NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Dabrafenib for treating unresectable, advanced or metastatic BRAFV600 mutation-positive melanoma [ID605]

I am Sarah Garner, the mother and carer of Peter Garner. I have been nominated to speak about my experiences of Dabrafenib by Melanoma UK.

I am not at all sure that I regard myself as a "patient expert" but I have had the experience of watching my brave 14 year old son so ill with melanoma that I did not expect him to see his 15th birthday, and yet he recently celebrated his 18th.

In 2011 Peter was in hospital with extensive tumours in both lungs and throughout his chest. He required oxygen and morphine which was administered by a patient controlled pump.

He was no longer eating and struggled to even sit up in bed. He slept a lot of the time. I hardly left his bedside and my thoughts were turning more and more to hymns and funeral arrangements.

We were lucky and were able to get dabrafenib on a named patient basis. 36 hours after the first dose Pete said that he felt hungry and filthy and demanded a bath followed by chips. 4 days later he came home and ten days after that he was back at school full time.

He experienced no side effects and had an excellent quality of life. We were able to take a family summer holiday in Finland cycling, swimming, rowing and bear spotting.

15 months later resistance had built up but by then another treatment- not previously available in the U.K. and certainly not to a 14 year old- was offered and again Peter responded well.

Dabrafenib has allowed me to glimpse the adult in my youngest child and allowed his three siblings to grow up with a much loved baby brother.

Pete is attending college studying for a BTEC in music. He always says "debrafinib didn't keep me alive- it allowed me to live"

He is still symptom free but remains stage 4 melanoma and is fully aware of what that means, but he does not waste a second feeling sorry for himself.

In my opinion Debrafenib is a very important treatment for melanoma for four reasons, and I think these are well exemplified by Peters story.

1.Melanoma is often discovered late as symptoms are slow to show, but the drug works very quickly.

2. It produced no side effects.

3. Advances are being made all the time in the treatment of melanoma, and though the drugs effectiveness was not permanent it allows time for further treatments to be developed. I understand that its effectiveness can return after a break.

4. So many of the sufferers are young adults who will lose many years of life making it especially important to snatch any extra time they can.

Sarah Gore.