

**Impact of a Physician Education and Patient Awareness
Campaign on the Diagnosis and Management of Primary
Immunodeficiencies**

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To the Editor

Primary immunodeficiencies (PIs) are devastating disorders, primarily resulting from monogenic defects of the immune system¹, and affect as many as 500,000 people in the US alone². Left undiagnosed, PIs are often associated with severe morbidity and increased mortality³. Many PIs can be diagnosed easily, and effective treatment options are available⁴. However, awareness of PIs and their management is low amongst physicians and the general public, and many patients are left undiagnosed.

Considering the high morbidity and mortality associated with PIs, the Jeffrey Modell Foundation (JMF) initiated a Physician Education and Patient Awareness Campaign (PEPAC). To assess the effectiveness of the PEPAC in terms of referral and diagnosis rates and to gain information on the clinical and economic impact of PI diagnosis, three studies were performed in diagnostic and referral centers worldwide.

118 centers were contacted. All centers responded to the general survey, which focused on the numbers of patients being diagnosed and treated before and after the launch of PEPAC. Baseline reports, i.e. before PEPAC, were submitted in 2004/2005 and follow-up reports in 2006. The survey showed an increase in the number of diagnosed patients from 5,847 at baseline to 23,107 in 2006, corresponding to an annual increase of 98%. Increases were also observed in the numbers of patient referrals (+79%), diagnostic tests performed

(+492%), patients receiving treatment (+77%), and patients receiving intravenous immunoglobulin (IVIg; +65%).

The impact of PI diagnosis on clinical outcomes was assessed by comparing health parameters in the year prior to diagnosis (based on a retrospective review of patient records) with the year following diagnosis. 86 centers responded and records of 532 patients were analyzed. Data were collected in 2006 and reviewed by JMF's Medical Advisory Board. The analysis revealed decreases in the number of infections, antibiotic usage, days in hospital, and days missed from school or work in the year following diagnosis (Table 1).

The economic impact of PI diagnosis was assessed by a retrospective cross-sectional analysis comparing costs in the year prior to diagnosis with the year after diagnosis and treatment. A prevalence-based approach was used to assess medical costs, considering hospital inpatient, outpatient and pharmaceutical costs. Summing together costs related to acute, severe and chronic infections, physician/hospital visits, antibiotic costs, hospitalizations, and school/work days missed, the average annual cost for an undiagnosed PI patient was \$102,736. After diagnosis and treatment, the average annual cost was reduced to \$22,696 (excluding the costs of diagnosis and treatment), corresponding to a gross annual saving of \$79,942 per patient.

The survey results demonstrate that effective education of physicians and enhanced public awareness of PIs led to increased diagnosis and referral. Moreover, diagnosis of patients led to improved health, as evidenced by

decreased rates of infection and reduced need for antibiotics or hospitalization. These clinical improvements translate into gross economic savings of approximately \$80,000 per patient per year. Treatment may add costs of \$25,000-35,000 annually, but costs for diagnosing and treating patients with IVIG remain less than 50% of costs for undiagnosed patients.

Table 1. Clinical parameters in the year prior to diagnosis and in the first year after diagnosis of a primary immunodeficiency.

	Value in year prior to diagnosis	Value in first year post-diagnosis	Change (%)
Acute infections (<i>n</i>)	6.4	1.8	-71.8
Physician / hospital / ER visits (<i>n</i>)	70.9	11.8	-83.4
Severe infections (<i>n</i>)	4.3	0.6	-86.0
Pneumonias (<i>n</i>)	2.8	0.6	-78.6
Chronic infections (days)	44.7	12.6	-71.8
Time on antibiotics (days)	166.2	72.9	-56.1
Time in hospital (days)	19.2	5.1	-73.4
School/work missed (days)	33.9	8.9	-73.7

References

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