



International Childhood
Cancer Awareness Day



Creating a brighter future for young people with cancer

**Patricia Blanc European Parliament, February 20th, 2013
International Childhood Cancer Awareness Day**

Good afternoon.

I am really honoured to be here today. Thank you for inviting me to share my experience as a parent who sadly lost a child to cancer.

We created the charity "**Imagine for Margo**" to raise awareness and to raise funds to support European research in Pediatric cancer, in partnership with the European network ITCC (Innovative Therapies for Children with Cancer).

My daughter Margo was 13 years old when, 4 years ago, a doctor told us: we now know why your child has headaches- she has a brain tumour".

He confirmed that it was the most aggressive form of cancer and that our daughter had only "a few months to live"

Sadly, still not enough people realize this, but yes, children can have cancer.

Cancer remains the leading cause of death from disease in children and young adults

Just a few key figures:

1 child in 440 will have cancer before the age of 15.

The numbers are increasing by +1.5 % each year .

15 000 children and young adults are diagnosed each year in Europe, 3 700 will lose their battle. This means that 10 kids a day are dying of cancer in Europe.

Margo was one of those children. She left us after 16 months of a courageous fight enduring 3 brain surgeries and very aggressive and invasive treatments and protocols, all of which proved inefficient.

Let's talk about treatments and protocols!

When Margo got sick she was offered a standard protocol involving a chemotherapy which had existed for 20 years and which was mostly given to adults!

A few months to live...but a standard protocol...And nothing better than a therapy developed decades ago.

Don't you think something is wrong here?

We followed the protocol, as recommended, with constant hope. Things actually got better for few months. We even got to a remission stage and clean MRIs.

But when things seemed to be under control we came back to the same old chemotherapy as maintenance mode.

The same medicine which had proven to be inefficient to cure this cancer was then prescribed to prevent the illness from coming back.

As we had feared, the cancer came back 3 months later and it was even more aggressive. Margo had suffered a relapse.

So, why did she remain on a standard and inefficient protocol? Why, at the point when the illness seemed quite under control, could we not have an innovative treatment, nor be offered a clinical trial?

So yes, I am not a doctor, I did not know anything about cancer, but **my husband and I from the beginning had decided to fight against the disease.**

In an open discussion with our doctor from Institut Gustave Roussy, who was very kind and supportive, we wanted to take the next step and examine all possible solutions. We spent hours on the internet, contacted our personal network, and tried to find any possible solution.

We contacted Doctors from everywhere (in Belgium, in Germany, in the US - at Duke, Columbia, and St Jude's-, ..., and even in Israel and China).

We tried to find any innovative treatment; any new drug, any vaccine, even nanoparticle or electrical field solutions.

We found out that there were very few clinical trials for kids under 18. We also discovered that there were very few overall clinical trials in Europe compared to the US.

We finally learned that the FDA had recently approved a new protocol and we discussed with Margo's doctors whether she should get it.

It was not the ideal treatment of course, just offering maybe a few more months to live. But for us as parents, every single second with your child alive is just so precious.

This new drug gave Margo 4 additional months, during which time we tried desperately to find any other possible solution.

There were no possible clinical trials in France.

We finally found 1 in the US, but Margo, at this stage, was too weak to make the trip.

As you can see, **in case of therapy failure, it is very difficult to identify possible solutions.**

And time is a key issue.

I hope that my story, which is also the one of many parents will make you realize how important this new Clinical Trial regulation is.

And I have 2 requests for you:

Since we created the association Imagine for Margo, I have participated in a few international oncology congresses and I am very active in trying to improve new drugs development.

We are also raising money to fund a new Clinical Trial for children with cancer.

We raised more than 200 000 euros with our race/walk in Paris last year to help launch a Clinical Trial on brain tumours.

This Clinical Trial, will ultimately benefit 150 kids in 5 European countries.

Do you know how long it took for this CT to get all the approvals? 18 months!

And now we are fighting with pharmaceutical companies to get the drugs as quickly as possible!

So this is my 1st request:

-Simplify the administrative process: Today, researchers have to apply multiple times for a CT, with different applications in different countries and legal systems!

This is a time consuming and energy draining process for them.

It is also expensive. Money should be spent on more CT specifically designed for children, and **NOT on paper work!**

I am asking you to consider the simplification and harmonization of the approval process and the conduct of CT process

My second request is for the creation of a specific fund dedicated to paediatric CT

Today, only 2% of research funds are dedicated to pediatric research

Rare diseases have no economic value for pharma. They are not interested in investing in the subject which is actually a matter of Public Health safety.

The situation today hurts innovation and, as a result, we are stuck with only old drugs for our kids

Academics are working together to make things move forward and they do invest energy in some new treatments and studies that pharma will never be interested in due to no financial value.

But academics could do much better if they had enough money to do it

This is why I am asking you to consider the creation of a specific fund dedicated to paediatric CT.

This fund would be paid for by the European Union and the pharma industry
It could be financed through a minor tax on medicine sold by pharma or the implementation of an incentive for pharma like in the Creating Hope Act voted in the USA in July, 2012

I truly believe that this fund would increase the number of CT and improve innovation in drug development

We really need you to **create and adapt a legal framework that will speed up the process** and will also lead to the development of more **specific and innovative drugs for our kids.**

Time is of the essence!! Do not forget that 10 kids are dying from cancer each day in Europe and many others from rare diseases.

Speaking for parents, I urge you to **make it happen.**
Thank you for your attention