

Cancer Connect

The St George's newsletter for people affected by cancer

Issue 10, August 2023

Teen survivor of rare cancer inspired to be a nurse thanks to team who saved her life

A recovered paediatric cancer patient is hoping to follow in the footsteps of those in our paediatric team at St George's Hospital who saved her life.

Zoe Magness recently celebrated her 18th birthday and was four years old when doctors found a tumour on her right lung.

She began chemotherapy treatment immediately and was transferred to the paediatric intensive care unit (PICU). Zoe only had a slither of one lung working, as the cancerous tumour pushed her heart and working lung across her body.

Zoe was diagnosed with Type 1 Pleuropulmonary Blastoma, a childhood lung cancer – so rare that she was one of less than thirty people in the world to be diagnosed with the disease. The cancer was discovered in 1991 and there was little known about its cause.

Zoe's mother, Nikki, said: "Zoe was unconscious in intensive care for seven weeks. At one point we were told to call our family to come and say their goodbyes, but the PICU team never gave up, trying different ways to support her breathing, giving her a tracheostomy and dealing with a pneumothorax in her healthy lung."

After three months, Zoe improved and St George's started to feel like a second home. Nikki said: "The nurses and play specialists did kind things to keep Zoe entertained and supported us throughout Zoe's cancer treatment."

After nine rounds of chemotherapy, Zoe was transferred for specialist surgery at Great Ormond Street Hospital to remove the lung that had collapsed due to the cancer. This led to other organs collapsing on one side, causing her to develop scoliosis which required further surgery.

Despite a challenging start to life, Zoe is inspired from her experience to become a children's nurse. She said: "I'm grateful to the staff at St George's Hospital for always being there for me throughout my life. Thank you to the nurses who told me to follow my dreams and never give up."



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Macmillan Information & Support Centre
Email: cancer.information@stgeorges.nhs.uk

Is bowel cancer genetic?



SW Thames Cancer Genetics Team (left to right): Kelly Kohut, Lead Genetic Counsellor, Dr Heidre Bezuidenhout, Consultant Clinical Geneticist, Ms Nina Fowler, Genetic Counsellor

Bowel cancer is one of the more common types of cancer, affecting about 1 in 14 men and 1 in 17 women at some point during their life, typically after the age of 60.

Most bowel cancers do not have a strong genetic link. They occur by chance from a combination of genetic, lifestyle and environmental factors. However, we know that for around 5–10% (5 to 10 in 100) of bowel cancers, a variant (change) in a single gene can be the cause in a family. Families with a higher chance of getting bowel cancer due to a gene variant are offered options to manage this, including regular bowel screening (colonoscopies).

If you have a diagnosis of bowel cancer, it is now routine care that you have a screening test performed on your tumour to see the chance that you may have a gene variant. Depending on the results of this screening test, you may be referred to genetics for further discussion about genetic testing. If you are concerned, please speak to your treating team for more information.

Even if a person's bowel cancer is not due to a gene variant, there could still be increased screening recommendations for other relatives, depending on their family history.

For more information about genetic links in bowel cancer please visit:
www.bowelcanceruk.org.uk/about-bowel-cancer/risk-factors/family-history/

Look Good Feel Better

Look Good Feel Better (LGFB) is a wonderful cancer charity aimed at boosting the physical and emotional wellbeing of both men and women living with cancer.

Workshops are led by volunteers in the beauty industry that provide advice for cancer patients experiencing changes to their skin, eyebrows, eyelashes, hair, and nails to improve body confidence.

The sessions introduce wellbeing initiatives such as meditation to help reduce feelings of isolation and anxiety.

Sharon, a patient at St George's attended a workshop and said: "The LGFB volunteers presented us with a make-up bag filled with top-of-the-range cosmetics. The session was intimate and relaxed."

"We all left feeling privileged, exhilarated, looking good and feeling much better. This was not just a makeup tutorial, but a beautiful encounter. LGFB is exactly what it says on the tin."



Look Good Feel Better Volunteers

LGFB will be celebrating its 30th year next year. For more information: www.lookgoodfeelbetter.co.uk

Claire's story



Following our story about the Milestone Celebration Bell in our last newsletter, we would like to share Claire's story from the position of someone who is living with cancer on a long-term basis. This has a whole set of issues dealing with the on-going diagnosis and all the consequences of the treatments. We are very grateful to Claire for sharing with us her feelings and hope it will help us all to better understand and support such resilient people like Claire

At 34 years old, I valued my active life: Fit and healthy I enjoyed swimming, socialising with friends and working full-time for a high street bank. During this time I was diagnosed with the first of three multiple life-changing conditions.

In February 2001, I was diagnosed with bilateral breast cancer, and started chemotherapy within three weeks of my first visit to the GP. By July 2001, I had a bilateral mastectomy with reconstruction. I was rushed into intensive care two months later, and placed on life-support due to heart failure: I was not expected to survive. In 2009, I was diagnosed with a malignant melanoma and in 2014, a rare blood cancer. I underwent a stem cell transplant as the only curative option.

Now medically cancer-free, I live with heart, kidney, and neurological damage.

I am grateful for medical science and the brilliant staff, yet there are days when I question if it is all worth it.

Making the best of my situation doesn't get any easier with time. It's easy to measure the physical decline, but what can have a more extensive impact is the often-hidden toll on my mental health. Articulating these feelings can be difficult, especially when I'm expected to express gratitude for being alive.

Not expressing the more challenging emotions does not mean they go away. I believe we should find a way of processing them that suits us, whether that means talking to others in a similar position, talking to a counsellor, writing them down or screaming at the moon!

Wandsworth & Merton Carers' Centres:

A Carer is someone, who without payment, provides help and support to another person who would not be able to manage.

We understand the value of the role of the Carer and the importance of ensuring they remember to continue looking after themselves. We offer support with benefits, 1:1 support, training, and workshops as well as back care and body massage, and much more.

One service user at the Wandsworth centre said, "I would like to thank all the wonderful staff for all their help and assistance over the years. This centre was a lifeline for me at a time when I was desperately seeking help and advice. Had it not been for the staff here helping us, supporting us guiding us, I don't know how we would have coped!"

Wandsworth Carers' Centre:

Tel: 020 8877 1200

Email:

support@wandsworthcarers.org.uk

www.carerswandsworth.org.uk

Merton Carers' Centre:

Tel: 020 8646 7515

Email: info@csmerton.org.uk

www.csmerton.org



Voice - Future Voice Plans

Voice is looking forward to a busy year supporting Cancer Services with new projects

RESOURCES

Macmillan Information & Support Centre

Ground floor, Grosvenor wing,
St George's Hospital

Tel: 020 8725 2677

Open: Mon - Thu 9am - 4.30pm,
Fri 9am - 4.30pm

Closed Bank Holidays

Visit our webpage on
St George's website

Macmillan Cancer Support

Helpline: 0808 808 00 00

Mon - Sun 8am - 8pm

www.macmillan.org.uk

Citizens Advice

Tel: 03444 111 444

www.adviceguide.org.uk

Turn2us (financial support)

www.turn2us.org.uk

National Debt line

Tel: 0808 156 3800

www.nationaldebtline.co.uk

Step Change (debt advice)

Tel: 0800 138 1111

www.stepchange.org

Age UK

Tel: 0800 055 6112

www.ageuk.org.uk

Law Centres Network

(free legal advice)

Tel: 020 3637 1330

www.lawcentres.org.uk

ACAS (Advice on workplace rights)

Helpline: 0300 123 1100

www.acas.org.uk

VOICE is the cancer patients/carers user group. We work with the hospital's Cancer Division to improve services.

There are two exciting new activities that Voice members are assisting with:

The first was a new series of videos named IMPACT which stands for "I'M Prepared for Anti-Cancer Treatment and aims to support patients having Systemic Anti-Cancer Treatment. It joins the successful prehabilitation videos created for Get Set For Surgery. These initiative have been developed by the Trust in partnership with Cancer Patients to ensure they have relevant health and wellbeing information. In the months ahead there will be invitations for patients to contribute their views and opinions.

The second is the George's Green Club. The group meets in one of the many lovely gardens at St George's on the fourth Wednesday of every month from 2 -3.30pm to enjoy a gentle stroll while listening to guest speakers. Tips and guidance on how to create good smartphone photographs are given. The aim is to exhibit some of these works in the hospital.

However, the best outcomes are the conversations and opportunities to meet up with fellow patients and carers who enjoy the support that this always produces.

For further information, please contact estelle.legalliot@stgeorges.nhs.uk



The Cancer Connect editorial team would love to hear your comments about our newsletter

If you would like to make a comment, want more information about any article or have a suggestion for a future article, please email the Macmillan Information & Support Centre at cancer.information@stgeorges.nhs.uk

You can also visit the centre on the ground floor of Grosvenor Wing, St George's Hospital.

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