Ayrshire and Arran Voluntary Support Group



Newsletter

Volume 5, Issue 1

Coeliac UK Voluntary Group Newsletter - Issue 1 - June 2013

Dates for Coffee + Chat Mornings in Sainsbury's Café
10.30 - 12.00 noon



Come along for a chat and meet other group members at either Irvine Sainsbury's store or the Prestwick store. This is a good chance to meet other members and discuss issues, new products, etc. in an informal and relaxed setting.

<u>Prestwick</u> - Saturdays 27th July 28th Sept 23rd Nov

<u>Irvine</u> - Sundays 25th August 27th Oct

Important Newsletter Update

As costs for printing and posting have risen drastically in the last 16 months the committee has decided that this will be the last issue of the newsletter that will be posted to members. Most members receive an electronic copy which is much less expensive to organise and much less time consuming for us volunteers. As we are aware that not all members have access to e-mail we are happy to continue posting the newsletter to some members but are asking for some help from those who wish to continue to receive the newsletter this way. The committee aims to produce 3—4 newsletters per annum. If you wish to receive a copy of the newsletter by post please send 4 self addressed C5 envelopes and stamped (to the value of 2nd class post, currently 50p) envelopes to:-

Mrs Wilma Brown, 4 Firth Road, Barassie, Troon, KA10 6TF.

Your help and cooperation in this matter are appreciated.

The Committee

Message from Coeliac UK

Unfortunately the community pages have been discontinued on the BBC red button service. The BBC television text service has switched from being powered through the analogue signal to a digital one, and there are restrictions on the space available. Unfortunately this means that the updates that were available through this service were discontinued from the end of March. There are other ways you can access the monthly updates to the Food and Drink Directory:

on our website <u>www.coeliac.org.uk</u> by following the links on the electronic newsletter, eXG via a 24-hour recorded message on the Helpline 0845 305 2060, select option 1 via post - please call 0845 305 2060 to request a copy.

Some of the group members who attended the annual post Christmas lunch at The Carrick Lodge in Ayr.



AMUSEMENT CORNER From William Boyd

Nice wee story from 'Across the Pond' carried by The Sunday Times (21-04-13) under the headline, 'Buy our cereal - it's Crap'.

A couple are enjoying booming sales of their cereal after changing its name to 'Holy Crap'. Brian and Corin Mullins developed the gluten-free product to cater for Mr Mullins's allergies.

It was originally called Hapi Food and sold at farmers' markets in British Columbia, Canada, but they changed the name after one of their customers exclaimed: "Holy crap! This is amazing".

Sales have now increased from 10 bags a day to more than 100.

Wonder if they're doing mail order? Wonder what rate of import duty is levied on Crap? Since it is Holy Crap is there a religious dispensation? And just how do you declare a box containing Crap to those ever so jolly types at Customs?

Mini Food Fair — Saturday 14th September 2013, Walker Hall, Troon 10 am—3 pm







Minutes of the Annual General Meeting held on Tuesday 16th April 2013 at New Trinity Church Hall, Saltcoats

Present

All 18 members attending the meeting signed the attendance sheets.

Apologies

Helen Duffy, Ann Boyd, Susan McHarg, Eileen Cochrane, Marion Flinn, Patricia McLaughlin, Lorraine Findlay, Andrea Grant, Margaret Millard.

Welcome and Introduction

Wilma Brown welcomed everyone to the Annual General Meeting and thanked everyone for attending. After the official business there will be a delivery of Gluten free fish and chips from Jack McPhee's in Troon for everyone to sample then recently joined member Karen Booth would like to speak briefly about gluten free products and choices.

Summary of the year

Wilma Brown gave a summary of the group's activities undertaken over the last year.

This was another busy year with the monthly Coffee and Chat mornings still proving popular attended by both regulars, some who come when they can and others who come along just after diagnosis. These Members find it beneficial to be able to talk to others who have lived with Coeliac Disease and can give helpful tips on their queries and worries.

For Awareness Week last year a small group met in the Red Lion in Prestwick. This was rather last minute so this year's event will be better organised.

In August 20 Members and partners enjoyed an Indian meal in Ayr India at the seafront in Ayr. The staff were very helpful and we can certainly recommend the restaurant.

In September Carol Evans from Glutafin gave a talk on their products and brought lots of samples she'd made for us to try – that proved a popular event with almost 40 attending.

The Glasgow Group held a Food Fair in September and lots of our Members supported this. Several new companies were there and everyone enjoyed tasting their samples or taking away their freebies to try at home.

In November about 30 Members, and a few of the general public who joined us, got some new recipe ideas from the cookery demonstration by Sainsbury's in their Irvine store.

Our most recent gathering was our post Christmas lunch at the Carrick Lodge in Ayr in January where 20 of us enjoyed a 3 course meal in a small private area which created a lovely atmosphere.





Minutes of the Annual General Meeting 2013 (continued)

The committee do try and hold events in different parts of Ayrshire & Arran to encourage Members from all areas to come along to something but there are some who are happy just to receive the information. If you have any ideas on places that might be suitable to hold a meeting/event or suggestions for an event, please let us know although the ones with food certainly are most popular.

Wilma added that if anyone runs out of their prescription Glutafin products, they can now be purchased in branches of Holland and Barrett.

For children with Coeliac Disease, Glutafin and Juvela have leaflets explaining the symptoms, what they can/can't eat and how to deal with eating at parties, going on holiday and lots of other useful information, ideas and recipes. There's also a Glutafin/Dr Schar website - 123milly.com -- that has information, games, recipes, quizzes and stories. It's bright and colourful and worth a look even for grown-ups!

Petrie Fine Foods support the Farmers' Markets in the area and further afield and many Members go along and buy products from them. They have donated a £5 voucher for the raffle tonight.

More good news is that Pizza Hut and Dominos now do square gluten free pizzas and lots of their toppings are gluten free.

Wilma also reminded all attending that the Coeliac UK website has lots of information not just for the newly diagnosed and seems to be constantly updated.

Awareness Week or Gut Feeling Week is from 13th – 19th May and the emphasis this year is on targeting IBS sufferers and as many Coeliacs have experienced, IBS is a common diagnosis of our symptoms. The committee have posters, leaflets and symptom cards here if anyone would like to take some to distribute - please feel free

There are several ambassadors campaigning for Coeliac UK, Dr Chris Steele and his son are raising awareness by encouraging family members to be tested and recently diagnosed mountaineer Joe Simpson is supporting us too. He suffered for many years but put his symptoms down to the conditions in the countries where he was climbing.

There is to be a Parliamentary Reception in June so if any of you would like to help by bringing Coeliac Disease to the attention of your local MP, there is a letter that can be downloaded from the website asking them to join the All Party Parliamentary Group on Coeliac Disease and DH to help raise awareness of this widespread but sometimes misunderstood condition.

According to the Coeliac UK website there will be fantastic press coverage for Awareness Week with articles in the May editions of several magazines

For our Awareness Week we are trying to arrange an outing to Pizza Hut in Kilmarnock so watch out for details







Minutes of the Annual General Meeting 2013 (continued)

Our major event this year is the Food Fair on Saturday 14th September in the Walker Hall in Troon with Juvela, Petrie Fine Foods, Glutafin, Dietary Cards, Claire's Kitchen and several others coming along with their products, so please spread the word.

Spells in hospital seem to prove stressful as several members have complained about the lack of understanding of a gluten free diet.

Finally, thanks to you for listening, to all the committee members for their hard work throughout the year, to Joanne for keeping our money in order and to Catherine for her secretarial duties and producing the newsletter. If you have any ideas for that, please let us know.

Catherine Logan thanked Wilma for all her hard work throughout the year with new members' liaison, sending out newsletter and general communications.

Approval of Last Year's Minutes

The minutes of the 2012 Annual General Meeting were proposed by William Boyd, seconded by Alex Shaw.

Treasurer's Report and Approval of Last Year's Accounts

Joanne Samson distributed a summary of the financial position to all those attending the meeting. The accounts run from 6th May 2012 until April 2013 and started with a balance of £994.88. The income over the last 12 months was from the raffles throughout the year, collection tins & personal donation and deposits for the meals the group has organised. The biggest outgoings shown are refunds to Catherine & Joanne for paying the deposits for the organised meals. Biggest outgoing for the general running of the group is again for the printing and posting of the newsletter and some minor expenses this year for thank you gifts for speakers at the events the group has held over the last 12 months. Balance at the end of the financial year was £894.82.

Accounts were proposed by William Boyd, seconded by Janet Hamilton.

Election of Office Bearers

As there were no other volunteers the following people were willing to stand for re-election as office bearers.

Catherine Logan – Secretary, Joanne Samson - Treasurer, Wilma Brown – New Members' Liaison

These nominations were proposed by William Boyd and seconded by Jess McEwan.

Jess McEwan, Helen Duffy, Ann Boyd and Janet Hamilton agreed to remain on the committee as ordinary members. Bruce Wilson agreed to join the committee.

These nominations were proposed by William Boyd and seconded by Alex Shaw.

Minutes of the Annual General Meeting 2013 (continued)

<u>AOB</u>

1 – Beverley Grant asked if she should be able to get Glutafin mini crackers, savoury biscuits on prescription. Wilma Brown and Catherine Logan suggested that she should be able to get these products on prescription but needed to see a dietician before she could get any products. Catherine also directed Beverley to the article in a recent newsletter about the withdrawal of luxury products from prescription but wasn't aware of the withdrawal of crackers.

2 – More places to eat out – Tudor at Burns Statue Square, Ayr, Dragon Royale, Chinese restaurant, Kilmarnock, The Canny Man, Lugton, Pizza Hut in Argyle Street, Glasgow, La Tasca in Omni Centre beside the Playhouse Theatre, Edinburgh, Mama's Pizza, Edinburgh, GF pizza & GF beer, Land & Sea, Polmont – 1st Saturday lunch time GF products, Kings Manor, Edinburgh – GF food on menu, Hand Made Burger Company – Braehead/Silverburn, The Old Scotsman, Edinburgh – Buffalo burgers in GF bun.

Bruce Wilson recommended the Howard Lodge in Carlisle who supply GF B&B

- 3 Catherine asked members for article for the newsletter and recommendation of foods for kids
- 4 Some recommendations for GF butchers were given Findlay's Butchers, Portobello GF haggis, black pudding, sausages, W P Tulloch, West Kilbride GF sausages, Bicket, Saltcoats, Hendersons, Hamilton, GF black pudding.

Catherine Logan, Group Secretary, 16/4/2013

100000000000000000000000000000000000000	
	Ayrshire & Arran Voluntary Support Group Financial Report May 2012 - May 2013
Opening Bank Balance	994.88
Income Raffles Donations Meal Deposits Total Income	55.00 69.50 <u>180.00</u> 304.50
<u>Expenses</u>	
Postage	123.84
Printing & Stationery	32.89
Hall Rental	65.00
Gifts	41.85
Biscuits	5.98
Meal Deposits Refund	<u>180.00</u>
Total Expenses	<u>449.56</u>
Closing Bank Balance	<u>849.82</u>

A CAUTIONARY TALE By William Boyd

One of the problems of being coeliac is the risk of eating something for quite a time that you imagine is safe only to discover that it isn't, so my own recent experiences should provide a cautionary lesson for us all.

I have always referred to the 'Wee Book' as I like to call it, the Food and Drink Directory compiled for our benefit every year, at considerable expense I've no doubt, by Coeliac UK. Once I've seen something listed in there I know it is OK to eat it - forever more. Therein lies the trap. I don't always go back and check the current Directory, nor do I diligently check the website every single month to see the latest updates. And I'll bet neither do you!

Now I have a liking for chutney, but the vast majority of chutneys do contain gluten so they are off our menu. Sharwoods Green Label chutney however was listed so blithely I went ahead to eat it. Just by chance recently I had a look at the label and there was no indication that anything was adrift. Neither was I suffering a stomach problem; indeed my GP said I looked well. Fine! But all was not well. Casually I thought that I'd better see that it was still listed. To my horror, NO, it's NOT. Back to last year's wee book and, yes, there it was listed. My eyes were not deceiving me. I am not senile - yet! The rascals have now 'de-listed' this product. It may be that there is no significant amount of gluten in it, but the manufacturers have obviously decided that it is too much bother to continue complying with current legislation.

Can we take the risk? As coeliacs, we probably shouldn't ever take the chance and certainly never regularly. As I agreed with my GP two years ago, one single 'transgression' may not matter other than perhaps a sore stomach, but to have some gluten bearing food getting in 'under the radar' all the time is very dangerous for us. So the moral of the story is that anything declared as gluten free today, may not be tomorrow. We all need to check both the current Directory and the website updates.

My own personal view is that once a foodstuff had been declared GF, then the manufacturer should not be allowed to de-register it willy-nilly. It really is a bit naughty of them. It would even be better if the product was withdrawn from the market, or clearly re-labelled, or re-branded. At least then warning bells would sound in our heads.

Another trap for the unwary is that food producers who specialise in GF also produce non-GF foodstuffs which are sitting on the same 'Free From' shelf beside GF foods. Recently I was able to warn a lady who lifted a Mrs Crimbles cake that this did contain gluten. I had made the same mistake about a year ago. She was rather horrified at this until I explained that the Free From section was also for the benefit of those with Dairy allergies. Most Mrs Crimbles products are GF, but that particular cake is only free from Dairy produce, not gluten free. It does actually say 'not suitable for coeliacs' on the package, but it is in small print so I have to reach for my glasses. (Ah, the penalties of age!). Eternal vigilance is therefore the only answer.

One piece of better news is that I notice Heinz are now labelling those soups and other products which do contain gluten in the 'allergy advice' box as containing gluten. This is a helpful development for us, but again the print size is overly small.

I'll offer my best wishes to all my fellow coeliacs and remember - keep reading the instructions!

Members enjoying fish & chips with tea & coffee after the AGM.

