

How Blood Transfusion Services contributed to Hemophilia Care and Future Challenges

Dr. h.c. Cees Smit, long-term user of plasma products

EBA, European Parliament, January 22, 2019 Brussels

Dear Mrs.Grossetête, dear mr. Balas, dear Members of Parliament, dear Audience

I am a long-term user of plasma products for hemophilia thanks to medical achievements in the 'public' blood transfusion services 50 years ago and especially Judith Pool in the USA and Jean-Pierre Soulier from France

On my first slide, you see a 'black and white' picture from a hemophilia clinic in The Netherlands in 1965 in a situation where there was no treatment for hemophilia at all and the life-expectancy was around twenty to thirty years. Around 1965, Pool and Soulier invented how to isolate the missing clotting factors from human blood plasma and the lives of hemophiliacs and their families drastically changed. In 2015, two generations later, the life of young hemophiliacs shows a totally different picture and at the same time the hemophiliacs from the 1965 photo became older.

On the second slide, you see recent life-expectancy data from our long-running research project 'Hemophilia in The Netherlands, part 6'. You see that the life-expectancy is now almost equal to that of males in The Netherlands without hemophilia. In the blue circle, you see the decrease in life-expectancy because of the hiv-infections that tragically hurt the hemophilia community in the eighties. In The Netherlands, Belgium and the Scandinavian countries this tragedy was less outspoken than in countries like Germany, the UK and Italy where they much more used plasma products from paid donors from the USA.

Based on my experiences, I see the following challenges for the EU in the next years:

1. Plasma collection in the EU should become more self-sufficient

From history, we have learned that depending on plasma that has been collected in just one country can be dangerous. Examples, hiv in the eighties in the USA and later 'mad cow disease' in the UK. But even if the quality is regulated, as it is at present, there might be a shortage so it is important to promote self-sufficiency.

So, therefore, we need to collect more plasma within all EU countries. However, we also need more cooperation between EU countries. If potential relapses in the plasma supply in a particular EU country occur, other EU countries should be able to supplement.

At the moment, this is actually the case with immunoglobulin shortages in countries like Romenia, Scotland and the UK.

So, that's why I personally perceive blood and plasma as a 'strategic resource' and the EU should be much more alert in this area. Also, because the increasing international tensions can also severely hurt the EU with severe availability problems.

2. Independent groups of users of blood and plasma should be established in the EU and in the EU countries

We also need within the EU an independent patient group that can represent the interest of often one-time and irregular users of blood and plasma.

There are specific interest groups at the moment, but most often their financial dependence from industry is a problem.

3. Legal issues

History has also learned that the legal position of the recipient of blood and plasma products is not good. Therefore, I am in favour of a 'no-fault compensation' system to cover the damage through unforeseen side-effects like hiv in the eighties or BSE later in time.