



Vilnius, Lithuania
24–26 May 2024



Nigel Deekes - TFR

Second attempt



Diagnosed on 2012 – Imatinib 400

- Slow responder – missed the then guidelines of MR3 at 18 months
- Very unusual in no side effects
- Considered Nilotinib as missing targets
- Stayed on Glivec as so well
- Set up my group after 1 year due to nothing UK specific
- Joined CML Advocates
- Attended conference @ DX year 2
- Extremely good & useful allowed me to be a very informed patient
- So many changes – at that time
- No Children
- No TFR
- Less TKI's fully available in UK

Offered DESTINY UK trial 50% dose 2015

- 2 arms – MR3 & MR4
- 1 year 50% then stop if MR3
- I was a good MR3 – 3 years
- I knew from Horizons unlikely to work
- Took the trial as I felt I couldn't tell patients TFR seems safe if I wasn't willing to try it
- Monthly testing
- Numbers fell for the first few months
- About month 7 started to rise
- Month 12 over MR3 – retest just under MR3 so stopped
- Clearly I was going to fail
- After 1 month I was over MR3
- Resumed Imatinib
- Good response to TKI again

Second attempt November 2022

- I was keen to try again
- Data from Horizons / all safe
- Pushed my team to agree
- Nick's here today – thanks for the support
- They knew I knew my stuff so agreed to TFR2
- My wife was not keen
- No side effects – why stop ?
- Why stop.....
- No data at all for issues but
- Dx 45 – say I die hopefully 85
- 40 years of taking a powerful drug
- Sooner or later it catches up ?
- I knew it was pretty well 100% safe
- Restarted last time no issues

How am I doing ?

- 16 months off treatment
- No withdrawal issues
- Testing every 3 months now
- I Still feel well – I was lucky
- Usually 2-5 cells detected
- In 13 years only ever had 1 undetectable
- Latest PCR April was.....
- My second undetectable !
- I'm very positive for the future

TFR is a personal choice – we shouldn't push too hard as many will not be comfortable

- As me – TFR must always be by full agreement
- Always with excellent / regular testing
- TFR via an experienced team
- Never think of restarting treatment as failure
- Restarting is still at a point guidelines aim for so not failure
- TRF – it's a treatment holiday / a better view
- I felt the extra years on treatment are / were key
- It's not a race / competition

A final thought....

- May I ask those here today with CML to raise their hands
- May I ask those here that are TKI to raise their hands
- I have thought for some years we here are disproportionate
- Given TFR may be an option for a low percentage why / how have so many in this room got there ???



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