Deficient diagnosis

MEPs have joined forces with health experts in demanding EU-wide action to raise awareness of a little-known but potentially deadly disease. Martin Banks reports

It is said to affect up to one in 250 people. It is often debilitating and sometimes even fatal. But a recent debate in the European parliament heard that relatively little is known in Europe about primary immunodeficiency (PID), a deficiency in the immune system that causes recurring infections.

The lunchtime event, organised by Brussels PA company Interel, in parliament last week was told that because of such poor awareness, Europe lags well behind other parts of the world, such as the US and Asia, in the treatment available for people with PID. The message, therefore, was clear: the EU and member states need to step up to the plate and focus more attention on improving patient care.

According to Slovakian EPP member Miroslav Mikolášik, who opened the debate, the key is early diagnosis and equal access to treatment. The sooner the condition is diagnosed, the better the chances of survival. Member states, he said, also have an important role to play in alleviating patient suffering by including PID in all newborn screening programmes for rare disorders.

Another keynote speaker, Jose Drabwell, spoke eloquently and passionately about how it had taken “years and years” before she was diagnosed with PID. She encouraged member states and MEPs to sign a “call to action” which explains the steps national governments can take “to understand, appropriately diagnose and manage PID”. Drabwell, who chairs PID’s International Patient Organisation, said,
Current scientific estimates of the rate of PID show:

- Around one in 8-10,000 people has a genetic primary immunodeficiency that significantly affects their health
- PID affects at least 10 million people worldwide
- Experts estimate that the actual incidence of some form of PID in the general population is between one in 250 and one in 500
- This compares with a prevalence of one in 700 for type one diabetes and one in 1000 for multiple sclerosis
- While each of the more than 160 identified PID conditions may be rare, taken together, they are more common than childhood leukaemia and lymphoma combined