**UROLOGY SUPPORT "US" FOR NORTH WEST KENT AGM - MONDAY 7th SEPTEMBER 2020**

**MINUTES**

Attendees: Paul rainer, John Slade Anton Thorn, Peter Harfleet, Bob Clarke, Mick Carey, Terry? David? Christine’s iPad, Paul Pearson, Geoffrey Wells, Nigel Jennings

Apologies: John Deadman, Ray & Pat Wells, Hazel & Charlie Thorn, Claire Blackman, Jon Burgess, Christine Underwood, Emilee Pendee, Ray Smith.

Introductions: Paul Rainer opened the Zoom Meeting at 7pm from his holiday in the Lake District by explaining the current situation in holding meetings and stating that Zoom meetings are the way forward in the short term and hoping that we might be able to have a meeting in Spring Next year.

Updates: Anton Morgan-Thorne Macmillan Engagement Lead for Kent & Medway. Macmillan are having a major restructuring of the organisation to increase people at the patient interface, investing £2.5 million on technology to ensure the organisation is not caught out if there is another lockdown. Anton reported that East Kent has its full quota of CNS nurses and he is working with Cynthia Matarutse, Head of Cancer nursing at Medway, to ensure that Medway have a full complement of CNS Nurses. He is also working with the Medway Maritime Trust to get support group information displayed on the Trust’s display system and on the reverse of parking tickets. Anton confirmed that the Macmillan Help Line is staffed with cancer nurses and that Macmillan will be sending out a questionnaire for completion.

Updates:

Claire Blackman – Macmillan Urology CNS Medway Hospital.

The Urology team has slightly changed and we are now organised by tumour specific but this does not mean we cannot be contacted about any other tumour site as we are all working as a team. The team consists with:

Claire Blackman lead Macmillan CNS Bladder pathway

Christine Underwood Macmillan CNS prostate pathway

Gemma Vowels Macmillan CNS kidney pathway

Angel Williams urology CNS pre prostate pathway

Sadly Alison Smith has taken ill health retirement so will no longer be a part of this team and any of Alison's previous patients are welcome to contact any of the CNS's and consideration will be made about filling her post in the near future.

Other members of the team are; Hazel Samson band 4 cancer support worker, Emmille Pendi urology CNS and Sarah Wills-Lee Urology CNS.

We are still providing BCG and mitomycin treatment, BCG and mitomycin are treatments for bladder cancer, to patients for 1 year if no recurrence they are going onto cystoscopy surveillance isolation required. TRUS biopsies going ahead as normal isolation and swabbing required prior to procedure, instead of template biopsies under general anaesthetic in some circumstances we are carrying out trans perianal biopsies under local this is to avoid admission to hospital. Cystoscopies are going ahead as normal swabbing and isolation required

All cancer surgical procedures are going ahead again with isolation and swabbing required, we are contacting patients as soon as the plan involves surgery to avoid delay in procedure going ahead.

CPEX, is a fitness test for surgery and can include a plan of exercise to help you reach a level of fitness for surgery, is now taking place in the community for cystectomy and Kidney patients.

 Pre assessment is going ahead as normal again isolation required prior to assessment for cystectomy patients the stoma nurses are attending their pre assessment appointment. Pre- cystectomy patients are having a virtual clinic appointment with Mr Bhat.

TRUS and RAPID access clinics are running as a telephone clinic with the CNS and support worker calling all patients and sending information, if urgent patients are bought in for a face to face appointment this includes testicular penile and for urgent DRE.

Our 2 week wait referrals are all meeting national targets so there is no delay at present.

All MDM, Multi-Disciplinary Meetings, patients are telephoned in clinic and followed up by the CNS or support worker following clinic.

All HNA's, HNA is a health needs assessment carried out at diagnosis during treatment and after treatment if the patient accepts, are being sent out and correspondence is being put on electronically.

New metastatic prostate clinic has been set up and nurse lead to provide to cut down on consultant clinics and provide a compassionate service with a longer appointment time.

PSA telephone clinic has been put on hold for the time being due to COVID but this something that will be nurse lead in the future.

Twocc's, are a trial without catheter, which are happening as normal no isolation required.

We are looking into a new referral system to introduce vacuum pumps for post Radical Prostatectomy to assist with erections - this would be a telephone appointment to consent and the patient would watch a DVD at home and self-teach, the CNS is always around to give advice with complications. The benefit of this would be a quicker process than we have in place now.

Treasurer’s report: Financial situation as of 31 August 2020 -

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| --- | --- |
| **FUNDS TO DATE:** |  |
| **PETTY CASH** | **£49.35** |
| **BANK ACCOUNT** | **£1,946.55** |
| **TOTAL** | **£1,995.90** |

Report - Financial report;

* Overall we are still in a good position as our end of year balance is only down by £128.57 from the start of the financial year.
* We were fortunate to receive a donation of £200.00 from St. Mary’s Gillingham Green Masonic Lodge.
* Major expenditure items for the year were the deposit for the rescheduled Summer Social, Web-site set up costs, postage and banner purchase.

The report was accepted by the members and a vote of thanks was proposed by John Slate & seconded by Paul Rainer – accepted with thanks.

**Election of officers** – it was proposed that in the current circumstances that the committee would be elected as it currently stands with no nominations for elected. Proposed by Bob C and seconded by Paul P and carried unanimously.

**Open forum and items discussed**: bladder cancer, neo-bladders, programme of support to the group delayed due to the pandemic, use of Facebook as a medium for contact. Currently the group do not have the skills within the committee to act as the administrator. Anton kindly agreed to speak to the Macmillan communication team on the legalities and impact of GDPR regarding the use of Facebook.

**Web Site Report from Charlie & Hazel Thorn:** At the 2019 AGM it was suggested a website would be a good idea. Charlie offered to get one up and running through the host he uses for his own. By October 2019 a website was online which has been adapted as time gone on.

There are 5 ‘My Stories’ giving members the opportunity to describe their various operations and recovery. There are 3 bladder cancer stories and 2 prostate, different hospitals, different surgeons, in Medway and Maidstone. There is a gallery of photographs; of members, speakers and events up to Christmas 2019. Graham Elder of St Marys Green Masonic Lodge is pictured presenting a cheque. John Cottis also pictures giving a talk on Walking for Health; he was from the Swale Footpaths group.

There is a page of links to other websites, local and national, Charity and support groups.

The leaflets with the website address have not been able to be distributed due to the cut back in clinics, so the information is not yet getting to those who may need it. The last 2 enquiries have come through the nurses, so they at least are putting the word out. We welcome more stories and photos to refresh the website. If you would rather have Charlie come to interview you and help you write about your journey on the cancer pathway, he will be glad to do it.

The meeting passed on their thanks for the work that Charlie & Hazel had put in to launch & develop the web site - <https://urologysupportwestkent.co.uk/index.html>

**Meeting close**: Paul Rainer thanked all for attending and the meeting closed at 7.53pm.

Peter Harfleet

10 September 2020.