

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

Issue 111: March 2021

Website: www.rpcsg.org.uk

THE MARCH MEETING.

The March 2021 meeting was held by Zoom and was attended by 37 RPCSG members and 12 people from other support groups from as far apart as Harrogate, Cardiff, Cornwall, Basingstoke and North Hants.

The guest speaker was Sarah Gray of Tackle. Sarah introduced herself as the National Support and Development Manager for Tackle Prostate Cancer. She has been in the post for six months. Previously she has worked in Health and Social Care, Macmillan, Parkinson's UK, British Lung Foundation and then PCUK.

Sarah talked about the organisation 'Tackle' and how can we work together and raise awareness in the community.

The Tackle Prostate Cancer Federation consists of around 95 prostate cancer support groups and was formed 12 years ago. Their policy is that we are all stronger by working together and with more collaboration.

The board of trustees includes many men who have suffered prostate cancer, including the chairman Ken Mastris.

The work of Tackle is to provide support to Support Groups to help them to give better support, to provide small grants, information and advice on how to connect. Tackle holds campaigns and promotes awareness. It operates the only national user-led helpline. It complements the services of PCUK. The patient representative is RPCSG member Steve Allen.

Tackle has three main aims:

Supporting patients and their families.

Provide support so that groups can better support their members.

Campaign on issues, driving awareness and having a loud voice.

The voices of carers, patients and partners are all involved.

Tackle recognises the need to do more. They want patients to be able to access support at the point of diagnosis. In order to raise the profile of the group there is a need for a full time person working with professionals and networks to raise their profile.

There is a need to reach communities that are currently without support, and a need to reflect communities and the diversity of socio-economic levels as well as ethnicity.

Some lottery money has been a big help.

It is essential to take account of the ease of access. Some people including those who are working may find it difficult to come to a group. Support needs to be readily available close by without the need to travel far.

Tackle works with charities to develop new services. Hearing stories is very essential to learn of any issues.

Tackle works with health care professionals but this has been difficult recently on account of the covid virus and has delayed progress.

Tackle wants to share experience for peer support. One approach is sub-groups such as walking, cycling or partner groups.

Tackle is aware that much more needs to be done for prostate cancer awareness. Family members also need to be aware of the risks. There are barriers in some ethnic communities.

Over next 12 months Tackle intends to listen to other groups and gather baseline data, then look at issues and opportunities. Small working groups will be brought together enabling the sharing of best practice and to remove barriers. New ideas will be tested and shared. The web site will be refreshed and make access and information easier.

Sarah mentioned Prostate Cancer Research that is funding 11 projects. They also want to look at why there are barriers to discussing important aspects such incontinence and sexual function and other body issues.

Sarah then invited comments from the participants. Further points were raised:

Personal contact is much preferred as booklets are not sufficient in themselves.
Information is needed before important treatment decisions are made.
Bone density scans are important.

Suggestion that some hospitals are not publicising support groups adequately.

There is a lack of consent before treatment starts in that treatments may be proposed without full consideration of alternatives.

Should support groups be open to all men over the age of say, 50 in order to promote awareness? It was thought that this would dilute the effectiveness of the groups and there are other preferable means to raise awareness in the public.

Sarah was thanked for her thorough and enlightening talk.

NEXT RPCSG ZOOM MEETING - 9th April 2021

The April group meeting will be held by Zoom with a talk by a representative of the Medical Detection Dogs organisation. This meeting is a week later than usual due to the Easter weekend. Further detail and the link will be sent to all members before the meeting.

RPCSG WALK

The Government's road map out of lockdown says that from the 29th March the 'stay at home' ends and groups of up to 6 people can meet outdoors. We plan to have a walk whilst observing this rule. If more than six members want to join the walk that will be fine, we will just split into more groups each of six or less people. Social distancing will be observed.

The walk will start at a free car park at Aldermaston Wharf on Tuesday **6th April 2021 at 10:30**. This is a pleasant walk alongside the River Kennet to Woolhampton and is around 4½ miles total. Please bring your own refreshments for which we will make a stop along the way.

To arrive at the starting point, approach Aldermaston on the A4 Bath Road, then take the A340 Basingstoke Road for about 500 metres then turn right into Station Road. Then take the first left turn into Mallard Way and immediately on the right is a free car park. If you use a sat nav put in RG7 4UX, this will take you into Mallard Way but make sure to take the immediate right turn into the car park after turning off Station Road.

All members and partners are invited to this walk. Just arrive at the Mallard Way car park before 10:30.

If you have any queries about the walk please call Richard Brown on 07973 662925.

COFFEE MORNING

Provided that the lockdown plans do not change we intend to hold a coffee morning at the Flower Pot in Aston on the **20th April 2021 at 11:00 a.m.** Hospitality venues should be able to serve customers outdoors under the 'group of six' rule. We will meet in the rear garden of the pub and maintain social distancing. I will confirm this arrangement nearer to the date.

CHRISTMAS !!

Yes it is time to start thinking about Christmas already. As most of you will know our Christmas group meeting is traditionally a Christmas Social occasion at which we have a hot and cold buffet meal in St Andrew's church hall. This is a very enjoyable occasion with a quiz and raffle. The Christmas event could not be held last year on account of the coronavirus.

The external caterer Mange Bien has provided the meal for many years and delivers an excellent service. We have been in touch with Mange Bien and provisionally reserved the date of the 3rd December 2021. It was fortunate that we did so as they have had a huge increase in interest and bookings for their service.

Below are some words written by our Social Secretary Alex Miles:

Something to look forward to

Well, it's been a funny old year, hasn't it, with meetings all held on Zoom, and very few opportunities to meet in the flesh, although we may have walks and coffee mornings back on the agenda sometime soon.

We're hoping that, a little later in the year, we may be able to meet again in St Andrew's Hall. With this in mind, and with the need for something to look forward to, I'm hoping to be able to organise our usual Christmas Dinner event. I have provisionally booked Mange Bien, our usual excellent caterer, for the evening of Friday 3 December, in the expectation/hope that we'll be able to go ahead this year. For those who like to plan ahead, this might be a good time to reach for your diary!

In the shorter term, we're waiting on being allowed back into St Andrew's Hall. What we'll do on the first evening we can get together there again is not yet decided, but Committee may decide to make this a celebratory social event, in which case I'll organise something for us – possibly a 'bring and share' buffet-style event.

In the meantime, stay safe (and distanced).

Alex Miles
Social Secretary

Steve Parkinson
Newsletter Editor.
NewsEditorRPCSG@yahoo.com

DISCLAIMER

This newsletter does not offer medical advice. Nothing contained in the newsletter is intended to constitute professional advice for medical diagnosis or treatment or to advocate or recommend the purchase of any product or use of any service or guarantee the credentials or appropriateness of any health care provider. Members are strongly advised to consult with an appropriate professional for specific advice tailored to their situation.

This newsletter may refer to named providers and their products or services, and such reference expresses no inference upon any aspect of any provider's business, services or products, and expresses no recommendation or preference for any such products or services.

DATES FOR YOUR DIARY.

Tuesday 6th April 2021

A walk from Aldermaston Wharf to Woolhampton.

Friday 9th April 2021 will be a Zoom talk by the Medical Dogs Association. This is on the second Friday of April as the first Friday in April is Good Friday.

Tuesday 20th April 2021

We intend to have a coffee morning at the Flower Pot in Aston. This will be confirmed later.

Friday 7th May 2021 is being arranged, we hope for a talk by an RBH oncologist. More detail later.