Endocrine concerns and quality of life in thalassaemics

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Abstract

I would like to tell you a main message: to fight against this disease is always useful. Imagine you are a little kid and want to play with your friends, you want to run with them play ball with them but you couldn't. You have to stay at home or sit on the side and watch it is a hard thing to do for a kid. However, the help of your parents, the encouragement and the patience of your doctors, the support of associations are crucial issues to continue the fight. Patients have to remember that continuing their treatments strictly is the main aim to reach in the next future the cure.

Introduction

I was born in 13 April 1979 in Istanbul Turkey. My grandgrandparents origins are from Crete. When I was 5 years old, my skin color was a little bit pale and I had eating disorder. My parents got suspicious and take me to a doctor. After the blood tests, I was diagnosed thalassemia major and started to transfuse blood every month. And also started to use Desferal 5 days in a week. But the main problem was neither me nor my parents knew anything about Thalassemia.

In 1989, my parents participated a meeting of TADAD (Thalassemia Patient Parent Association) and became members of this organization. At that meeting Dr. Duru Malyali gave us the book named *What you need to know about Thalassemia*. I remembered that my parents were so happy because they finally learned something about this illness after a long time. I also remembered my dad explained what is thalassemia and how we should live with this illness. Later my father became the vice president of TADAD and he's been this position for over 20 years. And for the last 6 years I have been the general secretary of TADAD. Dr. Malyali wrote many books and booklets about Thalassemia to inform people about this illness.

In 1991 TADAD invited Dr. Beatrix Wonke and Dr. Mary Petrou to Istanbul to examine Thalassemia patients in our Headquarters. One month later I went to Whittington Hospital in London to see Dr. Wonke. After the blood tests, Dr. Wonke decided that I am not a major Thalassemia but my disease is an intermediate form. Also Dr. Wonke suggested that I should have splenectomy operation. After that operation my blood transfusion period changed from one month to three months and my Desferal usage reduced to 3 nights a week. Till 1998 twice a year, I kept going to London to see Dr. Wonke for my treatment. In 1998 I started to my university education in London Glamourgan University and my major was business administration. During my education, I was in control of Dr. Wonke and her team. When I was 20 years old, Dr. Wonke suggested me to start hydrea and by the help of hydrea, I transfused blood every six months. I am still using hydrea 3 capsuled a day.

After graduating from university I returned back to Istanbul and established a company on plastics after that in textile and information technology sectors. But besides my business life I continue my treatment in Whittington Hospital. In my general tests my ferritin is around 1000 and my endocrine tests are in normal values.

In 2003 I met with my wife and after 3 years we got married in 2006. Before marriage my uncle Duru ordered me and my wife to have electrophoresis test in 3 different laboratories. After 3 years we decided to have a kid but no matter what we have tried we could not. Here I would like to thank you Dr. Duru Malyali. He took met to Gynecologist Dr. Semra Kahraman, who has good relationships with TADAD. After the tests again (as all the patients know our life is tests.) Dr. Kahraman diagnosis was that I have azospermia. She suggested the in vitro fertilization technique to have kids. She also told me that it is an endocrine complication. After a small operation they found sperms and fertilized them with my wife's eggs in a laboratory. 9 months later my son was born who is 1.5 years old now.

Due to my business I need to travel a lot. During these travels I get tired very quickly and that is a big problem for me because sometimes I need to make 3 or more meetings a day and at nights I feel very low and tired as well. Actually endocrine problems started way back from my childhood. Imagine you are a little kid and want to play with your friends, you want to run with them play ball with them but you couldn't. You have to stay at home or sit on the side and watch it is a hard thing to do for a kid. When you became a teenager you couldn't drink with your friends do any kind of sports. This has also psychological problems. After a while you get fed up with this illness, tests, blood transfusions and medication usage. You try to run away from all this, and become a antisocial person. I suggest that besides all of these problems life is still good you should hang on to it.

I am 32 years old and as you see I am a tall and healthy looking person. Thanks to my parents I looked more normal than many Thalassemia patient. I want to say all the patients to continue their treatments strictly. And I hope one day the hematologists in my country make the necessary changes to make life much easier for us the patients.

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