Launch of the Primary Immunodeficiencies (PID) Call to Action

“Driving Diagnosis for Optimal Care”

PID European Initiative Report
Brussels, 28 April 2010
European Parliament Launch of the Primary Immunodeficiencies (PID) Call to Action

In honour of World Immunology Day, the Jeffrey Modell Foundation (JMF), a global charity and patient organization, dedicated to the early diagnosis and treatment of Primary Immunodeficiencies (PID), held an event on 28 April at the European Parliament in Brussels.

The lunch debate, gathered over 45 participants from the European Parliament, European Commission, health groups and medical community. These included 13 expert immunologists and clinical thought leaders from across the JM Centre Network in Europe including Germany, Hungary, Ireland, Italy, the Netherlands, Poland, Sweden and Switzerland, to officially endorse the Primary Immunodeficiencies (PID) Call to Action.

The event aimed at raising awareness of Primary Immunodeficiencies amongst Members of the European Parliament, the European Commission and the Member States to ensure that each European child and adult has the best chance of being diagnosed early and effectively treated.

Member of the European Parliament from Slovakia, Dr. Miroslav Mikolášik in his opening words said: “I hope by today’s endorsement of the Primary Immunodeficiencies Call to Action, we will pass a strong message to all Member States to include PID in their national health plans, and achieve optimal treatment of these rare diseases”. He also stressed the need to use the opportunity created by the institutional turnover, in particular with the new Commission in place, and Commissioner Dalli, to raise awareness of PID and the importance of early diagnosis to address the disease.

Dr. Mikolášik welcomed the opportunity to meet high level medical experts from national Jeffrey Modell Diagnostic Centers to discuss the PID situation in their countries and learn about the important work being carried out by the Centers. "By working together we can make important strides towards a healthier Europe. I count on your support, and on your active participation to relay the message in your respective countries”, he added.
In particular, **Prof. Reinhold Schmidt**, Director of the Clinic for Immunology and Rheumatology at Hanover Medical School, Germany who chaired the event, welcomed the opportunity to bring this discussion to EU leaders, stressing that “PID remains widely under diagnosed and leads to severe and sometimes fatal consequences for the babies and children born with this condition and place a heavy burden on the health systems in which they are treated”. He in particular deplored the lack of training and knowledge in immunology and immunodeficiency amongst health professionals. He further pointed out findings of the recent peer-reviewed study that the average cost of a patient who has not been diagnosed is €75,000 per annum, while after diagnosis and treatment costs to the healthcare system averaged €16,000 annually. Prof. Schmidt added that a patient who receive an early diagnosis and adequate treatment can leave a normal life, work and therefore be productive for society.

**Prof. Lennart Hammarström** from the Clinical Immunology Karolinska University Hospital in Sweden, highlighted the role of awareness raising amongst medical specialists and the key role National Reference Centers, such as the ones created by the Jeffrey Modell Foundation play in early diagnosis of the PID patients. “These Centers are crucial in advancing and improving the care of PID patients, and in building registries of information which enable an integrated approach to PID recognition and treatment across the EU”. Prof. Hammarström also stressed the need to understand the economic benefits of early screening as screening, diagnosing and treating PID patients is beneficial to society, improve their quality of life enabling them to contribute to the workforce. “There is a real economic value behind the early diagnosis of PID, but Member States need the incentives and support from the EU institutions in order to advance the cause of PID”, he concluded.
The patient perspective was presented by Mrs. Jose Drabwell, Chairwoman of the International Patient Organisation for Primary Immunodeficiencies (IPOPI), who shared her personal experience of living with PID and the true suffering she endured due to a lack of knowledge and misdiagnosis. She was waiting for a correct diagnosis for 20 years, this example exemplified the economic burden of undiagnosed PID patients on the health system. She highlighted the role of patient organisations in raising awareness of Primary Immunodeficiencies, not only among the general public, but also amongst GPs, nurses, politicians and the media. “Do not take “no” for an answer..., I talk to everyone who wants to listen to me,... by raising awareness we can make things happened”, she said.

Dr. Grigorij Kogan responsible for Chronic Diseases at the European Commission’s DG Research presented the role of the EU funding programmes in supporting research in rare diseases, and in particular explained the procedure to follow for researchers to apply for EU funded projects under the Framework Programme Seventh (FP7). Asked about the amount of money devoted for rare diseases under FP7, he answered that on average and annually (depending on the call for proposals), 30 to 40 million Euros is dedicated to rare diseases, to help advance research and therapies, and develop new drugs and medical devices to improve the life of patients, including those with PID. He encouraged all researchers also from the US to actively participate and follow opportunities presented under the EU programmes.

Co-Founder of the Jeffrey Modell Foundation, Fred Modell concluded the debate by presenting the 24 years of achievements of the Foundation in research, diagnosis, treatment of patients, and advocacy of these diseases. Under the leadership of JMF, the US Centers for Disease Control and Prevention (CDC) declared PID as a “serious public health threat” at a similar consensus conference.
With the support of the US Congress, JMF initiated a physician education and public awareness campaign to address these disorders. Fred Modell believes that the success of JMF can be replicated in Europe, adding "what we need is more targeted long lasting initiatives that will measurably impact patients lives, address timely and precise diagnosis, access to safe and effective treatments and disparities of care".

The event concluded with participating from the Members of the European Parliament and representatives from the medical and patients community signing the PID Call to Action. The JMF together with the entire PID Community will continue their efforts to see more EU officials endorse the document and encourage patient organisations, and clinicians to relay the messages widely to their home countries around Europe.

Photo gallery

Launch of the PID Call to Action, EP, 28 April 2010

Prof. Reinhold E. Schmidt, Mrs. Vicki Modell, Dr. Miroslav Mikolášik, Mr. Fred Modell, Dr. Grigorij Kogan

1 See more pictures at: http://www.davidplas.be/clients/interel/20100428_PID/