

Patricia Blanc Speech to European Parliament, February 2012 National Childhood Day Event



Good afternoon.

I am really honoured to be here today. Thank you for inviting me
and for taking into consideration parent's experience and opinion.

We have created the charity **"Imagine for Margo"** in order to raise funds to support european research in Pediatric cancer, in partnership with ITCC.
I strongly believe that it is altogether, and with a co-operation strategy with we will make the difference for our children and teenagers.

My daughter, Margo was 13 years when she was **diagnosed with brain cancer**, a glioblastoma stage 4 with a very poor prognosis. "few months to live" as her doctor said.
Obviously it was a huge shock, a life suddenly dramatically changing and also a discovery: "children can too have cancer!". And yes they unfortunately do!
This is not enough known, but it should.

A quick reminder of key figures:

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

Figures are increasing, +1% each year for kids, +1,5 % for teenagers.

In France 2000 children get cancer every year and 500 of them will not be cured.

That was the case of Margo. She left us after 16 months of a courageous battle with 3 brain surgeries, very heavy treatments and various protocols, all inefficient.

Let's talk about treatments and protocols!

When Margo got sick she was offered a standard protocol with a chemotherapy existing for 20 years and mostly given to adults!

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 proposed, with still hope and actually things 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 old medicine proven to be inefficient to cure this cancer was then given to prevent the illness to come back.

Obviously the cancer came back 3 months after, even more aggressive. Margo was on recidive.

So, why to remain on a standard and inefficient protocol? Why not at the point where the illness seemed quite under control, do not we have an innovative treatment, nor be proposed 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 fate.**

In an open discussion with our doctor from Institut Gustave Roussy, who were very cooperative, we wanted to open the next step to all possible solutions.

We checked during hours on internet, contacted our network, and tried to find any possible solution.

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

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

**We found out that there were very few clinical trials for kids under 18.
There were very few clinical trials in Europe compare to the US.**

We finally learned that the FDA had recently approved a new protocol and discussed with the doctors for Margo to get it.

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

This new drug gave Margo 4 additional months, during which we reopen discussion for any possible solution.

There was 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.

We were fortunate enough that Margo's doctor had requested approval to get the drug as exceptional procedure but the approval process took so long that when she finally got the drug, it was too late, Margo was gone.

As you can see, **in case of therapy failure, it is very difficult to identify possible solution.
And time is a key issue**

I hope that my story, which is also the one of many parents will make you realize how much **we need you.**

We need you to **create and adapt a legal framework** that will lead to an efficient European cooperation that not only will **speed up the process** but will also lead to the development of more **specific and innovative drugs for our kids.**

As parents representative, I urge you to **make it happen.**

Thank you

Brussels, European Parliament, February 2012, on International Childhood Cancer Day Event.