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# LIVING WITH CML

Patient stories to help better understand daily life with Chronic Myeloid Leukemia (CML)



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Nigel Deekes is a patient that has been living with CML since 2011 when he was diagnosed at the age of 45.

Nigel lives in the UK, is married with two children. He is a keen and active squash player and works full time running his own real estate business, employing around 40 people.

Nigel is a Trustee of CML Support and also the founder of CML UK, being a Facebook support group. Additionally, he is a member of the TFR CML Advocates Network working group.

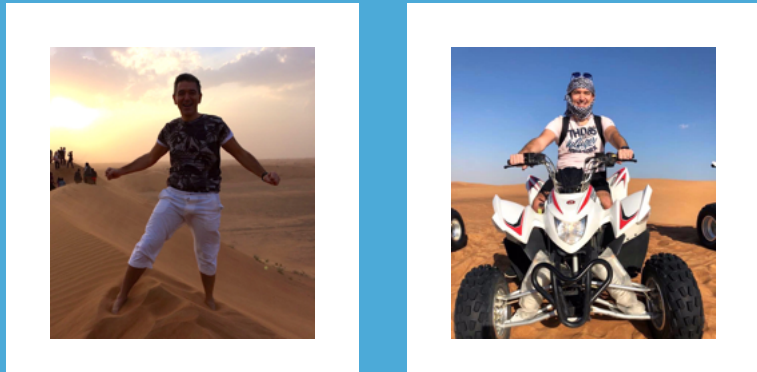


Nigel with Dr Flaghavan and Kris Griffin at a Birmingham Support Group meeting, 2017

Approached to enter the UK Destiny trial where medication is halved for 12 months and then TFR attempted, Nigel was keen to join although felt potentially had not been at a deep enough response for long enough.

Successfully completing the half dose treatment regime whilst seeing numbers gradually increase, Nigel attempted TFR however this proved unsuccessful with his numbers rising above MR3 within a couple of months.

Nigel resumed treatment on full dose Imatinib and regained deep response quickly; subsequently over the last four years progressing to MR4.5 and undetectable.



Having many years ago suffered with a detached retina, when Nigel saw flashing in his eye once more he naturally assumed the issue had re-occurred. From visiting the hospital with eye issues, Nigel was flabbergasted to be diagnosed with CML 12 hours later.

Placed onto Imatinib and responding relatively slowly against the current guidelines, Nigel continued with Imatinib seeing his levels gradually fall to MR3 and subsequently MR4.

Understandably scared and concerned about a potential shortened lifespan and not seeing his children grow, the diagnosis and the first few months were understandably worrying.

Nigel returned to work after only two days' absence and continued to work full time with very few issues or side effects from then on.



Nigel with his family in 2019

Whilst a second attempt at TFR is not so widely prevalent in all countries yet, Nigel's view is that next year on his 10th anniversary, and having had a further 4/5 years in deep molecular response, the time may well be right to once more attempt stopping.



## Inspiring CML patients

"My life with CML has been rewarding which is an odd thing to say.

It has given me a deeper knowledge and understanding of the illness and the ability to connect with fellow advocates and patients to provide reassurance and knowledge.

My journey is positive in that I returned to work very quickly and without interruption and with minimal side effects since."



The CML UK patient advocacy team attending the CML Horizons Conference in Poland, 2018.



Joining the CML global awareness campaign "Today Together" on World CML Day, 22nd September

"CML is a scary disease, particularly in the early days or when your levels are not falling as fast as they should but it is not always a race, both in time and in-depth of response.

**Find a doctor you can trust** and with whom you can build a relationship.

**Educate yourself** with regard to your illness, the help and questions you may need.

**Finding a support network** I feel is very important, be that online, peer to peer or within your family. This network will help you both emotionally and psychologically, as well as of course helping you realize you are not alone.

*It is so good to give reassurance that for the vast majority of CML patients, life can be both long and normal."*



Nigel advocating for CML with Bloodwise, the blood cancer research charity.

Send your supporting comments to Nigel on Facebook by clicking this button

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