

Name - Nicky Hayward

Age - 60

Lives - Shieldhill, nr Dumfries, Scotland (moved from Bath in October 2020)

• **How did you find out about the FLAIR study?**

Through the Haematology team at the RUH. The FLAIR study is aimed at patients with Chronic Lymphocytic Leukaemia (CLL), and involves trialling a mixture of cancer drugs.

• **Why did you choose to take part in this study?**

I was advised I'd have the best chance of achieving enduring remission from cancer if I were fortunate enough to be randomised to the targeted drugs being trialled. People in my position only very recently have a far greater chance of living a normal life stretching well into the future, since the advent of targeted drugs.

My father died of another type of B-cell cancer – non-Hodgkin's lymphoma – at the same age that I was when I enrolled on this trial. At the end of his life, he was keen to take part in a trial to help others, even though he knew it was too late to change things for himself. I am aware that there may be a familial link involved here, so for that reason too I was keen to take part in research. I have a daughter in her 20s and hope by the time she reaches her mid-50s that effectively routine management of this disease will be possible.

It also feels like giving something back for the help and support of the fantastic people who run the Oncology Department and the Haematology and Trials teams.

• **How did you find taking part in this study?**

This was the first time I've ever taken part in research and I felt supported throughout by a team who couldn't have been more helpful. I did initially find the literature describing the risks involved, and everything I should consider, a bit overwhelming - but I am happy to say that I didn't experience a single adverse effect whilst on the medication.

By around eight months on the drugs I had not only lost all the nodal swelling (in my neck, armpits and groin), but my blood results were also showing I was MRD (Minimum Residual Disease) Negative – in other words, I was in complete remission. When this condition was further confirmed by scans and a bone marrow aspiration, I was able to stop taking the drugs two years in, and I haven't looked back since.

This may be unusual, but I felt fit and well throughout my time on the trial and am back on course in my life, enjoying all the energy and strength I had before I was diagnosed with CLL.

• **Did you learn anything new?**

I learned how incredibly complex the disease CLL is. People present with diverse manifestations of the illness. I feel eternally grateful to the professionals who do all the studying and gain the cutting-edge expertise from which we, as patients, can passively benefit.

• **What was positive about your research experience?**

It was the most incredible privilege to have been able to enrol for the trial. Not everyone can be accepted and it's nerve-wracking, once you've made up your mind to go for it, waiting to hear whether or not you've met all the inclusion criteria.

Everyone in the department (A12) and Haematology - including the kind people in reception, the Friends of the RUH volunteers, the phlebotomists and pharmacists and the medical staff in the connected William Budd ward - played an important part in supporting me and others taking part in the trial. The Trials Team were brilliant, answering endless questions both when I was considering my options and throughout the treatment period. They were wonderfully reassuring and supportive.

• **Do you have a message for someone who is thinking of taking part in research?**

It does feel good to know you're providing data at the same time as undergoing treatment, as the only reason we have what's on offer now is that someone before us enrolled on previous trials. Let's face it, there are risks in everything. We're all so individual that one in a million of us might have a reaction to a treatment that no one else does. But this goes for all the licenced treatments too.

We do not know the long-term effects of drugs we're only starting to use now, of course, and that's one reason volunteers are needed. What I do know is that even 10 years ago – with the treatments and scientific knowledge available then – I would have been unlikely to have lived more than a handful of years beyond diagnosis, whereas now I have the prospect of a future. Should issues crop up in time to come, I reason I'm still ahead of the game as I've been gifted a lease of life I would otherwise have been unlikely to enjoy.

In terms of a legacy, aiding scientists with cutting-edge research feels like it's up there with worthwhile causes we might support. Right now, having opted for the trial feels like a win-win for me: I was able to access the latest treatment option, am experiencing vastly improved health and the prospect of enjoying ongoing, symptom-free remission whilst contributing to the research data too.