



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

NEWSLETTER
APRIL 2024



Welcome to the third edition of our Newsletter which has been designed to be as informative as possible to everyone affected by GIST Cancer. It contains information about our most recent Patient / Carer meeting held in Cardiff and some of the exciting research projects that GCUK are funding and supporting.

We are also working on updating our website at the moment, and one of our new Trustees, Cathy Hampshire, is reviewing the 'Patient Stories' section and would welcome some new

material. There are many ways in which you can become involved in supporting GCUK and we hope you will consider doing so. Finally a huge thankyou to all those who are involved in fund raising for the charity in so many diverse ways.. – we hope you enjoy reading about them all.

Our next Patient / Carer meeting will be held in London in October and we look forward to seeing many of you there.

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



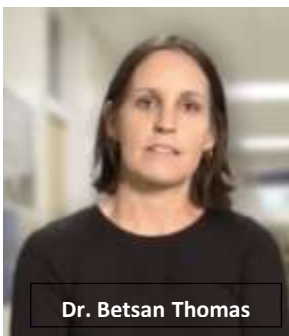
CARDIFF

GIST Cancer UK Patient / Carer Meeting

Marriott Hotel, Cardiff, Friday 12th April 2024.

Another very informative and inspiring GCUK Patient/Carers meeting was held on Friday 12th April at the Marriott Hotel in Cardiff. GCUK Chairman Nic Puntis welcomed attendees who were a mix of GIST Cancer patients, carers and medical professionals.

The first of the morning speakers was **Dr Betsan Thomas** (Consultant Clinical Oncologist) from the Velindre Centre / GIST Cancer in Wales who spoke about the latest treatments, trials and research being carried out at Velindre.



Dr. Betsan Thomas

Of the approx. 700 new GIST cases diagnosed each year nationally, 30 – 60 of these are new cases occurring in Wales. The 'TARGET Team' of clinicians at Velindre uses ctDNA / tissue genomic testing to identify targetable mutations and facilitate their entry into clinical trials. These trials include the

'Peak Study', (which is evaluating the use of a drug called Bezuclastinib in combination with Sunitinib with imatinib-resistant patients), and the use of Ablative Radiotherapy to treat localised lesions.

Radiotherapy

How does radiation work?

- Use of high energy X Rays or particles to damage cancer cells
- Causes DNA damage



- Useful treatment option for selected GIST patients
- It is a radiosensitive disease
- Low doses may be useful for bleeding or pain
- High doses may be used to 'ablate' a localised lesion which is enlarging: personalised approach needed



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.

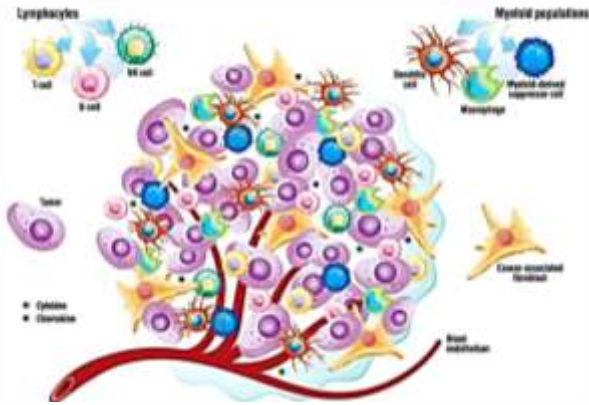
Our second speaker for the morning was **Dr Zoe Walters** (Associate Professor in Translational Epigenomics / Cancer Sciences at Southampton University) who gave a superb presentation about the latest grant research into the Tumour Microenvironment. It was wonderful to hear about the very good progress in this research which will be co-funded by GCUK & Sarcoma UK..



Dr. Zoe Walters.

Zoe explained how abnormal cells, such as cancer cells, can change the cells, molecules and structures in their microenvironment. However, it is the **Tumour Microenvironment** (TME) that can affect *how* a tumour grows and spreads.

What is the Tumour Microenvironment?



- The tumour microenvironment is composed of a diversity of cells, and it is this diversity that can support or restrain the development of tumours.
- In a tumour, the diversity of cells and their metabolism is dependent on the cell states, location, and the nutrient availability within the TME
- The researchers are studying the **signals** across these diverse metabolic pathways within the TME to look how these indicate patterns of support or inhibition of tumour development.

GCUK funding of the research into the tumour microenvironment by Dr Zoe Walters and her team at Southampton University will enable greater understanding of how cancer cells are affected by their TME, and they are working to develop therapeutic strategies to predict and neutralise resistance and survival tactics deployed by GIST cancer cells.

We were all excited to hear about the research taking place and hope it will eventually lead to new GIST cancer therapy strategies creating the potential for improved outcomes.

Our 2024 GCUK and SUK PhD studentship

- Technology development has outpaced our ability to fully analyse the data
 - Integration of scRNAseq and spatial transcriptomics especially difficult
- Analysis requires skills in computer sciences, bioinformatics, cancer biology & immunology
 - International shortage of computational biologists/bioinformaticians
 - Computational biology and genomics a strength at University of Southampton
 - Access to cutting edge genomics technologies and high-performance super computers for data analysis
- GIST Cancer UK co-funding a 4-year iPhD studentship
 - Medical Research Council integrated PhD scheme

University of Southampton, Linköping University



Dr. Lesley Storey

Our afternoon speaker was **Dr. Lesley Storey** (Senior Lecturer in Psychology at Anglia Ruskin University).

Lesley's presentation on 'Qualitative Analysis about the quality of life with a GIST diagnosis' really resonated with many in the audience.

Preliminary findings/areas to take forward

- Classifying experiences as common or stratified can help to inform both future research interventions.
- Socio-demographic data was relatively unimportant compared with life-stage.
- Links such as the effect of physical problems on mental and emotional state are important when assessing quality of life
- Existing informal social support seems to be preferable to formal or peer support. Pairs with limited support networks may need to be the focus of support offered

Attendees found the question / answer sessions with the speakers and the informal discussions with other patients & carers very helpful. The insight into the research taking place into rare cancers gave everyone much hope that future scientific/ clinical discoveries and practices will be very beneficial to patients who are diagnosed with GIST rare cancers. So much progress has been made in diagnosis & treatment since 2010 and GIST Cancer funding is really enabling this to continue apace.

The next GCUK Patient /Carer Meeting will take place on 4th October in London. We look forward to meeting up with old and new GIST Cancer patients and their carers at the Millennium Gloucester Hotel, South Kensington.

CLINICAL TRIALS NEWS

Nic Puntis (GCUK Chairman) presented information about a new clinical study which is about to embark in the UK. The IDRX-42 Phase 1b trial has opened for enrolment at the Royal Marsden Hospital, London.

StrateGIST 1 : First in Human study of IDRX-42

- StrateGIST 1 (IDRX-42-001) is a Phase 1/1b open-label, first-in-human study of IDRX-42 in patients with metastatic and/or unresectable GIST
- Phase 1a portion of the study enrolled patients in escalating dose cohorts in a standard 3+3 design (US ONLY)
- **Phase 1b is OPEN for enrollment in the UK* and EU in MAY!!**

Phase 1b

One or two dose levels selected using tablet formulation (suitable for late-stage development and commercialization)

Dose 1

Dose 2

Up to ~30 patients across four planned cohorts, to acquire additional safety, PK, and response data
Informs dose selection(s) for Phase 1b portion (RP1bD)

* Opening in May 2024 at the Royal Marsden Hospital. PI: Prof. Robin Jones

IDRX-42

The American drug company IDRX have already been running a Phase 1a trial of their drug IDRX-42 in America, and Phase 1b is being opened up in the UK on May 24th 2024 and then in mainland Europe.

The drug company IDRX was co-founded by Nick Lydon who was the inventor of Imatinib together with George Demetri who is a world leading expert on GIST.

Many GISTS develop resistance to TKI treatment (e.g. imatinib, sunitinib, regorafenib, ripritinib) during treatment, - usually driven by secondary mutations in the primary kinase oncogene (KIT or PDGFRA), so new therapies are being trialled to prevent the emergence of sub-clones or to treat TKI resistant GISTS. Phase 1b of IDRX-42 is one such trial.

- **Professor Robin Jones (at the Royal Marsden) is leading the UK trial arm, and he will be raising awareness about the trial with his network of GIST specialist clinicians when the trial opens.**
- **Phase 1b will enrol separate cohorts of patients determined by the number of prior lines of GIST therapy they have received. They are even hoping to enrol patients in first line (prior to any Imatinib treatment), which is most unusual.**
- **It is very exciting to have this new trial opening for GIST patients at all stages of their journey; it does however exclude Exon 18 and PAWS-GIST patients.**

The next GIST Cancer UK patient / carers meeting will be held on

FRIDAY 4th October 2024



At the Millennium Gloucester Hotel
Kensington, SW7 4LH

Annual Scottish Patient / Carer Meeting

Friday 6th December 2024

at the COSLA Conference Centre,
Edinburgh EJ12 5BH

PAWS-GIST CLINIC

9th August 2024

Addenbrook's Hospital
Cambridge, CB2 0QQ

To book a place please email
jayne@pawsgistclinic.org.uk



A PATIENT'S STORY: 'A chance finding'

by Cathy Hampshire (GCUK Trustee)

For many years I had been suffering with stomach pain, and at times bleeding. I had been to see different Gastroenterologists over the years and had undergone many procedures only to be told that it was IBS / needing to eat a high-fibre diet / a low fibre diet, etc. One weekend in early 2019 I had really excruciating pains in my stomach, I was being sick, couldn't eat or drink anything or stand up. I got an emergency appointment at the GP and was sent to the local hospital where I was put on a drip and had various tests. I was given antibiotics and sent home, the pain eventually disappeared.

About a year later the same thing happened again, and I went straight to the hospital, - had more tests and then a scan too. I went home with antibiotics and then had an outpatient appointment with an upper GI Tract doctor. He told me that there was a tiny lump near to my stomach and he would keep an eye on it, he thought it was possibly a cyst. I then had a repeat scan after 6 months. When I saw Mr Saha again, he said that the lump had returned and slightly bigger this time, about 2cms. He informed me that he had studied a rare type of cancer called a *GIST* for his medical studies thesis and he was going to ask the team if this little lump could be one!



A few months later, Mr Saha was back in contact, this time during Covid, so all conversations were on the phone. He had taken my case to the MDT and they did agree that I had a GIST; it was between my stomach and the start of my small intestine. Now to get it removed! I was reassured that once removed it was the sort of cancer that was not given further treatment. A date was set for June 2021, but this was cancelled for numerous reasons, and my GIST was finally removed on 6th October 2021. By this time, it was very large – at least 15cms in length, so full stomach surgery was carried out. I was in hospital for just over a week, and once home, made a really good recovery. Mr Saha rang me to let me know that the lab reports indicated that the cancer cells had not spread.

In the November 2021, I was asked to attend an appointment at St James' Oncology unit in Leeds. I was informed that I needed to take Imatinib as an adjuvant treatment for 3 years to prevent the GIST returning. I was unsure but agreed to take the medication. I was on the medication at a low dose for about 3 months, and had regular blood tests. One of these showed a spike on my ALT levels in my liver. It appeared that the drug caused my liver to react and I was taken off the treatment. So there followed a period of 3 monthly scans and regular blood tests.

After about 18 months I started to feel the same symptoms as I had prior to the original surgery and at one of my regular check-ups I told the doctor this. As I wasn't due for another scan for a further 3 months we had to wait to see what that showed. In May 2023, I was informed by the doctor over the phone that the GIST had returned (metastasised) with some small nodules in the jejunum of the small intestine, and one in my liver. Needless to say, I was devastated!!

I was put straight back onto the Imatinib, which had the same effect on my liver. I was taken off that and then given Sunitinib. This drug also affected my ALT liver levels. In October 2023, I started taking the 3rd available drug Regorafenib, on a very low dose. Recently the dose has been increased and the hope now is that it stops the nodules from growing and shrinks them.

In December 2023, following my attendance at the GCUK Patient / Carer's Meeting in Leeds the previous October; I put myself forward to become a Trustee on the GCUK Board of Trustees. I am now busily working on various aspects of work the Board undertakes and have taken on the role of reviewing the 'Patient Stories' for the GCUK website which is currently being revamped.

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

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

admin@gistcancer.org.uk

pawsgistclinic.org.uk

Time to give something back to the GCUK Community



GCUK is run solely by volunteers and we're always looking for new people to help and support the work that we do. If you have some time then do contact us and we can talk through the possibilities and how your skills, experience and enthusiasm can help. For example, we need help with in our 'fundraising' and 'new members' teams responding to requests and sending-out materials, you can offer support through providing a *Patient Story* (see elsewhere in this newsletter for more details) or why not join the Board of Trustees and help steer the future of GCUK. Training and support is provided in all roles and the time commitment can vary to meet your circumstances.

For an informal discussion or to find out more contact our secretary Mark Atlay
([email:markA@gistcancer.org.uk](mailto:markA@gistcancer.org.uk))

Thank you! Three hearts in blue, light blue, and red colors.

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

My name is Cathy Hampshire and as a recently appointed Trustee for GIST Cancer UK, one of my tasks is to update and refresh the Patient Stories area of our website which is currently having a revamp.

We will often use a patient or supporter story on our media platforms or to help raise awareness of GIST. The 'Patient Story' section is also one of the most frequently visited sections of the website so we're keen to ensure it contains a broad cross-section of patients' experiences.

Sharing your story on social media, newsletter, TV, radio, or amongst friends and family at an event is an impactful way to deliver a message and to help and support others.

I am 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.

This can be in the form of a short-written statement with or without a photo. We can also arrange to 'interview' people over the phone or video.



The aim is to update this section of the GCUK website with 10 or 12 new stories and rotate them on a regular basis.

We also want visitors to the website to be able to use the new search facility within patient stories to make finding someone with similar experiences easier.

Please get in touch with me if you wish to participate or if you would like to find out more about what's involved. Email: patientstories@gistcancer.org.uk

Conference videos will soon be available.

The videos from the Cardiff meeting will be available on **YouTube** and on the GIST Cancer UK website at: <https://www.gistcancer.org.uk/>

FUND RAISING : For Research & Patient Support

A FANTASTIC FUND-RAISING EFFORT BY

KING'S ELY PREP SCHOOL

The children, families, and staff at King's Ely Prep have raised more than £17,000 for two cancer charities!

*"A phenomenal **£17,574** was raised by their Prep School community between January 2023 and December 2023 for Cancer Research UK and GIST Cancer UK. This is the highest amount of money ever raised for charity by King's Ely Prep., and the school could not thank their pupils, families' and staff enough for their generosity".*

The money was raised in all sorts of ways – bake-athons, sponsored runs, pre-loved sales, non-uniform days, and more.

On January 25th, King's Ely Prep welcomed Gill Burgess, (the Relationship Manager for Cancer Research UK in East Anglia) and Dr Ramesh Bulusu (Clinical Lead at GIST Cancer UK), to their Ely Cathedral Service so that they could each be presented with a cheque for **£8,787.42p**. Mrs Burgess and Dr Bulusu were both so grateful



GIST Cancer UK sent a very special thank you to the King's Ely Prep School community for their ever-present support, energy, and generosity, and the amazing funds raised which will be used to support GIST Cancer Research and patient support.

WOW!

... GIST CANCER FUND RAISING EVENT ...

Source of Life Project

Rotary
D1100 



A Rotary charity event, raising funds to fight pollution in the River Wye and Cancer.

Whether walking, running, biking, canoeing, or riding - join us to cover a part or the entire length of the 136 mile Wye Valley Walk.

50% of funds raised will support environmental charities in the Wye Valley, and 50% will support GIST Cancer UK.

WHEN
School Summer Holidays
Aug/Sept 2024

Register and make a donation to take part.

WHY NOT COME ALONG AND JOIN IN?

- You, your family, or friends, who have been affected by Cancer.
- You, who care for our environment and for the life of our rivers.
- You, who enjoy the outdoors - walking, running, biking, canoeing, and riding.
- Just join on one day during the school summer holiday 2024, or do the 10-day September Challenge.

Drewe Lacey, - who is a GIST Cancer patient and GCUK Trustee will lead this project. He and others will endeavour to walk the entire 136 miles across a 10-day period, beginning on the 11th September at the source on Plynlimon and ending with a celebration in Chepstow at the mouth of the Wye on the 21st September.

..... tell all your friends, and let's raise lots of money for some life-changing causes.

50% funds raised will each go to support GIST Cancer UK and to support environmental charities in the Wye Valley.

For further information please contact: Drewe Lacey or one of the team at source.of.life2024@gmail.com

£2,500 raised so far for GCUK by James taking on the Three Peaks Challenge on 27th April!

I am doing the Yorkshire 3 peaks challenge on 27th April with 8 other lads who have agreed to help me raise money for [GIST Cancer UK](#). This started off as a challenge of friends but when I mentioned raising money for this charity they all got right behind me even when I know there are other charities close to their hearts which they could've raised money for. I have so much love and respect for all of these lads. I have been blown away by the donations so far and appreciate each and every one!

When I was originally diagnosed, my local hospital and doctor did not know what GIST cancer was and I sat with my GP who googled it for me to try to understand it more. I then reached out to GIST Cancer UK who helped me understand what my diagnosis meant and also invited me to a seminar in London to meet specialists and other GIST cancer patients / carers. This really helped me to understand the different types and how it affects people differently but also get some closure by talking to other people who were at various different stages of diagnosis. I can't thank them enough for their help and this is the first of hopefully many fundraising events / challenges I will do to support this great charity.

Any donations will be greatly appreciated... *James Head.*



Many thanks to Bethany Hunt and the 42 people who completed the 3 Peaks Challenge on a windy 6th April.

It went amazingly well, and £3620 has been raised so far with some more to come in. Well done everyone!

Congratulations!! ... that's an amazing achievement and effort on the part of everyone and the funds raised will be put to good use at [GIST Cancer UK](#).

