



As I welcome you all to this, the fourth edition of our Newsletter, I reflect on what we have achieved over the last decade of GIST Cancer UK. We continue to support our patients with our patient meetings 3 times a year, and I would like to extend a huge thank you to all the speakers that have, over the years, made presentations to help patients understand about GIST. In the most recent meeting we learnt about some research projects, a very interesting talk about nutrition as well as about how cancer cells communicate with their surroundings, - had tails and could be treated with Viagra to become more responsive to chemotherapy!

I would also like to thank all those that have fundraised for GCUK; we could not offer our services to the GIST community without your efforts.

Finally, I would like to make a request to anyone that might be considering getting involved in supporting GCUK. Please contact us for more information. Our next patient meeting is in April 2025 in Manchester.

*Nic Puntis* (Chairman, GIST Cancer UK Board of Trustees) .... [nicp@gistcancer.org.uk](mailto:nicp@gistcancer.org.uk)



## GIST Cancer UK Patient / Carer Meeting

Millennium Gloucester Hotel, London, Friday 5<sup>th</sup> October 2024.



Chairman of GCUK, Nic Puntis, welcomed everyone to the meeting and explained the Charity's priorities and what we do. The GCUK Trustees (present) introduced themselves, and outlined the areas they were particularly responsible for. Nic encouraged our audience and others to consider putting themselves forward to help with the running of GCUK .... we need more Trustees, and also volunteers to assist with the 'Helpline', and admin. If you can help, - please contact: <https://www.admin@gistcancer.org.uk>

The updated GCUK website was launched in September and Mark Atlay (GCUK Secretary) Introduced this to the audience.



Mark Atlay introduces the new GCUK website.

The update was in response to a survey of patients/carers and we hope users will find it easier to navigate and quickly access the information they require. Please take a look on: <https://www.gistcancer.org.uk/> and the meeting archive section on:

<https://www.gistcancer.org.uk/information/meeting-archive>

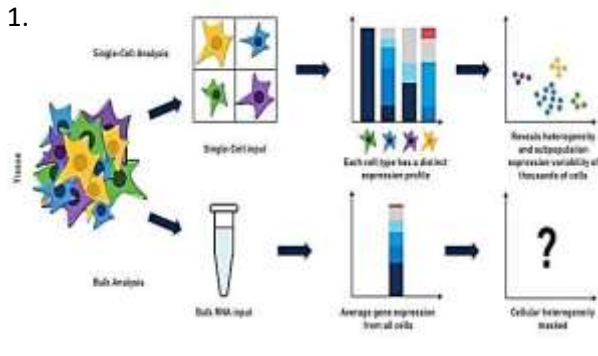
Without our amazing supporters, our GCUK Charity could not fund the research / support and meetings for patients/carers.

We are very grateful for the wonderful fund-raising projects and donations that have provided financial support. On page 5 of this Newsletter, you can read about some recent events .It's another way in which you can support the Charity, and we would be very grateful for your continued support and sponsorship from businesses, groups and individuals.

Our first speaker of the morning was **Dr Zoe Walters** (Associate Professor in Translational Epigenomics at the University of Southampton) and her presentation was entitled '**GIST Research at the University of Southampton**'. She outlined the current projects and an overview of new research that the team are hoping to get funded. First was an update on the Tumour microenvironment (TME) i.e. that tumour cells don't exist alone but exist alongside and are supported by other cells in their microenvironment (TME). The tumour cells and other cells in the TME 'communicate' with each other and this determines their survival ... or not. In an anti-tumour environment, the immune system has natural killer cells (NK) which can recognise the tumour and kill it. However in a 'tumour-promoting' environment, the tumour can hijack other parts of the TME, removing resistance and enabling it to develop and grow.

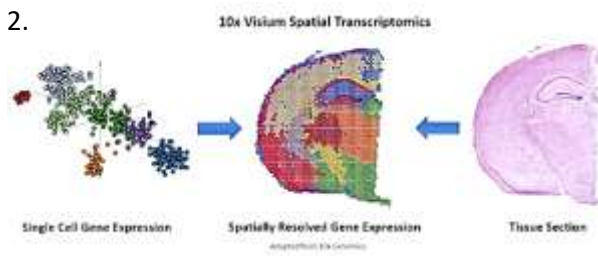
The aim is to better understand the TME and processes by which an anti-tumour environment can be maintained. By data analysis, scientists are investigating what causes the NK cells to stop recognising and killing cancer cells. The research team at University of Southampton want to make models of Wild-type (sdhd) GIST cells and repurpose / engineer them in order to get treatment to patients more quickly. Her team are also working on the understanding of the single-cell sequencing of a tumour cell to provide an 'Expression

**Dr Zoe Walters**

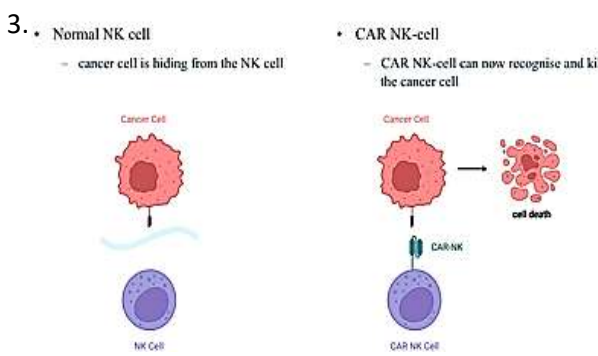


profile' (slide 1). Understanding of the single cell profiles of tumour cells will enable greater understanding of why tumour cells don't work normally.

Spatial Transcriptomics (slide 2) helps to identify the RNA location in tumour samples. Using this method, - researchers can identify which cells are 'talking together' and which immune cells are not recognising the tumour cells. Once the reasons for this are identified, they hope to re-activate the immune cells so they can resist tumour growth.



The University of Southampton uses a 'super computer' called IRIDIS which is used for data analysis in this research work. It is also capable of generating a model of a solid GIST cell thereby speeding-up research work. Dr Walters explained about two potential strategies/mechanisms and some of the new treatments that her co-researchers want to work on subject to funding:



- **CAR-NK cell** - (slide 3) is a type of innate immune cell (e.g. a white blood cell) that is genetically modified to target cancer cells. Researchers are working on creating a CAR-NK modified immune cell that will recognise and eliminate a GIST cell.
- **Alternative polyadenylation (APA)** – this has a significant role in discovering the GIST Cancer susceptibility gene. Who knew that cancer cells have long tail lengths!! Screening of APA 'tails' in data sets is being used by researchers to identify specific APA events that give rise to GIST.

We were all excited to hear about the research taking place and hope it will eventually lead to new GIST cancer treatments creating the potential for improved outcomes. GCUK now needs more funding to help to continue the process.

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

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

[admin@gistcancer.org.uk](mailto:admin@gistcancer.org.uk)

[pawsgistclinic.org.uk](http://pawsgistclinic.org.uk)

Our second speaker of the morning was **Professor Robin Jones** (Consultant Medical Oncologist) from the Royal Marsden Hospital. His presentation was entitled '**Clinical Trials including PEAK and GIST-related trials**'.

Professor Jones felt that researchers should now be focusing more on the early phase of cancer diseases. For example, scientists globally are working towards creating blood tests that could identify the molecular profile of a specific tumour early-on, to enable a more customised treatment for patients and reduce the side effects. He gave updates on several trials that were being used to treat adjuvant and metastatic disease:



**Professor Robin Jones**

- 3yr v 6yr trial being carried-out in France which confirmed that adjuvant therapy reduced recurrence more successfully with the 6-year treatment. The results of the Swedish adjuvant 3yr v 5yr trial are expected next year.
- Combination trials such as the PEAK trial – that used various combinations of Bezuclastinib and Sunitinib were in the second stages of treatments. Ripritinib and Avapritinib have proven to be effective but due to costs are not an available line of treatment in the U.K.
- The Intrigue Trial for patients having advanced GIST showed meaningful clinical benefit with Ripritinib and Sunitinib patients and is being followed up with another Ripritinib trial.
- The IDRX-42 trial that is being used with heavily pre-treated GIST patients is in its early phase with 73 patients. It has a favourable safety profile and is being well tolerated by patients.

He stressed it was critical to have interaction and collaboration by scientists across the World in order to get the approval of new drugs for use in the treatment of rare cancers like GIST. Professor Jones wanted to take and respond to as many questions as possible in the time left. Some of the information resulting from this was ....

- Are we trying to eventually get a 'one tablet fits all' drug? Answer ... yes but that is still a very long way off!
- Tumour cells that respond to chemotherapy can be treated with Viagra to change their shape so they become more responsive to chemotherapy.
- The standard dosage of Imatinib is 400mg but this is variably tolerated and so in consultation with the oncologist, different dosages can sometimes be trialled to see if that works better. There is a great deal of variation ... and he is aware of patients that have lived for more than 10 years on 100mg dosage.
- Regarding the toxicity of various generic brands of Imatinib – involve your oncologist early on if you are not tolerating the drug and get the prescription changed to a different brand.

Professor Jones concluded by saying that the ultimate aim was to get our immune system to recognise and pro-actively respond to cancers so that ultimately drugs are not needed.

After lunch members of the audience were invited to give feedback for a Sarcoma U.K. survey called 'State of the Nation Review'. The responses showed huge variation and will be used to inform and support a response from GCUK.



**Professor Robin Jones taking questions from the audience at the Patient Carer Meeting.**

**Conference videos** from the 5<sup>th</sup> October 2024 meeting in London **will soon be available** on **YouTube** and on the GIST Cancer UK website at: <https://www.gistcancer.org.uk/>



Our afternoon speaker was **Deborah Warner**, a Nutrition Scientist with a background in Genomics. In her work as a public health nutritionist she had worked with many cancer patients including one GIST patient. More recently she was herself diagnosed with Wild type GIST.

Her mantra was to: *'Prepare your house, your body and your freezer'*! She stressed how important it was for us to make the right choices about our diet. She encouraged us to:

- Have a 'Healthy plate' with a balance of Protein, Carbs and Vegetables... half of the plate being vegetables!
- Reduce the amount of processed foods that we eat.
- Gain muscle and preserve lean muscle mass.
- Eat a variety of foods with the vitamins and minerals, antioxidants etc. that protect us from disease.
- Hydrate regularly
- Chew our food properly

Deborah answered a lot of questions at the end of her presentation and warned about misinformation that was spread by adverts in the media which was repeated so much that there was a danger of them becoming 'science'!

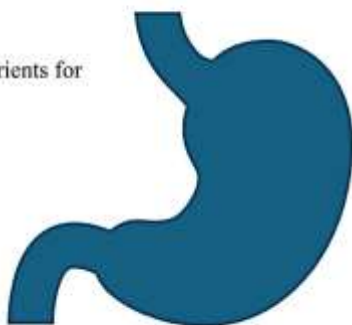


### Important considerations for cancer patients

To consume sufficient calories and nutrients for

- Recovery & healing
- Energy balance
- Maintain a strong immune response
- Organ function
- Mental health and stress levels

• Prepare house, body and freezer!



Many GIST Cancer patients have by the nature of the disease had to make adjustments to their diet as a result of surgery to their digestive system etc.

GCUK provides resources such as *'Eating after GI surgery'* and *'No Stomach?'*, which are available to download from the website at <https://www.gistcancer.org.uk>

→ Get information → GIST Publications.

The next GCUK Patient /Carer Meeting will take place on **11<sup>th</sup> April 2025 in Manchester**. We look forward to meeting up with old and new GIST Cancer patients. The venue and further details will be sent out in the New Year.



M A N C H E S T E R

### Scottish GIST Patient / Carer Meeting

**Friday 6<sup>th</sup> December 2024**

at the COSLA Conference Centre,  
Edinburgh EJ12 5BH

To book a place, please email  
[meetings@gistcancer.org](mailto:meetings@gistcancer.org)

GIST Cancer **UK** is unique.  
We are the only charity focusing *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.

**PAWS-GIST CLINIC**  
**6<sup>th</sup> December 2024**



Addenbrooke's Hospital  
Cambridge, CB2 0QQ

To book a place please email:  
[jayne@pawsgistclinic.org.uk](mailto:jayne@pawsgistclinic.org.uk)

# FUND RAISING : For Research & Patient Support

## Junction Inn Fundraising Weekend

A fundraising event for GIST Cancer was held over the summer bank holiday weekend and raised over £1,300. A big thank you to all who took part; donated and lost their hair either by shaving or waxing. A big thanks to Gav Sykes (organiser) and all the staff and punters at The Junction Inn, Normanton, Yorkshire.



## Fundraising Golf event for Gist Cancer

Congratulations to GIST Cancer patient Douglas McDavid who recently organised a fundraising 'GIST Cancer UK Golf event.

Douglas writes: "I decided to invite a few friends for a golf event at Close House near Newcastle, and we had a fabulous time, - an overnight stay and two rounds of golf. I wanted to thank GIST Cancer UK for all their support since my diagnosis. Big thanks to the venue for looking after us so well and donating some great prizes. £2113 has been raised so far and will be passed over to GIST Cancer UK.

Thanks also to GCUK Trustee David Lane, ( i/c GCUK fundraising) for his advice and help in ensuring the success of the event and sourcing the special golf balls."



**GIST not good enough !**

## ... SOURCE OF LIFE PROJECT...



From 11th - 21st September Drewe Lacey (a GIST Cancer Trustee and fellow GIST cancer patient) put his best foot forward to complete his 'Source of Life' project. Supported by family and friends Drewe walked 146 miles along the Wye Valley, with 11,219 feet of ascents. Drewe aimed to raise £8K for two causes close to his heart, - GIST Cancer UK and the River Wye environment. During the 11 days, Drewe was well supported by the Rotary Club with Civic receptions in Hereford, Ross on Wye and Monmouth. Thanks to generous donations his 'JustGiving' page today shows the amazing total of £9,390 has been raised! Further pledges are forthcoming, and it is expected that the project will hit **£10,000** against the original target of £8,000.

**50% of the overall total is pledged for GCUK.**

A big thank you to Drewe on such a brilliant effort. Nic Puntis (GCUK Chairman) said... "a positive attitude allows us to better than endure, but achieve something that we might think unachievable!" You can still donate on the JustGiving page for a further month - visit

<https://www.sourceoflife.co.uk>

*Thank you*





## Request for 'Patient Stories' on the GIST Cancer U.K. website.

The 'Patient Story' section is also one of the most frequently visited sections of the website and we're keen to ensure it contains a broad cross-section of patients' experiences. So we are looking for GIST patients and carers who would be willing to share all, or part of their GIST Journey with us. It could just be about your treatment pathway, surgery or anything else that you wish to share that might be of interest to others. Please get in touch if you wish to participate or if you would like to find out more about what's involved. Email: [patientstories@gistcancer.org.uk](mailto:patientstories@gistcancer.org.uk)

### David's Story

Hi, I'm David and it's difficult to say when my GIST journey started, as it took a while to get diagnosed. I had been visiting my doctor since around 2016 with abdominal pains and given many different possible diagnoses of IBS, appendicitis, gastritis to name a few.

Eventually on 10th of March 2022, I took myself to A&E with acute stomach pain. I had been on the way to work in Leeds on the train and I got stomach ache again, but this time it was really painful and I ended up making my way to Leeds General Infirmary A&E.



At first, they didn't know what it was and suspecting appendicitis, they transferred me to St James's Hospital in Leeds, where I then spent 4 days. Here they started the investigations, where a CT scan and a biopsy were carried out. The surgeon on call confirmed there was a large unknown mass in my small bowel, and I would have to wait for the results of the biopsy to come back to confirm exactly what it was.

10 days later...I had my appointment with the surgeon; he confirmed that the mass in my stomach was cancer, a rare type of cancer called GIST (which I had never heard of before). The tumour in my small bowel which was measuring 7cm by 7cm had perforated and that was the cause of the pain. It was too close to important blood vessels, so I was advised against surgery straight away and Imatinib was recommended to shrink the tumour before considering the removal.

I didn't start the Imatinib straight away because...I had just got married, we were two weeks away from going on our honeymoon, which unfortunately we had to cancel, but most importantly we were wanting to start a family. We were advised to freeze some sperm so IVF would be possible in the future. This was done and I started taking Imatinib a month later in April 2022. Thinking about the imatinib medication and the side effects I encountered, I mainly started off with headaches, sickness and fatigue. The hospital has changed the medication manufacturer a few times and some of the brands had more symptoms such as cramps in my hands and fingers, but I think I have now found the best option for me. I also take the anti-sickness medication in the evening after food, which I find very helpful. I have good days and bad days, but I feel I cope better now with the medication than when it was first prescribed.

The imatinib worked well to begin with and shrunk the tumour to about 5cm x 5cm by July 2022. Unfortunately, by October 2022, the tumour had become cystic and grown to 8cm by 8cm. The hospital gave me a choice, either keep taking the imatinib to see if it shrinks further or go for surgery, I chose the surgery which took place on 1st of December 2022 and was successful. The GIST was actually a bit bigger at 10cm x 10cm by the time it was removed. The surgeon undertook two resections, one to remove the GIST and the other to remove an inflamed diverticulum. I stayed in hospital for just under a week then I was allowed to go home.

I was advised to keep taking the Imatinib for at least 3 years after my surgery; - possibly life-long due to the fact that my tumour had perforated and was categorised as high risk of recurrence.

Looking back at the last few years...The cancer diagnosis of the GIST has been a rollercoaster of a ride for my wife and I. I have been very lucky to have been supported by my employer who I have to say have been great every step of the way, and I feel this cancer journey that I am on would have been a lot more difficult without the support of them.

I am also happy to say that we have now completed the IVF process and have a beautiful 6 months old daughter called Connie. I can't explain how much my outlook on life has change in these last few years from wondering about my own life and how long I had left to now being lucky enough to guide another little human through life the best I can.

I hope that me sharing my GIST journey can help others the same way that the patient stories I read helped me when I first stumbled on the website.

# Donations & Fundraising

Help support our work with patients and research for more effective treatment.

With your help we can achieve more

...

- The charity receives no government funding and is run by volunteers.
- Our donors and fundraisers support all our activities including the patient/carer meetings, the helpline, the forum, the clinics and the research.
- We appreciate any contribution you feel you can make - however large or small.



Organise a coffee morning / afternoon tea, cake sales

Leave a gift in your will.

Get match funding from your workplace to double the funds

## Support with Fundraising:

We have a range of products to help you raise awareness of GIST and PAWS-GIST cancer while you are fundraising.

If you'd like information, materials or support for your fundraising activities or just want to let us know what you're doing, then please

contact us at

[fundraising@gistcancer.org.uk](mailto:fundraising@gistcancer.org.uk)



Donate online (via JustGiving)

Take part in a an organised event e.g. a marathon, trek, swim

Organise a 'special' birthday event

Organise a sponsored event e.g. run / cycle/ hike /pub quiz

**\*\* Thank you so much to the current 'in memoriam' Just Giving pages that between them, so far, have raised over £12 K**

[Jo Parton is fundraising for GIST Cancer UK \(justgiving.com\)](#)

[Paine Family is fundraising for GIST Cancer UK \(justgiving.com\)](#) and [Kieran Fey is fundraising for GIST Cancer UK \(justgiving.com\)](#)

*Thank you!*

**VOLUNTEERING:** If you can help, - please do make contact and we can talk about what you might be able to do and the time you can give. We do recognise that time is precious or you may have other commitments, but even a small amount of time to help would be great! *Thank you!*