



WEST SUSSEX COELIAC GROUP

Newsletter – July 2023

2023 AGM – GROUP CLOSURE

In our last email we let you know that if nobody came forward to take on the Group Committee roles, the AGM would also be a Special General Meeting with a vote on the future of the Group.

Our 2023 AGM took place on Saturday 3rd June and without any Committee nominations being received, a vote was made to instead become a community group. The Committee will remain in place until the end of September, when the West Sussex Coeliac Group will close.

Full minutes from the AGM are available to read at the end of this Newsletter, or on our page that's currently still on the Coeliac UK website [here](#).

Thank you so much to all those who joined us for the AGM formalities and helped in taking the decision on what happens to the Group.

BECOMING A COMMUNITY GROUP

Community groups are a more informal arrangement where anyone who is a member of Coeliac UK and wants to hold an event for other members just needs to register as a volunteer with Coeliac UK.

If you'd like to become a volunteer, please let us know by emailing Gillian at gmcarr@ntlworld.com. She will then try to arrange an online meeting with everyone in the next few weeks, to talk through things. You can also register your interest with Coeliac UK by emailing volunteering@coeliacuk.org.

It's our understanding that if volunteers register with Coeliac UK, they will help with publicising any events to members through the website and in Crossed Grain, they will check that you have up to date information regarding the latest research and it also means that events will be covered by their public liability insurance. The balance of funds in our bank account will be ringfenced by Coeliac UK for 2 years for specific use by the community group.

Coeliac UK should soon be in touch with everyone to give more information.

COELIAC CHILDREN'S FAMILY DAY 2023

We were delighted to hold another Family Day at Butlin's in Bognor Regis on Saturday 13 May.

Thanks to the generous legacy from our previous Group Organiser, Anna Henderson, we were able to keep the cost for families at the previous 2020 prices, to make it as affordable as possible in these difficult times.

Those who came along had a great day and a number of people there expressed interest in holding other events for children in the future. It would be lovely to think that this could be a lasting tribute to Anna and we would encourage anyone interested to register as a community group volunteer with Coeliac UK.

Photos from the day can be seen on the news item [Family Fun Day 2023](#).

Our grateful thanks go to everyone who helped organise and run the event.

HASSOCKS COFFEE / BRUNCH

This event is planned to continue after the Group closes, with the current organisers as registered volunteers.

They are held at **The Barn Restaurant**, South Downs Nurseries, Brighton Road, BN6 9LY from **9:30 to 11:00** on the first **Saturday** of every other month, with next dates: **5 August | 7 October**.

'FAREWELL' MEAL

Ahead of the Group formally closing at the end of September, we would be delighted if as many of you as possible could make it to a final 'farewell' evening meal at **Cote Brasserie**, 1 East Street in **Horsham** on **Tuesday 19 September** at **19:30**.

Please note: As a large group, we will probably be placed upstairs and there is no lift. Payment in the restaurant is by card only.

Booking is required by payment of a £5 deposit per person. Receipt of deposit will be acknowledged to confirm your booking. Please pay by bank transfer before Tuesday 29 August to:

Sort code - 30-94-28

Account number - 63203368

Account name - Coeliac UK - West Sussex

Reference – Cote meal

Alternatively, payment by cheque, payable to "Coeliac UK – West Sussex" (write "Cote meal" on the back) can be sent to Gillian Carr at 56 Hogarth Road, Hove, BN3 5RH.

Please email Gillian at gmcarr@ntlworld.com to say you've paid a deposit.

Any personal information that you provide will be used by West Sussex Coeliac Group for the administration of and fundraising objectives of the charity and for no other purpose.

2023 AGM – MINUTES

MINUTES of WEST SUSSEX COELIAC GROUP AGM 2023 – Redeemer Centre, Guildbourne Centre, Worthing on Saturday 3rd June 2023 at 14.30 hours.

In attendance were 14 members, 3 non-members, including committee members Gillian Carr – Treasurer and Lisa Warring – Admin Assistant.

1. Welcome - Gillian welcomed everyone.

2. Apologies for absence – Tracey Martin - Secretary, Mike Butler – Group Organiser, Joan Holgate. Anne Romer, Dena & John Kitchener, Julie Prince, Hayley Sherrell, Sharon Teague, Irene Marshall, Silvia Meneghesso

Gillian took on role of Group Organiser in Mike's absence and Lisa role of Secretary in Tracey's absence.

Minutes and Matters Arising – the minutes were agreed and there were no matters arising that were not already covered by the agenda.

3. Election of Committee Members

The committee are stepping down this year and although there had been some expressions of interest in joining the committee no-one has come forward so the group will close.

See following point 6 about group future.

4. Group Finances Report

Gillian presented the accounts as in the Accounts Summary.

It comprises of the summary of what was left at end of 2022 on one page and the accounts to date (minus a few recent expenses for Butlin's and the AGM) on the other.

Butlin's expenditure was high. To ensure families were able to afford attending the day, all of Anna's legacy was used to subsidise this, which we feel she would have wanted.

5. 2022 review

Limited events last year.

Worthing informal group continued their coffee mornings, and are currently looking for a new venue.

Hassocks breakfast mornings have restarted, see next email/newsletter for correct dates, next one is Saturday 5th August.

There was a meal at The Tollgate, Bramber which we will hopefully repeat later this year.

We have no membership secretary so have no information on new members but they do receive the local group emails and newsletters if signed up to them with CUK.

Although technically this year and not 2022 Gillian said the Butlin's Family Day was a great success and some parents attending had mentioned they might be interested in keeping it going. One child had said "I'm in heaven" which probably sums up the whole day. Butlin's would be happy to host the event again but as previously mentioned in the accounts the costs were high and there was a lot of organising to do.

6. Future of the Group – 2023 Plans/Vote on Group Closure/Special Group Meeting

Nicholas thanked the current committee.

With the committee stepping down and no-one coming forward to take over, the group is left with 2 choices. Close for good or continue as a community group.

The group closing would mean there would be no formal CUK local group events held, or support for members, particularly new ones and children. A lot of us had been grateful to have a local group for support when first diagnosed as we didn't know where else to go and had made a lot of friends through the group. It would also mean our remaining funds would go back to CUK.

There were a lot of questions for Gillian, and discussions about how the community group would work.

Gillian explained the information we have so far from CUK about the community groups.

The community group would be comprised of CUK member volunteers who could organise events themselves.

We don't know how many other groups are currently doing this or how well it is working.

Diabetes UK already do this.

In practice what would happen is a member would register as a volunteer, then when they have an event to plan they would notify CUK who would support through publicity by email and/or Crossed Grain (though Crossed Grain needs adequate advance notice prior to publication). It is necessary to have a member so that these events would be covered by public liability insurance through CUK and CUK would make sure the volunteer was fully informed of the latest information that they might need.

The community group would mean our remaining funds would be taken back by CUK and ring-fenced for our use as a community group for 2 years. After this the community group would be expected to be self-funding for any events.

There is no formal training for volunteers but there is support from CUK such as volunteer lounges. Registering as a volunteer shouldn't result in any barriers such as needing checks, like school volunteers require, as we would not be holding any events where we would be taking responsibility for children. The parents would be in attendance if their children were attending an event.

Gillian and Phillipa (who is the Hassocks breakfast organiser) are already volunteers and will continue to be. We would hope other current volunteers would also continue.

We would no longer have newsletters and access to a new members list, and there is concern about these new members missing out. However they should be able to see events advertised through CUK, and we would need to ensure events are advertised up to date.

Informal groups of coeliac friends meeting can of course continue amongst themselves and liability would be covered by the venue where friends meet, although these wouldn't reach members in the community as they wouldn't be able to be advertised through CUK.

There was concern about the lack of support CUK had given the local group in recent years and wondering was the membership worthwhile. It was felt at times they were maybe not listening to groups on how difficult it was to keep them going, especially after covid. Gillian felt that membership was supporting the wider community in funding research as well as providing a lot of information for newly diagnosed members and being able to publicise events to reach out to them.

There were questions about when the committee would actually cease to exist, and would we still be able to hold events in the meantime. Gillian thought that we would be aiming to do this over a 3 month period to enable us to send out another newsletter, hopefully book some more events, allow time for people to volunteer (and maybe even come forward to set up a new committee).

The CUK members then voted unanimously to keep going as a community group.

7. AOB – none raised.

Tea and cake followed.

West Sussex Coeliac Group Annual Accounts Summary

Period 1/1/2022 – 31/12/2022

Opening Balance 7583.30

Income

Tollgate Deposits	130.00
Butlins Deposits	929.00
Total Income	£1059.00

Expenditure

AGM Food & space hire	153.74
Newsletter stationery & postage	17.65
Deposit paid to Tollgate	130
Total Expenditure	£301.39

Closing EOY Balance **£8340.91**

18th Feb 2023

Accounts Summary for 2023 to date (31st May):

Opening Balance	£8340.91	(This included £5000 legacy from Anna Henderson and £929 in Butlin's deposits)
-----------------	----------	--

Income

Butlin's	£2092
----------	-------

Total Income **£2092**

Expenditure

Butlin's	£8319
----------	-------

AGM Room Hire	£120
---------------	------

Total Expenditure **£8439**

Current bank account **£1993.91**

There are some minor expenses which have not yet been claimed for, amounting to approximately £60 (Butlin's copying for activity, photocopying & postage to people not on email, AGM catering & photocopying)

31st May 23

Attending:

* Members: Nicholas and Gillian Carr, Lisa Warring, Helen Blake, Maggie Brackpool, Richard Calvert, Margaret Mercer, Phyl Purkiss, Pam and Andy Whittaker, Ruth Hands, Christina Stanfield, Jenny Martin and Lorna Purches

* Non-members: John and Nicky Johnson, Richard Stanfield,