

Sevenoaks Area Coeliac Group

TALKABOUT

For all your gluten-free gossip, news and events

**June 2019
Edition 48**

**“Patients should be encouraged to join disease-specific patient support groups if applicable.”
See P8**

**Sevenoaks
Local Group**



Branch Committee

Group Organiser	Fiona Turnbull	01474 703869
	fi.turnbull@talktalk.net	
Secretary	Daphne Paterson	07717 471909
	dpater2@btinternet.com	
Treasurer	Mary Cunnington	01732 862925
	mary@june-cottage.com	
Newsletter Editors	Andrew Pilcher	07802 423455
	Rosemarie Pilcher	07928 280791
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Refreshments	Joy Oliver	01732 460849
	roliver912@googlemail.com	
	Sally Spike	01689 828883
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New Members Secretary	Susan Potts	01892 613258
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Note from the Editors

Dear Reader

Welcome to the 48th edition of Talkabout.

We have recently come back from Italy (again) and experienced, among other things, another Italian wedding. They really know how to party!

We hope you enjoy this edition of Talkabout and hope to see you at one of the forthcoming events.

Andrew and Rosemarie – The Editors

Sevenoaks Area Coeliac Group

We wish to thank Mike Wilcock for his continued efforts in getting Greg Clark MP to attend one of our coffee meetings and to support our members' quest with the CCG to have gf staples on prescription in West Kent area.

Finally, at February coffee in Tunbridge Wells, we had success and enjoyed an informative meeting with Greg.

We hope for a successful outcome...

Your Help is still needed!

Do you enjoy Saturday coffee?

Have you benefitted from discussions at Saturday coffee?

Do you attend Saturday coffee when you can?

If the answer is yes, could you think about lending a hand?

There is no need to attend personally every month. We just need someone to make contact with other 'willing helpers' to ensure there is a welcoming face at each coffee morning.

Please get in contact if you can help - fi.turnbull@talktalk.net

Forthcoming Events

Please come along to one of our events. We look forward to seeing you soon.

Coffee Morning - Third Saturday of every month

15 th June 2019	Sevenoaks
21 th July 2019	Tunbridge Wells
17 th August 2019	Sevenoaks
21 st September 2019	Tunbridge Wells
19 th October 2019	Sevenoaks

If you are newly diagnosed and want to find out more, this is a very relaxed way to meet with other coeliacs to share ideas and have a chat. We welcome everybody who is affected by this condition or is interested in finding out more about it.

We meet between 10.00am - 11.30am at alternate locations each month. One month at Sainsbury's Café in Sevenoaks (Otford Road, TN14 5EG) and the next month in Sainsbury's Café in Tunbridge Wells (on Linden Park Road, TN2 5QL, just off the A26 Eridge Road).

We look forward to seeing you soon - look out for the Crossed Grain magazine on the table.

Summer BBQ Saturday 10th August 2019

Please join us for our annual BBQ

Contact Daphne ~ dpater2@btinternet.com ~ to book your place and for directions.

Next Meeting Saturday 2nd November 2019

Otford Methodist Church Hall 2pm – 4pm.

More details to follow



Sevenoaks Coeliac Support Group

would like to invite you to our 2019 BBQ from 4.00 on Saturday 10th August in West Kingsdown.

We will be cooking up some lovely gluten-free food for you to enjoy without worrying about all the usual contamination issues.

Please come along with your family and friends and support your local group.
The children will love it too!

The cost is a minimum donation of £7.50 for adults and **FREE** for children under 10.

Bring your own cold drinks, glasses provided.

Please contact Daphne Paterson by 3rd August at dpater2@btinternet.com or telephone her on 07717 471909 to let us know how many of you are coming along and for directions.

Please also let us know of any other allergies

We are hoping to see lots of you soon!



Coeliac Awareness Stand during Coeliac Awareness Week

I was thrilled with the day at Darent Valley Hospital. There was a photo shoot at lunch time. The following photo includes 7 dietitians, two student dietitians, four Gastroenterologist Consultants and, of course, me.

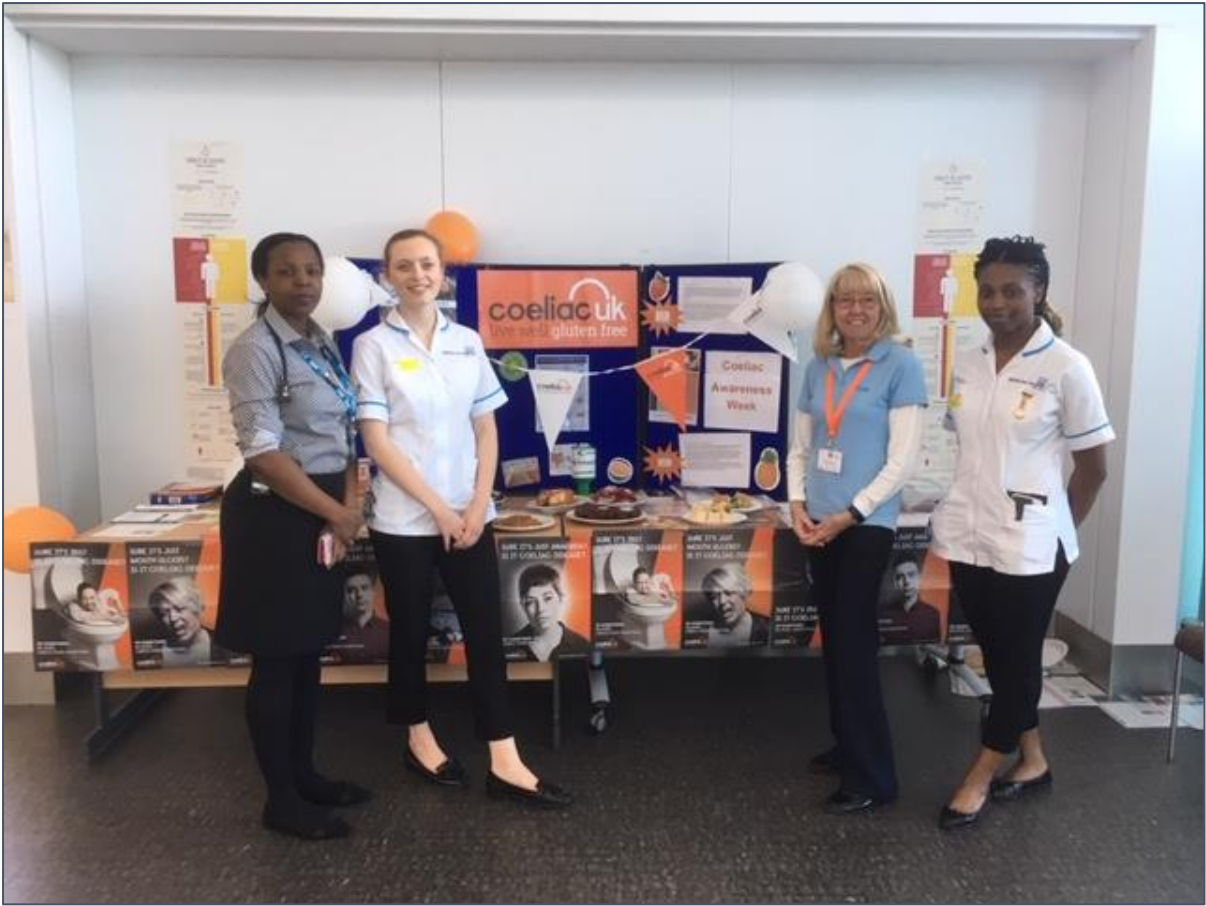
The dietitians were on an hourly rota to be on the stand during the day with us. Two of the Consultants spent time on the stand during the day as well. Great support was shown for Coeliac awareness by the staff.

This is the 13th year that Daphne and I have helped to 'man' the Awareness stand at Darent Valley Hospital. We collected £26.08 in the collection box.

We had G/F flapjacks and chocolate brownies for tasting all day. Furthermore, gluten free sandwiches and cakes were sent up from catering at lunchtime for people to sample.

Fiona Turnbull





A Tip for Us All from our Visit to Darent Valley Hospital

Do You Get Your Annual Follow-up?

In conversation with one of the Gastroenterology Consultants who supported the Awareness Week Stand, I mentioned that since my discharge many years ago from DVH to the care of my GP I had not had a single coeliac related appointment or blood test. He was kind enough to access and forward to me this extract from the British Society of Gastroenterology 'Coeliac Follow-up Guidelines.'

“Once the disease is stable and the patients manage their diet without any problems, annual follow-ups should be initiated. The physician should check on intact small intestinal absorption (full blood count, ferritin, serum folate, vitamin B12, calcium, alkaline phosphatase), associated autoimmune conditions (thyroid-stimulating hormone and thyroid hormone(s), and serum glucose), liver disease (aspartate aminotransferase/alanine aminotransferase) and dietary adherence (anti-TG2 or EMA/DGP), although the sensitivity and specificity of the latter cannot substitute for structured dietary interview.”

I have now requested for this to be done by my GP. I was delighted to find she took my request seriously and went through the long list, ticking off each item as she added it to the blood test form.

My daughter is in a similar position and has already had issues with her thyroid levels, causing tiredness similar to anaemia. This was eventually discovered but could have been avoided with regular check-ups.

The full document 'Diagnosis and management of adult coeliac disease: guidelines from the British Society of Gastroenterology' can be found at:
<file:///C:/Users/dpate/Documents/Coeliac/BSG%20guidelines%20on%20the%20diagnosis%20and%20management%20of%20adult%20coeliac%20disease.pdf>

The relevant passage is the first full paragraph in the right column of p7.

Interestingly, the previous paragraph ends:

Patients should be encouraged to join disease-specific patient support groups if applicable.

Daphne Paterson

Sevenoaks Area Coeliac Group Minutes of AGM 27th April 2019

Present:

Committee Members – Fiona Turnbull, Daphne Paterson, Joy Oliver, Sally Spike and Susan Potts,

Total present – 24 members of the group

Apologies of Absence –Mary Cunnington, Andrew and Rosemarie Pilcher

Group Organiser's Report

Fiona welcomed everyone to the meeting, also our guest speaker Mandy Carey New Volunteers Manager from CUK who will be giving an update of the ongoing work from CUK.

Minutes of the previous AGM held on 28th April 2018 had been distributed and read and were proposed as a true record of the meeting by Mike Wilcock and Seconded by Ashley Adams.
There were no matters arising.

Vacancies on Committee

Fiona Explained that we need extra help on the committee, although there are 8 committee members, it is appreciated this is a voluntary post and we all have a life outside volunteering.

Fiona explained that a rota for members to help cover the coffee morning dates had worked well for the last 2 years.
(Although there are only 5 members of the committee present today, we have a combined total of 146 years since our coeliac diagnoses. Proving we all have a very valuable coeliac knowledge to help our fellow members.)

Re-Election of Committee

Fiona thanked the committee for another very successful year together and their hard work and contribution to the local group.

Fiona explained that all posts are up for re-election but no nominations came forward.

The current committee:

Group leader

Fiona Turnbull

Group Secretary and Web Master

Daphne Paterson

Treasurer

Mary Cunnington

Refreshments

Joy Oliver & Sally Spike

New Members Secretary

Susan Potts

News Letter Editors

Andrew and Rosemarie
Pilcher

The committee were all willing to stand for another year.

The proposal by Blanch Murray, seconded by Ashley Adams to re-elect the committee en-masse was accepted.

Fiona thanked everyone and said she would be very pleased to take the group forward into our 17th year for Sevenoaks and into the 15th year for her as Group Leader.

Treasurer's Report

Donation to Coeliac UK 50th Anniversary Research Program,
£62.55 collected at 2018 AGM.

£34 collected from Bonus ball game at Summer BBQ.

A cheque totalling £96.55 was sent to CUK and a letter of thanks was received.

Fiona thanked Mary for her excellent book keeping; Mary Cunnington, Treasurer, was absent from the meeting. Up to date bank balance as of December 2018 was £4,398.64p but this does not take into account the expenses for the AGM booking and catering.

At present, our Sevenoaks newsletter is published three times a year. We feel it is an important resource as it enables us to reach those members unable to get to our meetings. We post out just over 100 copies of Talkabout every 4 months.

Fiona thanked Andrew and Rosemarie Pilcher for taking on the job as Newsletter Editors last year.

Fiona thanked Mike Wilcock, our Sevenoaks member, for the excellent campaign on behalf of the members in the West Kent CCG area after Gluten Free Prescriptions were withdrawn. This has been closely shadowed by the campaign co-ordinator, Ruth Passmore, at CUK.

Fiona explained the group are still concentrating on monthly coffee mornings with three big meetings a year.

Coffee mornings were manned by Members and the committee over the last two years and worked well. We feel this is a vital resource for newly diagnosed coeliacs to chat on an informal basis. Coffee mornings are held on the 3rd Saturday of the month at 10am to 11.30am at Sainsbury's Café, alternating between Tunbridge Wells and Sevenoaks, with no coffee meeting in December.

Fiona explained there were only 6 dates left to cover for 2019. Joy Hill immediately offered to cover the next coffee morning for 19th May at Tunbridge Wells.

Fiona ran through the events that were organised over the last 12 months.

Coeliac Awareness Week 17th May 2018

Once again, we joined forces with Darent Valley Hospital's Dietetic Dept. with a stand in the main foyer for one day. A gastro outpatient clinic that afternoon guaranteed people interested in coeliac disease. It is always a worthwhile event to help raise awareness.

The same day in the evening, Daphne and Fiona went to Marks and Spencer's Store at Blue Water for a Coeliac Awareness Evening and G/F tasting of M&S products. They met up with two members from the Medway Voluntary Support Group of CUK, telling them they had been at Darent Valley Hospital all day on the Awareness stand and that it had been the 12th year the Sevenoaks Group had been involved with that awareness day event at DVH. One lady became upset and said that we had spoken to her Mum 9 years ago, given her lots of leaflets and info suggesting she asked her daughter to go to her GP to ask for a Coeliac blood screen, but not to give up eating gluten in the meantime. She was diagnosed with coeliac disease following our advice.

Summer BBQ Saturday 30th June 2018

Fiona thanked Daphne Paterson and husband Bob for all the hard work in hosting the BBQ at their home and the rest of the committee for their hard work in catering for the lovely food that was available. We all had an enjoyable afternoon.

Group Meeting and Afternoon Tea 13th October 2018

Fiona thanked Mike Wilcock for a superb presentation on the lobbying of NHS England and West Kent CCG on the fight to have G/F prescriptions reinstated along with the national recommendations.

Members also enjoyed Afternoon Tea and home-made cakes.

50th Anniversary Gala Dinner Wednesday 28th November at the City of London Club

Daphne and Fiona were invited, at very short notice, to attend the Charity Gala Dinner and were proud to say the evening raised over £20,000.00 for the CUK Research fund.

A couple of days later, Fiona received a phone call from Sarah Sleet CEO of CUK to tell her that she was leaving at the end of February 2019 and wanted to tell the Sevenoaks Group herself and not hear it from a standard email. Sarah had worked very closely with Sevenoaks over the years, Fiona said she was sad to hear the news but very proud Sarah took the time to tell her personally.

Future Events

Coeliac Awareness Week 13th to 19th May 2019

Fiona has already been in touch with Darent Valley Hospital and will spend Tuesday 14th May in the main foyer with the Dieticians.

Fiona asked that if anyone had a couple of hours spare that day they would be most welcome to attend.

Fiona said that a committee meeting would be held at the end of the afternoon to arrange dates for the rest of the year.

There will be a Summer BBQ date to be arranged - look out for details soon.

Fiona then passed the afternoon over to Mandy Carey who gave an up-date on the ongoing work at CUK.

Members then enjoyed afternoon Tea, coffee, cakes and G/F goodies.

The meeting closed at 4pm.

RECOMMENDATIONS from members of places for eating out

- Bricklayers Arms, Chipstead – very popular, need to book early
- Weatherspoons, Crowborough
- Goudhurst Inn, Goudhurst – lovely roast
- Teal Café, Hildenborough
- Salters Fish and Chips, High Street, Tonbridge – gluten free offered on Monday nights
- The White Rock, Underriver (landlord/restauranteur is Coeliac)
- Bucks Head, Godden Green
- The George and Dragon, Chipstead
- The Barley Mow, Tandridge (also does gf snacks like steak sandwiches at lunch time)
- The Ghurkha, Woodcock Inn, 186 London Road, East Grinstead (very good Nepalese meals, most of which are gf)
- The Pizza Express Chain
- Cote Restaurants
- Hattusa, Turkish (Sevenoaks and Tunbridge Wells)
- Prezzo Chain
- Zizzis – they have a reasonable selection of gf food
- Indigo, One Aldwych, London (for a special treat of entirely gf meals)

- Gluten free lager, available at The Oak Tree Pub, Sevenoaks High Street
- Gluten free ales from the Westerham Brewery, all of which are gf and available at Majestic in Sevenoaks. Westerham Brewery do social evenings and cater for Coeliacs with gf pizza and their range of drinks.
- Very tasty bread from the Incredible Bakery company is available at the Organic Health Shop, High Street, Tunbridge Wells and from
- <https://www.incrediblebakerycompany.co.uk/> The red quinoa loaf has been particularly recommended by one of our members.

'Ranasbakeries' products are stocked by Foodies Delicatessen, 40 Camden Road, Tunbridge Wells

Here are some of a member's favourite restaurants around Sevenoaks:

<https://en-gb.facebook.com/pages/category/Seafood-Restaurant/St-Johns-Fish-Bar-222163574496422/> St Johns Fish and Chips in Tunbridge Wells – you can eat in if you like

<http://www.thaipadoxtd.co.uk/> Thai Pad Oxted

<http://www.deepbluerestaurants.com/oxted/menu/home-delivery.html>
Deep Blue Oxted

<https://www.phocafe.co.uk/> numerous locations in London

<http://www.italiancotto.co.uk/> Cotto London

<https://www.pizzahut.co.uk/restaurants/find-a-hut/london/strand/>
Pizzahut London – conveniently near Charing Cross station

Borders (High Rocks), Tunbridge Wells
Excellent meal, attention to detail and lovely location.

THANK YOU to everybody for their recommendations, please can we have more.

NCVO
(The National Council for Voluntary Organisations)

National Volunteer Week
1st to 7th June 2019

For this week, Coeliac UK requested me to sum up why I volunteer, and what I get out of volunteering.

1. I love leaving a group meeting feeling rewarded, knowing I have really made a difference.
2. However small it may seem, taking the time to talk can make a big difference towards helping someone in their time of need.
3. If I can help just one person at a meeting, it is a 'job done'.
4. I can shout
"THIS ISN'T GLUTEN FREE"
But the elderly, ill and very young children don't always have this voice.

This is why I volunteer.

Fiona Turnbull



Talkabout

Sevenoaks Area Coeliac Group

<https://www.coeliac.org.uk/local-groups/sevenoaks>

Please send your letters or enquiries to:

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29 The Paddock, Pembury,
Tunbridge Wells, Kent TN2 4NR***

Email: arpem321@hotmail.com