Spain on the move despite the crisis

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Spain on the move despite the crisis

A. What we have
B. What we miss
A. What we have

1. A good network of interactive PID groups
2. A great registry
3. A good network of patient organizations
A. What we have

1. A good network of interactive PID groups
   - Strong inter- & intranational collaboration
     • 2013 PID group in the Spanish Society for Immunology
   - Strong track of PID meetings
     • 1993-2013 biannual registry meetings
     • 1994 Sitges, INGID founded, first ESID Constitution
     • 1995, 2001 Juan March Foundation, Madrid
     • 2016 ESID Barcelona

2. A great registry

3. A good network of patient organizations
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<th>Center</th>
<th>City</th>
<th>Hospital</th>
<th>Name</th>
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<th>PID patients/year (2011)</th>
<th>Total PID patients</th>
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<td>La Paz</td>
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1. A good network of 20 interactive PID groups
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- 2012 figures
  - 3,000 patients followed
  - 700 new ones evaluated
Regional differences!
A. What we have

1. A good network of interactive PID groups

2. A great registry (REDIP, soon 20 yr old)
   - >2,000 patients registered (soon in ESID), second only to France.
   - 26 registering centers
   - Biannual meetings for contributors since 1993

3. A good network of patient organizations
2. A great registry (redip.org.es)

4.4/100,000 prevalence
A. What we have

1. A good network of interactive PID groups
2. A great registry (REDIP, soon 20 yr old)
3. A good network of patient organizations
B. What we miss

1. Better PID awareness
2. Newborn PID screening and sustained PID diagnosis and care during the crisis
3. A JMF Diagnostic and Research Center
B. What we miss

1. Better PID awareness
   - Health system
     • Expand REDIP to all regions
     • Increased reporting to JMF
     • Brief PID guide for primary care physician education
   - Public awareness (World PI Week!)
     • School, University, Administration, patient org.

2. Newborn PID screening and sustained PID diagnosis and care during the crisis

3. A JMF Diagnostic and Research Center
Brief PID guide for Spanish-speaking physicians

- **What?** Clinical features of main PID groups
- **Who?** Diagnostic & care units who can help
- **How?** Treatment options and prognosis
- **Why?** References and links (ESID, JMF, LASID, patient organizations, research networks)
Long 2013 PID guide for Spanish-speaking experts
B. What we miss

1. Better PID awareness
2. Newborn PID screening and sustained PID diagnosis and care during the crisis
   - Detection and diagnosis
     • No newborn screening in place
     • Fund cuts restrict diagnostic tests and labs
   - Treatment
     • Better outpatient/inpatient coordination
     • Fund cuts restrict access to some IVIG brands and SCIG expansion
3. A JMF Diagnostic and Research Center
B. What we miss

1. Better PID awareness
2. Newborn PID screening and sustained PID diagnosis and care during the crisis
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B. What we miss
Spain on the move despite the crisis

A. We have a great PID detection, diagnostic, reporting and treatment network

B. We need help to keep it running in the near future
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Thanks to
Eduardo López-Granados (Madrid)
Manel Juan (Barcelona)
Nuria Matamoros (Mallorca, REDIP)