



Hellenic  
Coeliac  
Foundation

Latest News and Views from  
the UK

20 June 2009

Amy Peterson  
Coeliac UK

**1<sup>st</sup> South European  
Coeliac Disease  
Meeting**



Σάββατο 20 Ιουνίου 2009

## Agenda

- Coeliac UK
  - Who are we?
  - What do we do?
  
- Gluten-free living
  - Food labels
  - Codex standard
  
- The future
  
- Questions



## History of Coeliac UK, Part I

### ➤ Pre-1968

- Elizabeth Seagal's son diagnosed
- Low awareness among HCPs
- Lack of gluten-free provisions from manufacturers



### ➤ 1968-1976

- Elizabeth and Peter Benenson co-founded the “Coeliac Society”
- Lobbied Parliament for items on prescription
- Catering guide
- 75 → 12,000 Members!!!
- Launch of gluten-free symbol
- Group Organisers' Day Conference



## History of Coeliac UK, Part II

### ➤ 1982-1998

- Introduction of Membership database on computer
- Registration of gluten-free symbol completed
- Coeliac cookbook launched
- Crossed Grain magazine sent to 35,000 Members and 1,400 HCPs

### 1998-present

- Website launched
- Full-time dietitian joins staff
- Name changed from Coeliac Society to Coeliac UK
- 22 full-time staff
- Crossed Grain registered trademark



## Present situation

- ~1000 new Members per month
- Participation in:
  - AOECS
  - CD MEDICS
  - BSG
  - NICE guideline
  - GASTRO 2009
  - International conferences (Iran!)
- Working with food sector
- Petitioning government
- Health Advisory Council and Network
- Facebook group (2,000 members)
- 96 local groups
- ~900 calls and email enquiries per month to Diet and Health team



# Campaigns





**Are you 1 in 100?**

Bloating? Tiredness? Anaemia?  
Or perhaps you suffer from Weight-loss? Diarrhoea? Depression?

If so, you might have coeliac disease.

Coeliac disease can affect anyone, of any age.  
Left untreated it can lead to osteoporosis or bowel cancer.

1 in 100 of us have coeliac disease but 4 out of 5 people don't know they have it.  
If you think you might be 1 in 100, ask your GP to help you find out.

For more information call the Coeliac UK Helpline: **0870 444 8804**  
or visit our web site: [www.coeliacuk.org.uk](http://www.coeliacuk.org.uk)

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Registered office: Coeliac UK, Suite A-9, Claxton Court, High Wycombe, Bucks HP11 2JG.  
Telephone: 01494 437278. Fax: 01494 424549. [www.coeliac.org.uk](http://www.coeliac.org.uk)



- Recognition
  - Healthcare professionals (mostly RDs) and management
  - New NICE guideline (GPs)
- Access to gluten-free foods
  - Prescriptions
  - Specialty substitute products
- Eating out
  - Catering training module
  - Hospital catering
- Research
  - Genetic profile
  - Risk of breast cancer
  - Cholesterol
  - Vaccine
  - Enzymes



## Support for Members

- Welcome pack and publications
- Crossed Grain magazine – news and recipes
- Food and Drink Directory
- Helpline
- Website
- Venue Guide
- Recipe Database



## What can I eat?

### Gluten-free

- Fruit and vegetables
- Meat, fish & poultry
- Eggs, milk, cream, cheese, yoghurt
- Rice, lentils, pulses & beans, corn, soya, potatoes
- Polenta, tapioca, sago
- Butters, margarines & oils
- Nuts & seeds
- Herbs & spices
- Wine, cider & spirits

## What should I avoid?

### Contain gluten

- Bread & rolls
- Pasta & wheat noodles
- Cakes & Biscuits
- Pizza & pizza bases
- Muesli & wheat-based breakfast cereals
- Cous cous & semolina
- Beers, lager & stout
- Soy sauce





## What else can I eat on a gluten-free diet?

- Substitute products eg gluten-free bread (on prescription or FREEFROM)
- Naturally gluten-free foods (unprocessed) eg meat, fish, milk, cheese, fruit, pulses and vegetables
- Mainstream processed foods that may be suitable on a gluten-free diet (eg cooking sauces, ready meals, soups, stock cubes)



## Frequent enquiries on Coeliac UK's Helpline

- HOW TO GET DIAGNOSED!!
- breakfast cereals (barley malt extract)
- confectionery products
- gravy
- eating out
- travel
- cross-contamination



## Processed food and drinks

- Food and Drink Directory produced annually
- Launched online Directory in 2008
- Updated monthly
- Lists over 11,000 products
- Information on labelling
- Crossed Grain symbol



# How the Coeliac UK Food and Drink Directory is produced

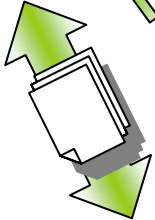
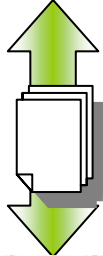
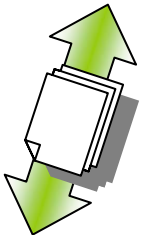


**Coeliac UK Food and Drink Advisers**  
 Correspondence sent requesting product lists in September and data returned in October



Directory distributed in January to:

- Coeliac UK Members
- Healthcare professionals
- Directory contributors
- All data are refreshed on an annual basis and updated in an on-going way with production of monthly updates



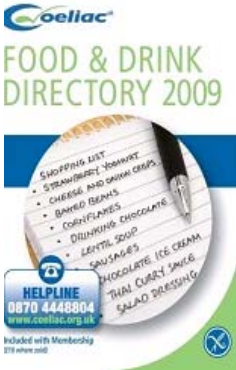
Mainstream food manufacturers

Specialty food manufacturers

Retailers' technical advisers

Discussions about factory environment, production line management, test values and quality control procedures

- Lists reviewed by advisers
- Confirmation of product suitability for inclusion in the FDD
  - Naturally gluten-free foods removed
- Data entered into database by Food and Drink Advisers in dialogue with manufacturers and retailers



Print Directory created from electronic database

# Allergen labelling Directive 2003/89EC

*All gluten-containing grains have to be in ingredients list*

**Added ingredients:**  
Strawberries (6%), Bananas (4%).  
raw cane sugar, modified maize starch

**Allergy advice:**  
May contain nut traces

Nutrition information	
Typical values per 100g	
Energy	245 kJ/58kcal
Protein	4.6g
Carbohydrate	7.2g
of which sugars	6.5g
Fat	1.2g
of which saturates	0.2g
Fibre	0.2g
Sodium	0.1g

Use by: see date on lid

**KEEP REFRIGERATED**  
Once opened consume within 3 days

## Country Foods

### Low fat live yogurt Strawberry & Banana



Country Foods' low fat yogurt is made with biocultures  
Lactobacillus acidophilus and Bifidobacterium lactis

  
Suitable for vegetarians

  
Gluten free

  
Made in the UK for:

Country Foods  
125 Kingsway, London  
WC2B 6NH

  
UK  
QQ999  
EEC

350g 

For further information please  
visit us at [www.eatwell.gov.uk](http://www.eatwell.gov.uk)



## Ingredients list

Manufacturers are required by law to

- ✓ list all deliberate ingredients, including grains that contain gluten
- ✓ regardless of how much they have used

This applies to ALL ingredients including flavourings, preservatives and E numbers



## Exempt ingredients

Some ingredients are gluten-free, even if they are made from wheat or barley

maltodextrin, glucose-syrups, dextrose  
distillates for spirits

- ✓ The source of these ingredients **do not** have to be labelled on the ingredients list
- ✓ They are **gluten-free** and suitable for people with coeliac disease



## 'Allergy advice' box

You may see an 'allergy advice' box on products, such as.....

**Contains  
wheat (gluten)**

**Contains  
barley, gluten**

However, manufacturers do not have to use one: ***by law, all ingredients must appear in the ingredients list***





## 'May contain'

- Manufacturers are given guidance by the Food Standards Agency on when to label a product with a **'may contain'** statement
- Therefore when you see one of these statements on a product, the manufacturer has assessed that there is a risk that the product could be contaminated with gluten
- **This is not compulsory in the UK**



## Codex standard

FAO/WHO Food Standards

**CODEX** alimentarius

Since the 1980s:

- products labelled 'gluten-free' if <200ppm
- no legislation but compliance amongst manufacturers



## What is the *new* Standard?

a dual system

≤ 20 ppm

Can be labelled  
as “gluten-free”

\* May apply to naturally gluten-free products, products which contain Codex wheat starch and pure, uncontaminated oat products which are less than 20ppm \*

21-100 ppm

Most likely labelled  
as “very low gluten”

\* May apply to specialist substitute gluten-free products (such as breads and flour mixes) that contain Codex wheat starch \*



## What does this mean for me?

- Clearer labelling!!!
- Most products in the current FDD are already <20ppm
- In UK, 'very low gluten' will mostly apply to prescription products; use of this terminology will probably be more common in Northern EU
- Less signposting on mainstream products
- Manufacturers will have 3 years to comply



## What will Coeliac UK do next?



- Get the message(s) out there!
  - NICE guideline
  - New Codex standard
- Educate caterers
  - Schools?
- Healthcare professional training module (CD MEDICS)
- Recipe competition
- New website

## Questions???

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Amy Peterson

+0044 1494 796 138

[amy.peterson@coeliac.org.uk](mailto:amy.peterson@coeliac.org.uk)

