



Welcome everyone to the first edition of the GIST Cancer UK Newsletter

NEWSLETTER
MAY 2023



Welcome to the first edition our Newsletter which has been designed to be as informative as possible to everyone affected by GIST Cancer. It contains information about our recent Trustees meeting, our recent patient / carer meeting and other work that we are involved with. We would welcome articles from you about your GIST journey and your fund-raising efforts or anything else of interest. We are always looking for more volunteers to become Trustees, - so please contact me on the email below if you can help in any way. Finally, can I draw your attention to **our Survey 'Have Your Say'** on page 4, and encourage you all to click on the link and complete it so we can ascertain your opinions. Thank you.

Nic Puntis. (Chairman, GIST Cancer UK Board of Trustees).... nicp@gistcancer.org.uk

TRUSTEES MEETING 13.4.23

GIST Cancer UK Trustees met in London for their regular Board meeting as they always do before our patients / carers information days. It was a very constructive and helpful meeting.

One sad item is that our former secretary, Sheena Kynoch had passed away. Sheena has been a stalwart of the group for many years, taking minutes and much more. Even after coming off the Board, she continued as a volunteer serving on the telephone helpline and sending out booklets on request. She will be sorely missed and we send our condolences to the family.



Among the useful ideas discussed were the value of a possible regular newsletter about our activities, and a suggestion for an email service which would be more useful than the present 'Listserv'.

We heard about our fundraising activities and future plans, and it was confirmed by our financial report that our finances are healthy.

Two new initiatives were discussed – a fresh approach to funding GIST research, and the possibility of more to help with Mental Health support.

We will have more on this after our next Board meeting in the summer.

We heard reports of various conferences attended by some of our Trustees and Jayne Bressington – representing PAWS-GIST. The reports are extremely useful, both in terms of what we learn, and as opportunities to interact and network with notable clinicians, and with other patient groups. Next month some of us will attend the SPAGN / New Horizons conference in Dublin on both sarcoma more generally, and GIST specifically.

Terry Weldon (Trustee)

**Patient / Carers Conference
London 14th April 2023**



Jane Means (Trustee and Social Media administrator)

GIST Cancer UK is unique. We are the only charity focussing solely on GIST cancer for the benefit of patients, carers and clinicians in the UK.

The charity is run by volunteer trustees who are patients, carers or those with a special interest in GIST Cancer.

Please always remember ... 'GIST IS RARE BUT YOU ARE NOT ALONE'.

<https://www.gistcancer.org.uk/>

admin@gistcancer.org.uk

pawsgistclinic.org.uk



LONDON

GIST Cancer UK Patient / Carer Meeting

Millennium Gloucester Hotel, London Friday 14th April 2023.

The first presentation in the morning was entitled '*Generic Imatinib*' – the *Cambridge Experience*' led by Dr. Ramesh Bulusu, (Clinical Oncologist MD at Addenbrookes Hospital). He explained the process of drug research, product development and its eventual availability for patients. He explained that the generic medicines (Imatinib) are of the same high quality as the brand name medicine (Glivec), but can vary in shape, size and colour.

Since 2016, multiple companies have marketed the generic drug, Imatinib and these have brand names such as Novartis, AmaroX, Teva, Dr Reddys, Sandoz, Accord and Lockhart to name a few.

Dr Bulusu reported on a small Cambridge GIST study that had recently taken place to investigate if all generic brands of Imatinib were equal in their effect. They found that there was a greater than expected toxicity seen with generic Imatinib than with the GLIVEC brand drug (Imatinib). However effects such as nausea, a bitter taste, bloating and abdominal cramps were experienced more in some drugs than others. Across the various brands there was also varying efficacy in the extent to which the Imatinib reached the blood plasma, and that this could impact on progression of GIST.

Generic Imatinib had been originally approved based on data from studies on its use to treat chronic myeloid leukaemia. It was recommended that further studies were now needed to assess the clinical experience with GIST with a regular review of imatinib plasma trough levels.

The second topic of the morning was entitled '*Recently Completed and Ongoing Clinical Trials*' presented by Andrea Napolitano (a locum Consultant Sarcoma Oncologist at the Royal Marsden Hospital).



Conference videos now available.

The videos from the London meeting are now available on the website at: <https://www.gistcancer.org.uk/patient-meetings-2023/>



Andrea Napolitano

There have been 374 Clinical Trials based on GIST studies, and 197 of these have been completed. These included the NAVIGATOR trial 2020, for PDGFRA (for those insensitive to Imatinib). The drug Avapritinib was proved to be an effective drug, but too costly for NHS resources. Despite the use of an expanded access programme, and real-world data to support the INSIGHT trial, NICE (National Institute for Health and Care Excellence) have not currently given permission for the use of Ripretinib (a fourth line drug) in the treatment of GIST (Exon 11 + 17/19 i.e. 20 – 25% of all patients). There are other promising trials including 3 v 5 years Imatinib (SSG Trial).

The take-home message at the end of the presentation was that there have been two recent positive trials but no new NICE approval. So:

- What can we do better as a community of doctors and patients?
- There are other promising upcoming and ongoing trials in the advanced setting which gives hope for new treatment options.

After lunch Dr Bulusu gave an update on the work with Paediatric and Wild Type (PAWS) GIST patients before patients and carers met up in groups for an open discussion about their concerns and sharing of stories and strategies. This part of the day was highlighted by many as one of the most important and helpful aspects of the conference.

The next GIST Cancer UK patient /
carers meeting will be held on
FRIDAY 6th October 2023
at the Novotel on Whitehall Quay



The Board of Trustees are in need of help with the following....

- Administrative Support
- Becoming a Trustee
- IT & Technical Support

If interested, - contact us on: admin@gistcancer.org.uk
for a discussion and to find out further information.

A PATIENT'S STORY: Turning the negative into a positive.

I had been having lots of acid reflux and generally trying to ignore it by consuming antacid tablets in large quantities. During a meeting, a friend (nurse) said – you should go to the doctor – they will be able to give you something to better control it. I hadn't really considered I had a problem, but the doctor gave me omeprazole which seemed to help for a few weeks. Then suddenly I felt weak, was sick and noticed that my poo was dark purple. My GP said I was severely anaemic and sent me straight to A & E. This was in Nov. 2020 and hospitals were really feeling the effect of the Covid Pandemic. I was given blood transfusions, scans and then an endoscopy and a colonoscopy.



Time passed and I had no word back from the hospital. My abdomen continued to swell, and I looked pregnant at 73yrs! In mid-January, my GP contacted the hospital and found that the colonoscopy scan had not been read as the locum doctor looking after my case had left! My GP managed to access the scan and could see it showed a large mass in my abdomen. As a result, I was fast tracked to have what they thought was a tumour growing from the ovary removed. The hospital didn't seem sure of its location so just in case they had a second surgical team on standby. I had a full hysterectomy and they realised that the tumour was in fact growing from the ileum of the small intestine. It was successfully removed with clear margins and the ileum resected.

So began my new life as a GIST patient! Analysis of the 14 cm tumour showed it to be Exon 11 with a high mitotic rate so therefore a high risk of recurrence. I was put on adjuvant Imatinib in April 2021.

I had a few side effects but the most difficult problem for me was nausea. I have found the information and support provided by GIST Cancer UK invaluable. Following a discussion on the on-line patient forum, -'Listserve', I was able to discuss with my oncologist and change the generic brand of Imatinib I was using with the result that I am coping much better with Imatinib and am rarely nauseous.

I attended a patient/carer meeting in Liverpool with my husband in October 2022 and found the day both uplifting and very helpful, and it inspired me to see if I could make a difference. I joined the GIST Cancer U.K. Board of Trustees in January 2023 with the aim of facilitating awareness of GIST, (a rare and not very well known cancer) to the wider community. At a board meeting in April, I was tasked with creating the Newsletter... and this is the first edition. I would encourage patients to attend the meetings as you learn so much both from the presentations and the networking with other patients/ carers.

I look forward to meeting you in Leeds in October.

Ros Langford. (Trustee)

Contact: Helpline 0300 400 000

Your opinion counts!

- The charity is presently reviewing key aspects of its current activities including the website, forum and print resources to consider how they might be improved and extended.
- It is also considering where it should focus its work over the next three years to provide even more effective support to the community.



GCUK would welcome your views to inform its deliberations and you can access a brief survey at:

<https://www.surveymonkey.co.uk/r/W6J6DK3>.

The survey should take less than ten minutes to complete and will be open until the end of May. Thank you.

FUND RAISING : For Research & Patient Support

Friends' haircuts help others.

Hello everyone,

I wanted to share a good news story with you. My daughter and her best friend recently had their long hair cut short to donate it to 'The Little Princess Trust' but they also asked for sponsorship from friends and family and nominated GIST Cancer UK as their charity of choice. So far they have raised £849 + gift aid!

My daughter, Immi, wanted to raise money for GIST Cancer UK after her beloved Grandmother, Pat Rentowl, was diagnosed with a GIST last summer. We as a family have taken much comfort from this charity since Mum's diagnosis - from the initial phone call to my Mum, to the conference in Liverpool last October, not to mention the email forum where Mum has met a fellow GIST-er in Rutland. We hope that the money raised will help the charity in some small way.

Blonde Immi donated 25cm of hair whilst dark-haired Ava donated 35cm. Their locks will be turned into wigs for children undergoing cancer treatment or with other illnesses that result in hair loss. Immi's grandmother received cancer care and treatment at Addenbrooke's hospital in Cambridge. Ava explained: "We thought that having our hair cut to help other people would be a good thing to do."

With very best wishes,

Ali Cooper

