TITLE: Battle for access: A patient's story about trastuzumab

TOBEKA DAKI: Tobeka Daki was diagnosed with HER2 positive breast cancer in 2013. In 2014, she was told by her oncologist that she needed trastrutamab (sold under the brand name Herceptin). At the time Tobeka had private health insurance, but her medical scheme told her she wasn't covered to receive this treatment. While coping with cancer, she wasn't able to work and subsequently lost her medical aid.

Tobeka is now receiving treatment in the public sector where trastuzumab is not provided because of its high cost. Unlike Tobeka, most women with HER2 positive breast cancer in the public sector that could benefit from trastuzumab are unaware of this treatment.

INFO ON MED FOR SIDE BOX:

Trastuzumab is recommended by the World Health Organisation as an essential medicine for the treatment of HER2-postive breast cancer. Trastuzumab is not provided in South Africa's public sector, and private insurers are not required to fully cover its cost in the private sector, given its extremely high price.

In South Africa, Roche has been granted multiple patents on trastuzumab that could block more affordable biosimilar products from entering the market until 2033 – more than a decade after patent monopoly protection has expired or will expire in the EU, US, India and other countries.

In South Africa only Roche's patented originator version of trastuzumab is available, sold under the brand name Herceptin. A full treatment course of Herceptin in South Africa costs approx. R485,800 - more than double the costs of equivalent products in India where patents have expired and competition exists.

Tobeka'S STORY (in her own words):

PULL OUT QUOTE:

"I strongly believe that if I can get this treatment I can live longer, see my two sons growing, see my grandson growing."

ADDITIONAL QUOTES EDITED TOGETHER TO TELL NARRATIVE STORY:

My name is Tobeka Daki. I am living in Mdantsane. I have two sons. I was diagnosed with breast cancer on the 13 November 2013.

On the TV show Isidingo, I saw Lerato who was a breast cancer survivor. When I saw her symptoms, I realised that maybe there was something wrong with me. I went to the doctor who examined me and referred me to one of the specialists. I did a mammogram and biopsy.

I went for surgery on 20 November 2013. After my surgery I had chemo for six months. Then I had radiation for six weeks. In March 2014 I was told by my oncologist that I am supposed to get Herceptin. My doctor and I applied to my medical aid but unfortunately it was declined. They claimed that the medicine was too expensive for them to cover.

In December I resigned from my job because I started getting really ill and I was scared that I might never recover again. So I chose to stay at home so that I could recover fully. Unfortunately when I left work, I stopped my medical aid as well. Now that I'm using a public hospital, the doctor hasn't mentioned Herceptin to me again.

When I spoke to the ladies in my breast cancer support group - who are also receiving treatment in the public sector - about Herceptin, none of them had even heard of it. I was lucky just to be told.

I strongly believe that if I can get this treatment I can live longer, see my two sons growing, see my grandson growing. I think government should provide Herceptin to every woman living with HER2 positive breast cancer so that we, including myself, can live a longer life and not a scary life like the life I'm living now. Even if have a headache, I get scared that the cancer is coming back. I don't think I am fully cured without the treatment that I was supposed to get.

This story has been edited for length and clarity from the transcript of interview conducted with Tobeka Daki on 16 October 2015. Following the interview, Tobeka was informed that the cancer had spread to her spine and that she would need to restart chemotherapy and radiation.



Photographer: Laura Lopez-Gonzales