



EUROPEAN CONSENSUS CONFERENCE ON PRIMARY IMMUNODEFICIENCIES



This poster is presented by the International Patient Organisation for Primary Immunodeficiencies (IPOPI), who have taken the lead on a joint project with the International Nurse Group for Immunodeficiencies (INGID), the European Society for Immunodeficiencies (ESID) and the European Federation for Immunological Disorders (EFIS)

SUMMARY

The World Health Organization currently recognizes more than 100 Primary immunodeficiency diseases (PIDs), and they represent a class of disorders in which there is an intrinsic defect in the human immune system. In some cases, the body fails to produce any or enough antibodies to fight infection. In other cases, the cellular defenses against infection fail to work properly. They are genetic conditions that range in severity and bare the clinical hallmarks of persistent, recurring infections. Left un/misdiagnosed, PIDs lead to a lifetime of chronic illness, permanent organ damage, disability or even death.

With funding from the European Commission's 2005 Public Health Programme, IPOPI, ESID, INGID and EFIS held an EU PID Consensus Conference in June 2006. The aim of which was to increase recognition of PIDs as a public health issue, and create a forum for experts to discuss and propose a consensual public health approach to PIDs.

Treatments in the form of antibody replacement therapies (immunoglobulins) are available, and have a long history of proven efficacy, leading to reductions in illness and burden on healthcare provider resources. The core issue with PIDs is therefore one of chronic under diagnosis, with symptoms often not recognised by doctors, sufferers or their families.

This poster provides a brief overview of the European PID Consensus Conference, which successfully brought together clinicians, patients, policy makers, regulators and manufacturers, and is an outstanding example of how the EU Public Health Programme can enable co-operation among organisations who play different roles in supporting improved care for a rare disease.

PIDs AS A EUROPEAN PUBLIC HEALTH PRIORITY

The recognition of PIDs as a European public health priority has gained momentum over recent years thanks to the support of the European Commission and European Parliamentarians such as Antonios Trakatellis MEP, John Bowis MEP, Caroline Jackson MEP, Godelieve Quisthoudt-Rowohl MEP, Peter Liese MEP, Stephen Hughes MEP, Catherine Stihler MEP and Chris Davies MEP. Their support gave confidence to the umbrella organisations working with patients, nurses and physicians in this field to collaborate on a project that would aim to develop a European framework for a public health approach to PIDs, and then articulate this to national policy makers, public health experts, researchers and the general public.

THE EUROPEAN PID CONSENSUS CONFERENCE

The project developed to meet these aims was the European PID Consensus Conference. This was held on 19-20 June 2006 at the Paul-Ehrlich Institute in Germany. The Conference convened 100 experts and delegates in clinical immunology, PID care, public health, genetics, EU/national ministries of health and agencies, academic centres, public health laboratories, professional organisations and patient groups, to identify and develop public health strategies that can be applied to PIDs.



EU PID CONSENSUS STATEMENT, RECOMMENDATIONS AND REPORT

At the conference, the multi-discipline experts concluded that:

- PIDs are widely undiagnosed and there is a lack of awareness of PIDs among the general public, healthcare professionals, healthcare policy makers and implementers.
- Effective therapies for PIDs exist and early treatment saves lives, prevents morbidity and improves quality of life. There is also evidence that early treatment is cost effective.
- There is a significant disparity of care within and across EU member states.

The multi-discipline experts developed a Consensus Statement containing these conclusions and also approved a series of recommendations that focus on three key areas where priority action is needed to be taken by Member State governments of the EU;

Priority Action 1: Awareness and Education

- Clinical protocols to reliably identify PIDs
- Epidemiological studies into the prevalence and incidence of PIDs and their impact on public health and costs.
- International patient registries expanded to assess the clinical presentation, natural history and genetic patterns of PIDs.
- Health campaigns developed to raise awareness of PIDs among the general public.
- Education programmes targeting the general public, healthcare professionals and healthcare policy makers and implementers.

Priority Action 2: Screening and Diagnosis

- Practical tools for efficient diagnosis of PID made available in every country.
- Evaluation of diagnostic tools for PID and research into the feasibility of screening programmes to prevent damage.

Priority Action 3: Treatment and Management

- EU guidelines developed to provide equal access to treatment and assure an optimum standard and quality of patient care in the appropriate treatment setting.
- Cross country initiatives set up to allow exchange of expert experience and education.
- EU treatment centre networks established in order to determine disease outcomes.
- Safest immunoglobulin treatments available to all patients who require antibody replacement.

Given these conclusions a Statement, Recommendations and Report were developed. Communication of EU Consensus Statement, Recommendations & Report

As important as the Conference itself, was the communication of the Statement, Recommendations & Report that resulted from it. A key part of this communication was the development of a Consensus Conference website: www.eupidconference.com. The website was an online forum, available in 5 EU languages, that provided pre-conference information and on-line registration as well as post conference documentation and outputs.

Following the Conference, the European PID Consensus Statement, Recommendations and Report was subsequently launched in October 2006 at the ESID/IPOPI/INGID bi-annual meeting in Budapest.

At the Conference a well attended press conference was held, which combined with launch activities of the Consensus Statement, resulted in sixteen significant news pieces in countries that included: Austria, Germany, the Netherlands, Portugal, Belgium, Hungary, France and Italy.

The EU PID Consensus Statement, Recommendations & Report was also made available in 10 EU languages (Spanish, Portuguese, French, German, Dutch, Hungarian, Polish, Swedish, English, Italian) on the Conference website and on CD Rom. This CD Rom was then circulated to all Conference attendees and over 400 key health policy decision makers in each of the EU Member States.



CONCLUSION

The European PID Consensus Conference has been a significant milestone for not only the European, but the global PID community. It provided a forum to not only explain the negative impact that non diagnosis of PIDs has on the health of sufferers and the healthcare systems that provide their care, but also to develop solid recommendations that could lead to improved diagnosis and appropriate treatment of existing effective immunoglobulin therapy. The next stage will be to ensure PID sufferers continue to take forward the recommendations and also have access to treatment both in hospitals, but also in the home across Europe.

The four partner organisations of this project would like to express many thanks to all those who supported them in the success of this project including the European Commission, clinicians, people with PIDs and their families as well as industry sponsors.

For further information please contact IPOPI at info@ipopi.org or visit our website www.ipopi.org



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