

U.G.I.

Upper G.I. Blues

Raising Awareness of & Funding Research Into
Upper Gastrointestinal Cancers

Newsletter

May

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Upper Gastrointestinal Cancers.

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Sandwell's March Meeting.

A big thank you to all of you who made it to our Upper G.I. Blues meeting on Friday 23rd March. With what started out looking like a disaster with our invited guest speaker getting his dates mixed up I hope turned out to be interesting and informative enough to encourage you to come again.

I knew that I should have contacted Dr. Harvey to remind him of the date, but with everything else going on I just could not find the time and hoped that things were organised in his diary.

The day was saved however by a very welcome surprise visit from Tina Davies. How we have missed her since she left us for places in the wilds of Wales. And then we had our own Jo Harvey step in to inform us that she had been elected onto a survey board into best practices for oncology clinics by NICE. Jo told us that she needs our help in this and asks that you email me at uppergiblues@blueyonder.co.uk with what you think was good practice at your oncology clinics and what you think could have been done better. One of the things that came up straight away was the need to travel to Queen Elizabeth Hospital, not only for blood tests, which could be carried out anywhere, but also for follow up oncology clinic and chemotherapy. One appointment that could result in three different visits to the hospital, and the extra financial burden that this puts onto the patient. Surely something could be done to improve this.

We were then joined by Dr. Nigel Trudgill who apologised on Dr. Harvey's behalf for not being there. I have since spoken to Dr Harvey who hadn't fixed the date in his diary but has said that he would look forward to speaking to us at a later date, and being sure of being there.

Dr. Trudgill went on to tell us of the fantastic successes he is having with the Radio Frequency Ablation system that our group funded. Being used mainly on patients who have had minor

tumours removed the system then makes repairs to the lining of the gullet and stomach that means that further tumours cannot develop in the area. This is great news for our patients and means fantastic savings for the trust funds if a full surgical operation can be avoided.

Charity Show Put On by School.

The year six students at Woodlands Academy of Learning, Willenhall put on an end of term show, "Woodlands Got Talent" to raise funds for both ourselves and the St. Giles charity. The idea for the show was thought up by Jasmin and Jamie Benton and soon involved members of staff, especially Mrs Everist, their class teacher and many of the year 6 pupils in a Britains Got Talent style show.



The Cast.

The following is an edited review of the show from Woodlands Head Teacher Tasmin Newton.

Spring term finished on a real high with “Woodlands Got Talent”, it was such a special evening with our children displaying their special talents. Mr. Fillingham and year 6 pupil Harry Fillingham were excellent comperes as they led us through the seventeen acts and the performance of our massed choir.

The judges had an unenviable job as all the performances were of an unbelievably high standard.

Their results gave a shared first place to Jasmin Benton who sang and danced to “A Million Dreams” and Jack Benton who performed “ Reviewing the Situation” from “Oliver”. Second place went to Evie-Jane Bird and Abbie - Leigh who sang “You Can Count on Me”. Third place was shared by Amiee Sidebotham’s dance routine and Tullia Warren’s Granny Rap. There was dancing for all as “Take a Chance” got everyone to their feet as they performed ABBA favourites.



The Judges.

A massive thank you to everyone who supported the event. To Mr Mason from Pool Hayes Secondary school for providing the venue, to the judges, and an extra special thank you to the Fillingham family and to Mrs Everist who really made this evening happen. It was such a special way to end the term with the bonus of us raising £440 to be shared between our chosen charities Upper G.I. Blues and St. Giles.

Parcreatic CNS at Walsall Meeting.

The April meeting at Manor Hospital welcomed a visit from Emma Kidd a Pancreatic Clinical Nurse Specialist.

As most of us are aware the pancreas is probably the most difficult part of the digestive system to treat for cancer and survival rates are very low. This is mainly because symptoms are not diagnosed until the tumour is in later stages. The role of the pancreas in insulin production and diabetes control and in aiding fat absorption into the digestive system. The symptoms produced by the cancer can include dark urine, abdominal and back pain, bloating and fatigue etc. All similar to minor ailments symptoms and ignored until too late.

When discovered the cancer can be treated by surgery if the tumour has not spread to other parts of the digestive system or by chemotherapy.

The pancreatic cancer support charity pancreaticcancer.org.uk has a number of support groups throughout the country and their ambition is to double survival rates over the next ten years.

The national support line No. Is 0800 801 0707 and a new support service Side by Side where you can speak to former patients is opening in Walsall on 18th June. Go on-line or phone the support line for details

Your UGI Team Will Always Be There For You.

I was diagnosed with oesophageal cancer in 2000 and officially discharged from clinics in 2005. Jo Harvey said at the time “It’s just a thing we have to do but if you have any problems we will still be here and just a phone call away. I didn’t realise then how close an eye they kept on patients.

In 2015 I was diagnosed with a different kind of cancer, Follicular Lymphoma, and had a course of Chemotherapy alongside a maintenance program and things went well until I suffered side effects of the maintenance side and had to come off the program. Things went well until just after Christmas last year when the lymphoma came back with a vengeance and I was started on a new chemo and antibodies program. Of all of the chemotherapy I have had this was the first time where I have reacted badly to treatment. My mouth became ulcerated, I couldn’t eat and lost weight rapidly, losing 20% of my body weight in just a few days and suffering from malnutrition. The haematology team were great in their care for me, but the weight loss was a real problem. Then Jo Harvey came to see me on the ward and said that the nutritionists would be up to see me as Mr. Whiting wanted me fitted with a nasal feed tube. I didn’t even know that Mr. Whiting knew that I was in hospital let alone what my problems were.

The nutritionists came to see me and talked about fitting an NJ tube or the possibility of trying high calorie supplements instead of the tube. They seemed to prefer the supplement option so I agreed to give it a try. Next morning Jo came to see me and said the Mr. Whiting was not happy that the tube had not been fitted and would be done that day. I soon found out that this was the right thing to do and started to gain a little weight and feel a little better.

A few weeks later, as we were setting up our Thursday sales stall Mr. Whiting spoke to me as he came into the hospital. He offered to fit me with a direct Jej feed tube so that the NJ tube could be removed. At the time I didn’t think that I would need the feeds much longer so declined. Wrong decision.

On Monday 23rd April I sent Mr. Whiting an email asking if he was still willing to fit a jej tube. I got a reply the next day saying he was on holiday and would be back the following Monday, no problem. On Thursday 26th April, again while setting up our sales stall I spoke to Jo Harvey and told her about the emails. Jo said have a word with Sonia (Miss Puig) when she gets here and see what she thinks, which I did. Sonia went through all of the problems that could occur because of my chemo program, which is on hold until my blood levels are ok, but said she would have a look at what could be done. Fifteen minutes later Kath Johnson our other CNS said “Sonia wants to see you”. I saw Sonia in the consulting room where she said “sign here, here and here. I’ve booked you in for Tuesday 8th May. I’m busy but I’ve put you on Johns list. I didn’t even know she could do this. Like I said this team is always there for you.

The Next Meetings.

Sandwell’s next meeting is on Friday 25th May at 2pm, Room 9 Education Centre where Sandwell & Dudley Macmillan Benefits advisor will introduce herself to us and then Dr. Philip Harvey will bring us up to date on the latest research program
Walsall’s meeting is on Monday 18th June. Speaker and topic to be arranged.