

Warsaw, September 20, 2016

## **Konrad Krzemiński asks the Minister of Health to speed up the drug reimbursement process**

**Konrad Krzemiński is 20 years old and suffers from paroxysmal nocturnal haemoglobinuria (PNH). Despite the initial negative decision by Health Minister Konstanty Radziwiłł and the National Health Fund for reimbursement of the drug Soliris (eculizumab), its reimbursement process has begun.**

### **A light at the end of the tunnel and the chance of a miracle**

Recently, it has turned out that reimbursement proceedings for Soliris (eculizumab) have begun. Currently, the application has been forwarded to the Agency for Health Technology Assessment and Tariff System in order to prepare a thorough verification analysis related to its presence on the Polish market, despite the fact that the authors behind the research associated with PNH emphasize the safety of Soliris.

*There is no doubt that not treating patients suffering from PNH with Soliris will lead to unnecessary suffering and premature death caused by this devastating disease – said Professor Peter Hillmen, co-author of the study entitled "Long term treatment with eculizumab in paroxysmal nocturnal haemoglobinuria: sustained efficacy and improved survival."*

Unfortunately, the administrative procedure on reimbursement and determination of an official drug price takes 180 days, which means that Konrad Krzemiński may not survive until the drug is available to him.

*At this moment I am posing a question to Minister of Health, Konstanty Radziwiłł: What is more important according to him – a long, tedious procedure associated with drug reimbursement or a man that you can save? How much do you think a human life is worth? - asks Professor Alicja Chybicka.*

Comments on the reimbursement process also come from Konrad himself, who again asks the Minister of Health to save his life.

*Minister, as a young man with the last glimmer of hope, I beg you to speed up the reimbursement process for Soliris which is my only chance for a long and happy life. It is currently in your hands and it is you who will decide whether I should live or die - said Konrad Krzemiński.*

### **Difficult treatment beginnings**

Although Konrad's disease was diagnosed only in the second half of last year, he has already endured hospital admissions lasting many weeks. His situation improved markedly after the administration of four doses of Soliris (eculizumab), bought for him by the Regional Hospital in Szczecin, however, the National Health Fund refused further funding. After discontinuation of therapy, his health deteriorated drastically, which resulted in a second liver transplant (the first transplant was caused by hepatic

vein thrombosis). This incomprehensible decision not to grant Konrad the drug, devastating in its consequences, means that, chained to a hospital bed, he can only count on a miracle.

### **Support from all around the world**

Thanks to people who want to help Konrad, news about his fate has reached as far as Canada, where the Canadian Association of PNH Patients has become interested in his case. The Association's President decided to write an open letter to the Minister of Health, Konstanty Radziwiłł, asking to save his life.

*[...] This situation makes me question if any of you would like to find yourselves in a position where you would need to explain a great tragedy to your citizens because of bureaucracy and costs, just when a human life could have been saved, especially when the efficacy of the treatment is proven? [...].* - wrote Barry Katsof, President of the Canadian Association of PNH Patients.

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