



PID is Primary
Immunodeficiency

PLEASE DIAGNOSE
CAREFULLY

Booklets to simplify the diagnosis of Primary Immunodeficiency available to key specialists to mark Rare Disease Day

These booklets contain personal diagnosis stories, which demonstrate the overall impact that diagnosis delay has on patients' lives, in terms of ill health, anxiety and stress and, in many cases, permanent health damage. Dr Philip Woods, Chairman of UK Primary Immunodeficiency Network said, "UKPIN is committed to working with all parties to improve access to specialist immunology services and bring the benefit of earlier diagnosis and therapy to patients with all forms of PID."

A review of newly diagnosed PID cases, published by the Campaign in 2009, found that in the two years prior to diagnosis, 85% of patients had been referred to other specialists before being referred to immunology.

The most frequent referrals were to respiratory (30%), paediatrics (15%), gastroenterology (10%) and ENT (5%). 35% of patients had two referrals and 15% had three or more. More than half of this group had been admitted as hospital in-patients prior to diagnosis. 27% of patients in the case review had waited seven or more years for diagnosis.

"We believe these guides will help reduce diagnosis delay and ensure that our patients are seen, diagnosed, treated and managed by the appropriate immunology specialist at an early stage," said Chris Hughan, Chief Executive of the PiA and a member of the Is It PID? Campaign's Advisory Group.