

(slide : introduction)

Good afternoon dear Members of Parliament,
Good afternoon Ladies and Gentlemen,

On the occasion of the launching of the Report Card on Adult Immunisation, I would like to take you with me back into time, not so far, in 2010, just 3 years ago.

Why ? Because that year, my wife Katrien and I had a dream...

...and that dream came true on the 17th of August.

(slide Lore)

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, ...from whooping cough after a fight of 18 days in intensive care unit.

What first appeared to be just 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 just to be sure, we decided to consult our paediatrician 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, one of the best university hospitals in Belgium.

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 thought that whooping cough was just a long annoying cough curable by antibiotics 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 ventilator because she couldn't breathe by herself anymore; then, she received a total blood transfusion and she was at the same time connected to ECMO machine.

Due to the toxins, her liver and her kidneys showed also signs of dysfunction 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. But even with this good news, something went wrong and she died from a blood poisoning.

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

Our first reaction was grief, a huge grief followed by a feeling of culpability. Have we done anything wrong? Are we such careless parents because we failed ? And above all this, one fundamental question remained unanswered: WHY?

We tried to find information on the web, and here what we've found is unacceptable :

- (*slide 2009*)

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

- (*slide 2010*)

We also discovered that, one year later, in 2010, when my wife Katrien was pregnant, the Authorities in Flanders organized during the European Immunisation Week a new campaign called "Pregnancy and vaccination" in which whooping cough was the main topic!

- Now, can you imagine our helplessness when we also discovered the letter sent by the Authorities to each gynaecologist and each GP and in which vaccination against whooping cough for the parents-to-be was highly recommended?

(*slide Tile Lore*)

We have been waiting for Lore for 3 long years, with several miscarriages, so 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? Well, I see 3 main possible reasons :

1 - nonchalance

- One GP 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.

2 – minimization of the problem

- 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 health "professional",revolting!

3 - A lack of knowledge about the disease

- Yes, that's for sure! When pertussis has been 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 azithromycin 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, as :

- 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 either. 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 the champion even thought for 14 weeks!!!

Pure nonsense this quarantine, we were not contagious anymore with the azithromycin that we took on the first day of the diagnosis.

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

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

But had the medical profession relayed the recommendations of the authorities correctly, we would have been revaccinated in due time, and our baby would more than probably still be with us today.

(Slide : CDC)

After analysis, what happened 3 years ago ?

One of us came home with a heavy cough, then contaminated the others present in the room including a defenceless little baby.

I mean one of us not vaccinated anymore because we didn't know that a booster was recommended.

That annoying cough has a name : whooping cough !

Since then, life goes on of course, but we go to sleep every night with the knowledge 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...

So, we decided immediately that the loss of Lore might not have been for nothing and we started our own awareness campaign by the creation of a website.

(slide in he media)

It didn't take a long time for the media to relay the story of Lore in Newspapers, TV, radio, plus our presence at international conferences and the support from well-known science-based websites blogs gave another dimension to our cruise.

We also have been asked to become members of the workgroup "Communication" of the health authorities in Flanders.

(slide CSS/HGR)

And recently, in August this year, The Belgian Superior Health Council decided to update its guidelines on whooping cough vaccination and to follow the CDC's recommendations.

The biggest change is that it is clear now for everyone that vaccination against whooping cough is allowed during a pregnancy.

Even more than that, women should get an adult Pertussis vaccine during the 3rd trimester of each pregnancy in order to transfer antibodies from the mother to the baby via the umbilical cord, and this, to give the baby a temporary immunity for the two first months of his life, just when he is the most vulnerable because too young to be vaccinated himself.

The Council recommends also the cocoon vaccination, not only for the parents, but also for the grand parents, brothers, sisters, childcare givers, crèche staff, all in one, for everyone who will come in the neighbourhood of the baby.

The Council also insists on the strict respect for the vaccination schedules and recommends vaccination for everyone , it also made clear that breastfeeding is not an obstacle for vaccination.

(slide other victims)

All those changes are more than welcome surely knowing that in the meantime, the bacteria kept on doing its deadly job and made other little victims in our regions :

I think particularly of baby Raphaël, Augustin, Jude, Anissa, Safora, and many others...

Same sad stories, same struggles for life, same helplessness at the end because their losses could easily have been avoided too.

As far as I know, I think that only the United States, the UK and Belgium have adapted their policy on whooping cough vaccination and, as a vaccine ambassador, I can only insist by the other countries to adopt the CDC's recommendations too.

It doesn't make much sense to fight alone against an invisible enemy.

It's all together, with one common strong vaccination policy, that we will be able to reach high herd immunity rates, which means that diseases can be kept at a distance, and better, that diseases can be eradicated !

(slide "Homepage")

Dear Members of Parliament,
Ladies and Gentlemen,

I would end my speech here by saying :

We cannot change anything in the past, it's too late for us, but you can build the future !

Whooping cough or any other vaccine preventable disease, please give them no chance !

This is Lore's legacy to the world !

I thank you for your attendance and for your attention.