

November 2016

Dear Friends,

I am always so happy to be writing about another year filled with lovely memories! It has been a wonderful year in so many ways. The most important of all, of course, was Aidan and Laura's wedding on 6 August. It was such a beautiful day and the weather was just perfect to add to the pleasure. Aidan and Laura had planned everything perfectly. Laura looked stunning in her long flowing dress and Aidan with his top hat; Jevan made an excellent best man too. They were able to invite so many guests and strong friendships that had developed over the years on both sides was lovely to see. Mark and I felt so proud!

Going back to the beginning of the year though, it was a busy time as there were big changes happening to the Cancer Drugs Fund; something I have been actively campaigning for from its birth. The public had been consulted on their views and there was an important meeting in London where we were able to meet some of the officials who were making decisions. Mark and I attended and aired our views but, as with most bureaucracy, little attention is paid to this in the end. One of my fears was that, as the new scheme came into effect, most of the drugs previously available for colorectal cancer, could not be accessed under the NHS. This has happened and the CRC patient today does not have so many options for treatment as the patient a year ago while the new access scheme comes into effect.

We felt so privileged to be invited yet again to the Annual Congress by Inspire2Live in February. This is an amazing event because the people are so lovely and Amsterdam is also a beautiful city.

Meanwhile, I was having concerns as my CEA (tumour marker) had risen again and I was given a CT scan. This was all clear although I have since had serious concerns during the year. In March we were ready to go over to France in our caravan. Although this time of year can have a damp feel to it, it is still lovely to be back there. We stayed in Nantes for the first week and didn't realise what a beautiful city it is. We then travelled eastwards along the Loire to Angers, Tours and Saumur before spending a week in Normandy at Merville Franceville Plage, a campsite along the beach.

We returned home in time for a meeting with the European Medicines Agency and Health Technology Assessment Teams. Of course these meetings require many hours of preparation in reading and understanding the documents and I always write a personal response that is added to the literature presented at the meeting. In February, I participated in an advisory capacity to a paper assessment for a new development CRC drug. It is so rewarding to be so directly involved as a patient advocate and with new technology, one can be in touch and prepare from wherever you are! Mark and I had a fantastic moment in August, sitting along the banks of the Loire under the shade of the parasol with laptop, printer / scanner on the grass in 40 degrees!

Towards the end of May, we were making plans for our second trip to France when we had a sudden call from Laura telling us that a 'crazy thing' had happened. Aidan had broken his tibia and fibula during a charity sports match. It took a few days for his operation but all worked out well, even for his surprise stag do in Frankfurt where his walking suddenly improved! We delayed our start to France but were still able to go little further south of the Loire this time, visiting many places we hadn't seen before. I had a wonderful surprise while on the ferry across. I was invited to take a place on the Board of Directors of Europacol. This was such an honour for me and I felt so privileged to be offered this position. I was so excited and so enjoyed the first meeting in London.

Soon after our return, we were flying to Barcelona as I was asked to speak at a satellite symposium of the European School of Oncology during the World GI Congress. The topic was Patient Empowerment and what

needs to change. I really enjoyed this, and as always, meeting such great people in the world of medicine again. Mark and I also lengthened our stay so we could revisit some of the famous places such as the Sagrada Familia, the Magic Fountain, the Boqueira Market and La Ramblas. So much had progressed on the Sagrada and it's wonderful to see the change. We returned with ample time to prepare for the wedding, choosing a dress and Mark being measured up for his suit.

Soon after the big day, we were back in London twice as we were invited to be part of the research team headed by Prof. Mark Lawler on Critical Gaps in Colorectal Cancer research, a big project undertaken by Bowel Cancer UK. Later I was part of the patient team with feedback. Prof. Lawler invited me to join the S:CORT group; Stratification of colorectal cancer from biology to treatment. This is again very interesting and a privilege to be among such knowledgeable people.

Towards the end of March, Mark and I returned to France. We chose to go down to Bergerac where we spent our honeymoon. We first stopped at Montsoreau for a few days, a village we wanted to stop at earlier in the year but the whole Loire Valley was flooded back in June and the people at the campsite had to move quite unexpectedly. This is a beautiful place but it was terribly hot and we chose places to visit that were cool. Langeais and Fontevraud Abbey were among these. We may not have gone there if not for the weather but they were incredibly beautiful and so interesting. We chose an off the road journey to Bergerac, stopping at La Roche Posay, where we went to such fantastic places such as Angles sur l'Anglin and Chauvigny. At Bergerac, lovely memories came back to us and after Aidan and Laura's wedding, these were poignant. Here, we also saw new places such as St Emilion. Really fantastic! Our return took us through La Rochelle, worth a trip on its own, but we got away sooner than planned as a group of medical students were about to descend on the campsite for a 'white night!'. So we returned to a favourite safe spot on the Loire, Blere. We were right next to the river again and the evening walk that took us through the beautiful flowered village and returned along the river bank was unforgettable. We did this every day. No wonder the French are happy....

Our most recent trip has been to ESMO 2016 in Copehagen for the World Cancer Conference along with Europacoln and the Expert Patient Advisory Group. It was a huge congress with over 20,000 attendees. It was really interesting and we were also able to meet as the patient group to hold discussions during our free time. This is a lovely group and I really feel that we are growing together and learning about conditions across Europe through knowing one another. Mark and I had never visited Copenhagen before. It is such a safe country where you can walk across school playgrounds during lunchtime and children go to school on their own from the age of 6. Belongings are left unsecured outdoors and there are no problems. It was lovely to see no fastfood and ready meals in the supermarkets; even the largest supermarket had very little and there were no obvious problems with obesity.

At my most recent visit to my knee consultant for a cortisone injection, I learned that I have a problem with my Achilles tendon and now awaiting an appointment with the foot surgeon. My knee has responded to injections well and I am putting off a knee replacement op for as long as I can. So lucky to be able to do everything I want to.

We have had a wonderful and successful year. Many times we think that we cannot match the previous year because it has been so full and fulfilling. Well, that's now a challenge!

Our love to you all and wishing you peace and love in your lives,

Barbara and Mark xxxx