launched a joint venture with Springboard, the catering education charity, to provide catering colleges with specially designed interactive online training material – this will be the first in a series of tools for professional development in the catering industry.
- 2.5 Between 2007 and 2009, the Charity committed £528,000 to research making us the single biggest investor in research on coeliac disease in the UK. The results of our investment in recent years are influential in the development of potential new therapies and understanding of the condition.
3. What next?
- 3.1 *Still missing...*  
But there is still more to do. We know there are still more people without a diagnosis than with one. We must keep the pressure up and this work will remain an important goal for the Charity.
- 3.2 Consistent management of the condition by GPs and others is still elusive resulting in poor quality of life and frustration for too many.
- 3.3 *Making shopping easier...*  
The Charity's Food and Drink Directory is still an invaluable source of information. But wouldn't it be better if you could look at the product on the shelf and see instantly if it is right for you? The introduction of new laws give us an opportunity to press for more manufacturers to use clear labelling. Where labelling on the packaging is not used, solutions should be available to you, taking advantage of new technologies such as mobile barcode scanning equipment.

3.4 *A gluten-free meal on every menu...*

While more restaurants than ever before are aware of gluten-free catering, it is by no means the majority. And food on the go is a particular challenge. The issue of stress-free eating out remains top of the wish list for our Members.

3.5 *More options long-term...*

Helped by the generosity of our Members and supporters, Coeliac UK is funding research in medicine and food technology which may provide alternative options in the future. Work on describing the genes that cause the condition will help us understand the precise mechanisms involved in the immune response. Work on understanding which fragments of gluten are toxic may lead to vaccinations or non toxic wheat. In the last three years, clinical trials on possible therapies have begun for the first time. But we are still many years away from solutions available to all and further investment will be needed.

4. The world around us is changing...

4.1 As we write this strategy, the fragile state of the economy is at the forefront of everybody's mind. The impact of a reduction in public spending on services is likely to be felt for at least the next five years. What will the impact be on the Charity's work? Will the rate of diagnosis slow? Will the quality of care diminish?

4.2 *From the doctor's care to self care*

There is a long term trend in healthcare to move away from doctor-led care to self care where the patient uses a growing number of information sources, of which the healthcare professional is just one. Financial pressures are likely to accelerate this trend.

4.3 The number of free information sources on coeliac disease is expanding rapidly. NHS Choices, Netdoctor, food manufacturers and retailers and even the BBC, all have web pages about the condition, diagnosis and the gluten-free diet.

4.4 So what role should the Charity play in providing information over the next ten years? Do we even have one? Another key trend across the world may provide us with an answer. In a world awash with information how can you make sense of it and who can you trust? The health consumer is seeking simple choices from trusted sources.

4.5 *Whose shoulder to cry on?*

One of the great strengths of the Charity has been the support it can provide to Members at meetings, in Local Voluntary Support Groups or through our Helpline. The internet's strength is its ability to put people with a common interest in touch with each other. On Facebook there are 204 coeliac groups alone with over 11,000 people following one London based group.

4.6 So what's our role? Are others better placed to provide that community of support?

4.7 *Make mine a skinny decaf latte with a twist of nutmeg on top*

Changing consumer values are affecting services provided by not for profit organisations just as much as global brands. A one size fits all approach to service provision is not an acceptable standard any more, even for a charity. Knowing something is gluten-free might not be enough for me. I may want to know it is gluten-free, lactose-free and vegetarian. Providing more personalised information will become necessary for the Charity to remain relevant to people but it will come at a cost.

4.8 *The future is digital*

Digital technology is not just for the geeks any more. The rise and rise of the mobile phone means that just about everyone will have access to the internet and useful online tools whilst out and about. The ability to access a food directory from your mobile phone already exists and our own Food and Drink Directory will be available in such a format in 2012.

4.9 *The international dimension*

The Charity is increasingly operating in an international arena. Labelling laws are set in Europe. Cooperation between coeliac societies across Europe is helping create more awareness and more consumer power.

4.10 *Devolution*

Devolution in the UK is ten years old. Few would have predicted how the move to devolved institutions would have established itself so deeply and the drive to devolve more powers to Scotland, Wales and Northern Ireland is growing. But this presents a real challenge for the Charity, fragmenting and increasing the number of decision makers we need to talk to, to make sure your needs are addressed throughout the UK.

5. The next ten years for Coeliac UK

5.1 We have taken a good look at what we have achieved and what we stand for. Looking forward there is still much the Charity needs to do on your behalf. Our vision and mission is as relevant today as it was at the beginning of this millennium.

5.2 Our vision

To see:

- a world full of choice for people with coeliac disease and DH
- and, eventually, a world free of the condition.

5.3 Our mission

To improve the lives of people with coeliac disease and DH.

5.4 Our work

We will achieve this by:

- providing independent and expert information and support
- campaigning for better access to diagnosis and care, and better access to food in and out of the home
- researching the nature of the disease and potential cures
- developing as a charity which works productively and effectively.

5.5 Our values

Our work will be informed by our values.

We will be:

- caring and supportive
- professional and expert
- independent and honest
- ethical and responsible
- dynamic and innovative.

6. Our aims for the next ten years

6.1 You have told us your priorities remain the same. You said the following priorities were 'very important':

- influencing the food industry 88%
- medical research 79%
- providing information to Members 60%
- influencing the Health Service 66%
- training the food sector 67%

Quote from the membership survey...

*“Coeliac UK was a lifeline to me when I was at a very low ebb. Thank you for help and real support via Crossed Grain magazine and Food and Drink Directory.”*

*“I have found the Food and Drink Directory a great help, never go anywhere without it! Crossed Grain magazine is also a great help, with lots of useful information and recipes, I try them all. Whenever I ring the Helpline, I have found them very helpful and even ask if there is anything else they could help me with. Many thanks for all the good work you are doing and the support you give.”*

And so, our six aims remain the same. But, we want to achieve even more ambitious outcomes and thus this strategic plan will cover a ten year period to accommodate the nature of challenges ahead.

## 7 Providing valuable information and support

- 7.1 The Charity provides valuable ongoing support and advice that cannot be easily obtained elsewhere and is seen as independent and credible. Over the last five years we developed increasingly sophisticated services which can be accessed online, by phone or on paper. Information on the right foods to eat remains a core service. What can I eat? What products can I find in shops? Where can I eat out? Even before people are properly diagnosed we provide support and advice. Being able to provide you with the latest information on health and management of coeliac disease is also important.
- 7.2 But over the long term the Charity believes that as far as possible the food sector and health service should change the way they work so that your needs are met in your everyday life. This means the nature of our service will change as improvements elsewhere take place.

7.3 In the meantime, the Charity will continue to take advantage of its own developing expertise and new technologies to provide you with services you value.

7.4 Our aim for the next ten years

We will maintain our position as the authoritative source of support and advice for people with coeliac disease and DH in UK and deliver valued services.

7.5 2020 Objectives

- We will ensure our services meet need by identifying the differing requirements of established and newly diagnosed people with coeliac disease, young and old and with differing ethnic backgrounds - using information gathered by new Membership forums, annual surveys and other data analysis to create a new service plan.
- We will use digital technologies to develop tools to choose foods and restaurants right for your diet when out and about.
- We will ensure our advice and information is of the highest standard by gaining formal recognition for its quality with accreditation from independent bodies.
- We will make Membership more inclusive by extending access to all those who support the Charity's core mission: with diagnosis or seeking diagnosis, friends and family, carers and supporters.

8. Improving health

8.1 The Charity has successfully influenced improvements in diagnosis and care of the condition. Working with Members, we used publicity and campaigning to put coeliac disease on the agenda of clinical leaders and healthcare policymakers. The challenge ahead lies in influencing decision makers in the NHS to create changes in practice throughout the Health Service in the UK.

8.2 But, we are experiencing a time of exceptional change within the Health Service which will present the Charity with new opportunities as well as potential threats. We will need to demonstrate how good healthcare is associated with improved quality of life, less ill-health for patients and more

cost effective use of Health Service resources. We will also have to respond to the challenges of self-diagnosis and self care.

### 8.3 Our aim for the next ten years

We want to see an accelerated rate of diagnosis and uniformly high quality care and management of coeliac disease and DH.

### 8.4 2020 Objectives

- We will work with healthcare professionals to see two thirds of people with coeliac disease and DH diagnosed and the average length of time taken for patients to be diagnosed halved.
- We will also work to see the percentage of those individuals first misdiagnosed with Irritable Bowel Syndrome reduced by 50%.
- We will establish recognised standards of care by working with national standards bodies.
- We will seek to ensure healthcare providers are achieving a minimum 90% of the recognised management standards by advising commissioners on appropriate services including prescriptions.
- To support our work influencing healthcare professionals we will extend our networks particularly into primary care as an authoritative source of information on the condition – providing online information and education.
- We will support the increasing emphasis on self care working with healthcare professionals and patients to make sure none are left behind.

## 9. Better food, found more easily

9.1 Undoubtedly, the quantity and quality of food found in shops has improved beyond all recognition over the last five years but there is still some way to go. The Charity has been successful in making the case to retailers that the demand is there to support the development of specialist gluten-free ranges and we see no reason why this will not continue. However, there is still a need to persuade producers and retailers that they should invest in making mainstream foods available to consumers with coeliac disease. This task has

been complicated by new laws on labelling making the standards for a gluten-free label tougher.

9.2 Our focus for the next ten years will be to ensure that choice in the mainstream market does not diminish and it becomes easier than ever before to select foods right for your diet. Our task will be made easier with more consumers and the drive to diagnosis will be just as important in securing this aim.

9.3 Our aim for the next ten years

We will improve access to a wider range of good quality products for people with coeliac disease and DH.

9.4 Our 2020 objectives

- We will work with retailers to see that specialist gluten-free products are made available in every leading supermarket regardless of size or location.
- We will work with manufacturers to ensure nutritional standards in gluten-free foods are at least as good as those in their gluten-containing equivalents.
- We will increase the number of manufacturers carrying the Crossed Grain symbol across Europe and increase the number of mainstream products in the UK identifiable as gluten-free.
- We will work with the industry to introduce the 'no gluten-containing ingredients' statement in a consistent and helpful way.

10. Good food on the menu

10.1 Eating out remains the biggest challenge for the consumer with coeliac disease. We still have a long way to go in making the case for change in the food service sector. This task has been made more complex by the introduction of new laws around labelling food in this sector. The first priority for our work in this area must be to persuade key providers to invest in change as we have successfully done in healthcare and retail.

- 10.2 We will need to secure changes by providing support to the industry in training and advice on catering practices.
- 10.3 Lastly, we will need to underpin the success of the change by encouraging demand providing consumers with easy-to-access venue guides and clear information on menus on selecting the right food for you.
- 10.4 Just as in improving foods available in retail outlets, our task will be made easier with more consumers and the drive to diagnosis will be important in securing this aim.
- 10.5 Our aim for the next ten years...

We want more gluten free choice on more menus so we can eat out with confidence and pleasure

#### 10.6 2020 Objectives

- We will target the UK's top high street restaurant chains to persuade them to routinely include gluten-free choices for consumers with coeliac disease.
- We will develop appropriate support and training material, based on research, to help caterers provide menu options within the law on labelling and support a range of catering training courses for the industry.
- We will achieve uniform provision of gluten-free catering in institutions such as hospitals, care homes and prisons where there is no choice in what to eat.
- We will help the food service sector promote their offer to consumers with coeliac disease by agreeing with the industry a standard notation for their menus and lobby for its routine use.
- We will promote the cause of catering for people with coeliac disease and encourage good practice using established catering competitions with top venue guides routinely commenting on availability of gluten-free options.

#### 11. Research which supports our aims

- 11.1 The Charity has invested significant funds into medical research in the last five years. However, such research is increasingly expensive and often demands multinational teams. It is unlikely we will be able to continue to

support research that makes a significant impact for the condition as a whole on our own and we will need to collaborate with others to pool our resources.

11.2 But money for research is not the only way the Charity can help. As the largest register of patients with the condition in the UK, the Charity's Membership is a great resource for the research community. What is more the Charity's own staff are an important source of expertise and they increasingly becoming involved as active members of research teams.

11.3 Finally, the Charity itself needs specific research to back up its work in providing advice and support as well as in influencing the food and health sectors.

11.4 Our aim for the next ten years...

We want to see funds for research related to the coeliac condition used more effectively and to build a stronger evidence base supporting the work of the Charity.

11.5 2020 Objectives

- We will develop international research networks to extend our research portfolio using links with European and global research partners, for example CD medics, AO ECS and Coeliac UK grantholders to secure partnerships.
- We will take a leading role in advocating the creation of an international research fund which will fund research into greater understanding of the diverse nature of the disease and effective management solutions.
- We will review allocation of research funding by the Charity to ensure that research supports the key evidence gaps in promoting better healthcare and food options whilst achieving value for money.
- We will continue to commit at least 5% of the Charity's income to supporting research of all kinds.

12. Charity infrastructure to support delivery

12.1 The Charity wants to achieve ambitious change in the food and health sectors which will require significant investment. At the same time as this change is achieved, the nature of our relationship with our core Membership

base is likely to evolve. We will need to consider how our different income streams can reflect those changes and provide the resources we need to carry out our work.

12.2 Whatever the future for the Charity, in terms of our relationship with our beneficiaries, our core purpose of improving the lives of people with coeliac disease and DH will remain the same.

12.3 Our aim for the next ten years...

We shall make sure the Charity's resources are in line with the strategic direction of the organisation and provide value for money.

12.4 2020 Objectives

- We will invest in the unique expertise of the Charity with a view to growing our business development capacity alongside business opportunities which will be reinvested to support the Charity.
- We will develop our capacity to make best use of digital technologies for service and business development opportunities.
- We will ensure we maximise our knowledge internally by developing infrastructure and processes to manage knowledge in support of all staff.
- The Charity will develop its volunteering programme, engaging a minimum of 5% of Members through a range of opportunities, achieving growth in Membership support, fundraising efforts and lobbying at every level.
- We will deliver efficient and effective services and maximise our resources by developing staff using external benchmarks wherever we can.
- We shall review our resources associated with devolved institutions reflecting the Charity's strategic need and value for money.

Join us and join in