

## **We had a dream...**

...and that dream came true on the 17 August 2010.

Our little baby girl *Lore* was born! In perfect health, so pretty and so lovely.

It was even more than a dream, it was a fairy tale.

But not for a long time, the fairy tale abruptly turned into a nightmare for the rest of our lives.

On 7(th) November, that means 83 days later, our sweetheart died from pertussis, yes, ...whooping cough after a fight of 18 days in intensive care unit.

What first appeared to be a simple common cold has very quickly been transformed into a tragedy. A tragedy that could easily have been avoided, had we been correctly informed - before or during the pregnancy - about the dangers of pertussis.

One week before *Lore* would receive her first vaccine, she had a little cold and also a little bit of fever. But nothing to get worried about, each baby catches a cold and gets fever sooner or later isn't it ?

But just to be sure, we decided to consult our paediatrician two days later and after auscultation, it seemed that her lungs were wheezing.

The doctor decided to hold *Lore* in observation for a couple of days, thinking that the problem might be a RSV virus just a little bit in advance in the season.

But after a negative RSV test, and after *Lore's* situation worsened further, they decided to transfer her to UZ Leuven, let's say one of the best university hospitals in Belgium.

First in a normal room in the paediatrics ward, but the day after, she was admitted in the intensive care unit.

For the first time at this stage, doctors thought that it could be whooping cough.

We, the parents, were totally lost ... Whooping cough??? I remember my first reaction was :

"But doctor, that's a disease that vanished from our civilized countries, no?"

We knew that the vaccine was still included in the vaccination schedule of a child, and that was it! For me, the last case of whooping cough dated from my own childhood, more than 40 years ago!

We thought that whooping cough was just a long annoying cough, and that with an antibiotic cure, she would be back home soon but we were rapidly knocked down when we heard from the doctors that there was no treatment. They can only stop the infection, but for the damages caused by the bacteria and the toxins, our little girl had to fight and to try to win the battle by herself.

From that moment, the descent to hell had begun ...

First *Lore* was connected to a respiratory system because she couldn't breathe by herself anymore; then, she received a total blood transfusion and she was at the same time connected to a heart-lung machine.

Due to the toxins, her liver and her kidneys showed also signs of dysfunctioning and she had to be coupled to a dialysis machine as well.

The 3 last days, we felt euphoric because the 3 last x-ray images of her lungs showed a real improvement. She was clearly fighting and gaining ground against the infection !

But even with this good news, something went wrong and she died from a blood poisoning (bacteraemia). A banal bacteria that everyone of us here has in his intestines entered into the blood circuit.

After a last attempt to renew her infected blood with healthy blood, the doctors finally told us that there was no hope anymore to save her.

*Lore* gently died in our arms when all monitoring values were dropped to zero.

Our first reaction was grief, a huge grief followed by a feeling of culpability. Have we done anything wrong? Are we careless parents?

And above all this, one fundamental question remained unanswered: WHY?

We tried to find information on the web, and there, stupefaction:

- We discovered that already in 2009 the Federal Authorities in Belgium organized a prevention campaign entirely devoted to whooping cough!

- We also discovered that, one year later, in 2010, the Authorities in Flanders (Northern part of Belgium) organized during the European Immunization Week a new campaign called "Pregnancy and vaccination" in which whooping cough was the main topic!

- Can you imagine our helplessness when we also discovered the letter sent by the Authorities to each gynaecologist and each doctor and in which the importance of preventive vaccination against whooping cough for the parents-to-be was highly recommended?

We have been waiting for *Lore* for 3 long years, with several miscarriages, and finally she came as the sun into our lives.

How is it possible that during these 3 years, we haven't seen anything of the campaigns?

And we were not the only ones because we asked our numerous colleagues if they knew something about it, and their answer was hopelessly "no".

So, here is my question again with other words:

How is it possible that during these 3 long years that we've been in touch with the medical profession, not even one doctor gave us the vital information?

*Is it due to nonchalance?*

- Maybe ... one general practitioner explained us that doctors are submerged with mail, folders, advertising, so much that they have to be selective and he admitted honestly that most of the mail goes even unopened into the trash bin.

*Is it due to a lack of concern?*

- Maybe ... the management of each crèche has been recommended to vaccinate their staff, but as it is not compulsory, no one does it. Furthermore, no one has a budget for it. That's a fine excuse! When you know that a vaccine costs 20 EUR per person for a protection during 10 years, 2 EUR per year...unbelievable!!!  
Is the life of a baby not worth 2 EUR ?

*Do they minimize the problem?*

- Yes, that's possible: the gynaecologist of a colleague told her that Lore had a lot of bad luck, nothing more. That there was only one chance in a million to die from whooping cough, and also that he did not see any advantage in the cocoon vaccination. Coming from a "professional", .....revolting!

*Or is it due to their lack of knowledge about the disease?*

- Yes, that's for sure! When pertussis was diagnosed, we told it to our family and friends, and for those who had been in contact with us the last days, we advised to take erythromycin or azythromycin to prevent any further contagion. Their normal reaction was to consult their own doctors, and here, we've heard all kinds of everything, and often very different opinions on the same topic.

May we vaccinate a woman during her pregnancy? Yes according to some, while others say it is absolutely forbidden.

May we vaccinate a cancer patient? Yes? No? No unanimity neither.  
A vague yes or no, without any foundation, without any justification.

Why so vague do you think?

Because no one of them knew what to do in the presence of pertussis.

They were only unanimous on the fact that we had to be placed in quarantine, for 6 weeks according to some, for 10 weeks for others and someone even thought for 14 weeks!!!

Nonsense this quarantine, we were not contagious anymore with the azythromycin that we took on the first day of the diagnosis.

And so it came that we were banished from some of our relatives at the moment we needed them most.

Our aim is surely not to find out who's responsible for this lack of communication, or to point a finger at anyone.

We are not in a Crown Court and we don't have to deliberate over the guilt or the innocence of a defendant.

It would be totally useless and it would not give us Lore back.

Anyway, I would like to end my speech here like a jury would do:

- To the question:

Did the medical profession ever tell us how dangerous pertussis is, certainly when there is a baby wish?

The answer of the jury is: unanimously NO

- To the question:

Did the medical profession relay correctly the recommendations of the Authorities to vaccinate the parents and the family of the baby-to-be, in order to avoid fatal consequences?

The answer of the jury is: unanimously NO

Do you realize that with only one YES answer, we would have been revaccinated in due time, and our baby would still be with us today because after analysis, we may say that one of us came home with an annoying cough, then contaminated the others present in the room including a defenceless little baby. That long annoying cough has a name : pertussis !

Since then, life goes on of course, but we go to sleep every night with the feeling,... no, the certitude that we contributed ourselves to the death of our own baby. That's a feeling, believe me, I don't wish this even to my worst enemy...

May all what we've been through serve for the future, may everybody learn from it, that such a tragedy never happens again.

In the name of Lore, that's our hope!

Thank you very much for your presence and your attention.

We love you little Angel, forever!

Mum & Dad

<http://users.telenet.be/Lore>

(NL FR EN)