

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)
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Income

Butlin's	£2092
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Total Income	£2092
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Expenditure

Butlin's	£8319
AGM Room Hire	£120

Total Expenditure	£8439
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Current bank account	£1993.91
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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,