



Newsletter EHC

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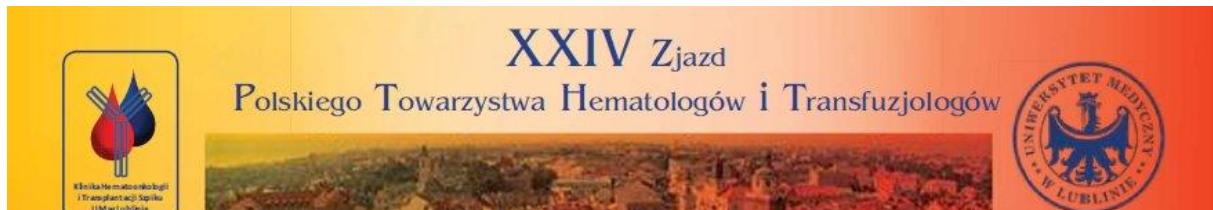
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News from the NMO's: Polish Haemophilia Society

Bad Blood movie shown during the 24th Conference of Polish Haematology and Transfusion Medicine Society



Polish Haemophilia Society took part in the 24th Conference of the Polish Society of Haematology and Transfusiology organized on 16-18 September 2011 in Lublin, Poland. During a discussion panel led by Bogdan Gajewski and Jacek Tabarkiewicz, MD, Marilyn Ness's *Bad Blood* movie was shown. The film presents the most painful tragedy in the history of medicine when in the 1980s people with haemophilia got infected with HIV and HCV via plasma-derived factor concentrates.

"The vital message of the film is that people making decisions about matters influencing others' health and life should never minimize the importance of scientific facts. It is safety that is of utmost importance when developing new medicines. If there should be even slightest supposition that the new product might be harmful, you have to stop its use. Today we know that future of haemophilia care is connected with recombinant factor concentrates. Their production tends to exclude human and animal proteins that might help in spreading pathogens – both those that are known and those that are still unknown. It is pathogens still unknown today that create the greatest risk because they cannot be detected by laboratory methods," commented Professor Jerzy Windyga from the Institute of Haematology and Transfusion Medicine in Warsaw. Many of the haematologists watching the film were visibly moved, and when the show ended the public clapped their hands.

Professor Wiesław Jędrzejczak, Poland's national haematology consultant, who also watched the movie, said: "You have to understand that at that time nobody knew and nobody could expect

what the consequences of using plasma-derived factor concentrates might be. It was hard to imagine the situation that did take place afterwards. It was a long process before specialists got to know everything and it took a long time before people realized all the consequences. At present all viral particles in the blood can be identified. However, there is a new danger: prions that cannot be detected by tests based on nucleic acid detection. And there is one more question: Cannot there be any other pathology connected e.g. with protein transformation that has not been detected yet?"

Official information about the presentation of the Bad blood film during the congress of the Polish Haematology and Transfusion Medicine Society

New National Programme of Haemophilia Treatment in Poland

On 26th September 2011 the National Programme of Haemophilia Treatment for the Years 2012-2018 was signed by the Polish Minister of Health Ewa Kopacz.

During a press conference at the Ministry of Health on the following day the Minister handed in a copy of the document to the President of the Polish Haemophilia Society Bogdan Gajewski. According to the procedure, as soon as such a document is signed by the minister it comes into force.

"It is great news. We are very grateful because the new Programme is a guarantee of good treatment for the coming years. Its creation was vital for us because thanks to it it may be possible to introduce truly European changes in haemophilia care in Poland," said Bogdan Gajewski.

The National Programme of Haemophilia Treatment for the Years 2012-2018 is more than a simple continuation of the previous Programme which covered the years 2005-2011. It contains many regulations that will improve the situation of people with haemophilia in Poland. For example, the per capita consumption of clotting factors shall grow and by the end of the Programme it shall reach the level of 6 IU.

The Programme stipulates creation of comprehensive haemophilia treatment centres. The document provides also for the purchase of recombinant factors, which currently have the best safety profile. So far, plasma-derived factors were in general use in Poland, the only exception being small children (previously untreated patients). Thanks to the new regulations, also other groups of patients will have a chance of being treated with recombinants. This is an important supplementation of the changes in haemophilia care initiated by the Polish Haemophilia Society (the above-mentioned use of recombinants for PUPs, introduced at the beginning of 2011, was another initiative of the Society) The creation of the National Programme of Haemophilia Treatment has shown that "good cooperation of patients, doctors and state administration is possible.

We hope that this cooperation will be continued. We hope also that it will soon be possible to make changes in the system of refunds for hospitals treating patients with haemophilia. Representatives of the Ministry of Health promised them during their talks with patients at the time when the Programme was being developed," concluded President of the Polish Haemophilia Society.

Adam Sumera



*Symbolic gesture:
Minister Ewa Kopacz and PHS President Bogdan Gajewski*