



2ND
SYSTEMIC
SCLEROSIS
WORLD
CONGRESS

February 2 – 4 2012

Madrid, Spain

*My Experience on Autologous Stem Cells
Transplantation*

My Story...

Diagnosed Scleroderma on May 1996 at the age of 15 by Dame Carol Black at the Royal Free Hospital, London

My conditions were discrete

Various tests had revealed oesophageal dysmotility and lung fibrosis

Started on various medications to prevent the worsening of the disease.

On April 2003 I moved to Italy where I exposed my skin under the sun during a hot Italian summer...Here my scleroderma began to give me problems!

My skin began to be thicker and tighter and my movements
always more difficult

I couldn't dress up by myself
I couldn't cook, wash or clean anything
My skin was darker

On September 2004 decided to fly to Gaetano Pini Hospital in
Milan where i met Dr Nicoletta Del Papa and her team

Again I did all sorts of tests to see how my scleroderma worsened
Dr Nicoletta Del Papa proposed me to do the autologous stem
cell transplant

Even though Dr Del Papa explained all the risks associated with
the transplant without hesitation I said: Let's do it!

During my stay in Milan I met the association which helped me
and supported me throughout my stay and during transplant.

Now I am part of this association because I recognize that there
are a lot of people who need our help.

Preparations before transplant

Had blood sample taken from my bone marrow

Quite painful but it is only for a few seconds

Doctors gave me a list of all the things i had to bring with
me during my stay in hospital

Pictures were taken of me before admission

1st Step : Mobilization

The mobilization was carried out through the use of cyclophosphamide

Step 2 stem cell apheresis

The catheter was connected at a machine which for the whole day brought out a quantity of my blood and held the cells requested
Couldn't eat for the time I was connected and I could not move or change position. It was quite very tiring.

At the end of the day the cells were collected and cryopreserved.
I was brought to my room to rest

During these days my hair started to fall. This was devastating and traumatic .

After I was dismissed, I isolated myself and didn't want to see anyone or go anywhere.

Step 3 Re-infusion

I was admitted again in hospital on March 14 in clean room

I was all by myself in the room, I could not have any contact with the outside world. This was the most difficult thing to overcome. I could only have one visit once a day and I could speak to them via intercom through a window.

On the 16° of March I began again the administration of cyclofosfamide via a central venous catheter

I used to feel very tired and very weak.

On the 21° March was infused my hematopoietic stem cells previous selected and cryopreserved

A couple of days later I started to feel very weak and had fever 39 °C

I stopped eating for a couple of days and I had 2 nurses that helped me to wash.

Many blood samples were taken to see if i had an infection, fourtunately the results were negative, but started on different antibiotics because one was not effective and another which I was allergic too.

I was very depressed and frustrated because I wanted to go home.
I had a psychologist that came to give me support

I also had abdominal pain .

After a third administration of antibiotics I slowly improved and the temperature went down

Step 4 Follow-up

After my discharge, for the first month I had weekly check up
After the first month follow up was every two weeks then after
a month and then after six months.

First 100 days after transplant I could not eat lots of food,
nurses gave me a list of what I could and couldn't eat.

There again the difficulty because I was tired after all the events
that I couldn't even be free to eat everything.

And when you're told "do not eat food like strawberry", I
guarantee you that you want a strawberry more than anything!

Was given antibiotics to take whilst home but fortunately no
infection was verified on me

7 years have passed since I had my transplant. When I think back to those moments I cannot forget all the difficulties and moments which I wanted to give up.

I had moments of despair, fear. For the first period I had panic attacks ,and seeing myself without hair made me feel more sick than I actually was.

But I tried not to lose the main objective that had led me to do the transplant which was to improve my conditions.

I now live almost a normal life, I am more independent than before and this means a lot. I wash myself without needing anybody, I cook for myself, I do the laundry and go for walks, all things I could only dream before the transplant.

My skin score has improved

My quality of life is improved

My thanks to Dr Nicoletta del Papa
She was near me at the moment of the decision and during all the steps of my transplantation from a professional and personal point of view.

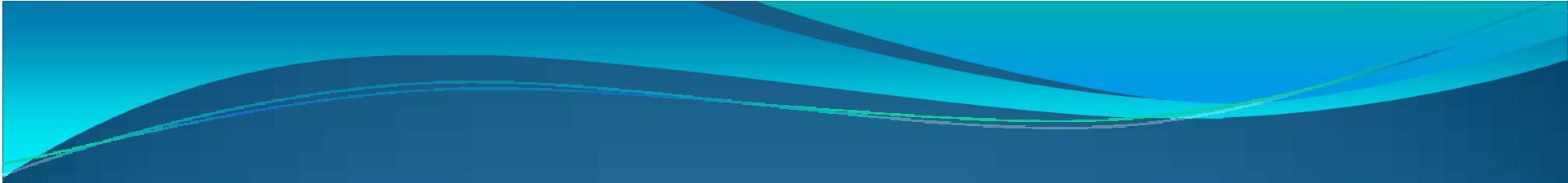
I lost my mum years ago and my doctor for me is not only my doctor but she if my friend, my confident and why not...my adopted mother.

I'm saying all this not just because i think these things but because she has come here today to hear me so i want her to know my gratitude and if i am here today telling you my experience is thanks to her!

I remember she was pregnant and even if at the end of pregnancy she was always near me not leaving me alone.

I often remember her that she had two babies: Her son and

MY NEW LIFE....



So if you ask me if the transplant has helped me
and improve my scleroderma?

My answear is: Definately YES!!!

Would I do it again?

YES...

Thank you for your attention!!!