

Spain on the move despite the crisis



SEI
Sociedad Española
de Inmunología

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JEFFREY MODELL
CENTERS

Summit

Berlin, Germany

— JULY 17-20, 2013 —



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

1. A good network of 20 interactive PID groups

				PID patients/year (2011)				Total PID patients						
Center		Contact		Clinic		Lab	Total	Registered / reported in						
City	Hospital	Name	email	Followed	New	Tested		JMF	REDIP	ESID	Other	Total	TOTAL	
1	Madrid	La Paz	Eduardo Lopez-Gr	elopezg.hulp@salud.madrid.org	674	293		967	YES	676			676	1643
2	Barcelona	Vall d'Hebron	Pere Soler	psoler@vhebron.net	492	100	100	692	YES	222	470		692	1384
3	Barcelona	Clinic	Manel Juan	mjuan@clinic.ub.es	27		276	303	NO	27		750	777	1080
4	Murcia	Virgen de la A	Ana M. García-Alo	anam.garcia20@carm.es	337	138	515	990	NO	59			59	1049
5	Mallorca	Son Espases	Nuria Matamoros	nuria.matamoros@ssib.es	220	35	110	365	NO	198	198		396	761
6	Cáceres	San Pedro de	Luis Fernández-Pe	luis.fernandezp@ses.juntaex.es	164	53	217	434	NO	7			7	441
7	Cádiz	Puerta del Ma	M Almudena Samp	mariaa.sampalo.sspa@juntaex.es	150	54	190	394	NO	8			8	402
8	Madrid	Gregorio Mar	Juana Gil	jgil.hgugm@salud.madrid.org	224			224	YES	145			145	369
9	Las Palm	Doctor Negrín	J Carlos Rodríguez	jrodriguez@gobiernodecanarias.es	140		160	300	YES					300
10	León	de León	Jose G Ruiz de Md	jgarciar@saludcastillayleon.es	137		137	274	NO	26			26	300
11	Córdoba	Reina Sofía	Manuel Santamaría	msantamaria@uco.es	198	24	48	270	NO					270
12	Barcelona	Sant Joan de	Laia Alsina	lalsina@hsjdbcn.org	47	37	100	184	YES	56	17		73	257
13	Madrid	12 de Octubr	Luis Allende	lallende.hdoc@salud.madrid.org	0		100	100	YES		149		149	249
14	Badajoz	Infanta Cristin	Josefa Melero Ruiz	jmelero@unex.es	45	15	60	120	NO					120
15	Oviedo	de Asturias	Lourdes Tricas	ltricas@telecable.es	53			53	NO		53		53	106
16	Sevilla	Virgen del Ro	Berta Sanchez	bersanchez@yahoo.es	63			63	NO	42			42	105
17	Badalona	Germans Trias	Carlos Rodrigo	crodrigo.germanstrias@gencat.cat	30	5	20	55	NO					55
18	Barcelona	Sant Pau	Oscar de la Calle	odcalle@santpau.cat										
TOTAL					3001	754	2033	5788		1466	887	750	3103	8891

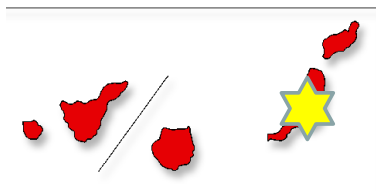
1. A good network of 20 interactive PID groups

- 2012 figures
 - 3.000 patients followed
 - 700 new ones evaluated

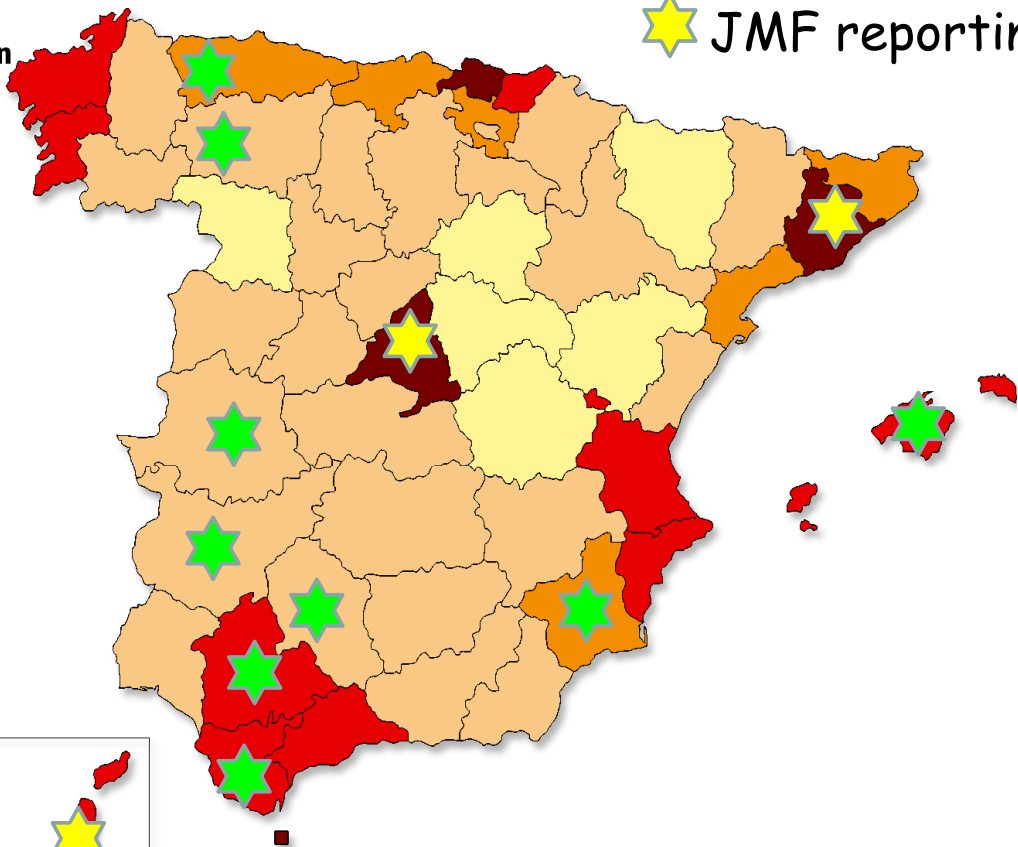
idad de población
(/km² en 2001)

- | Menos de 20
- | De 20 a 80
- | De 80 a 120
- | De 120 a 500
- | Más de 500

★ JMF reporting



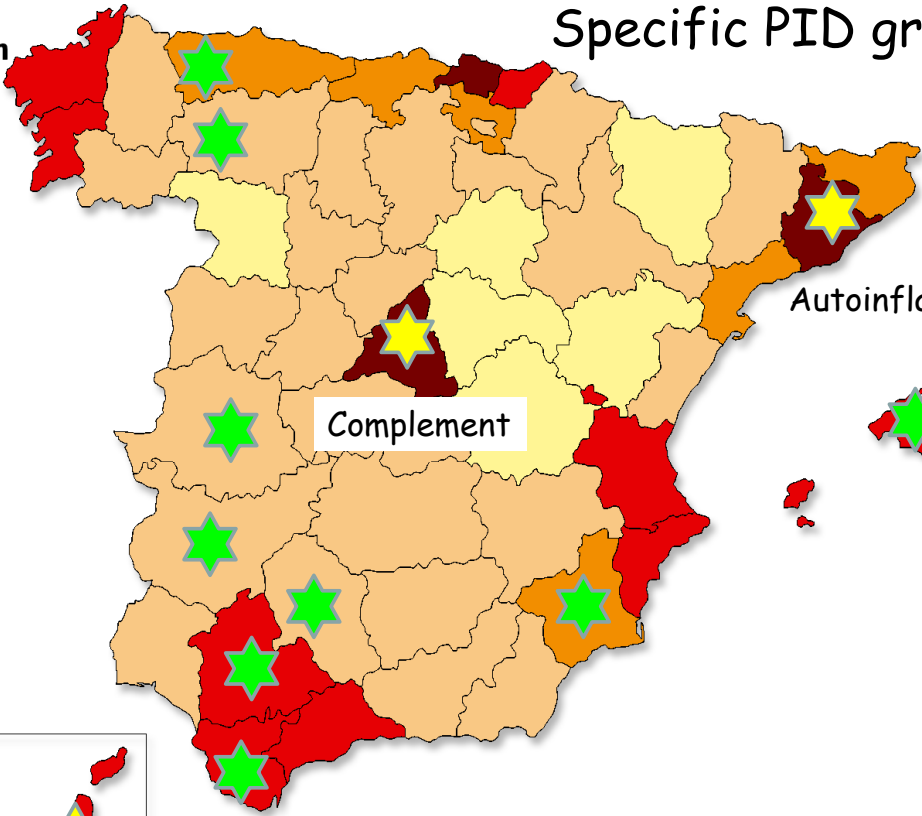
■ Regional differences!



Specific PID groups

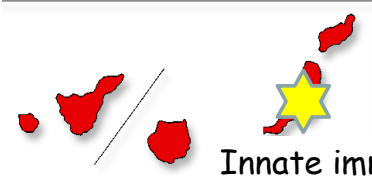
idad de población /km² en 2001)

- | Menos de 20
- | De 20 a 80
- | De 80 a 120
- | De 120 a 500
- | Más de 500



Autoinflammatory

Complement

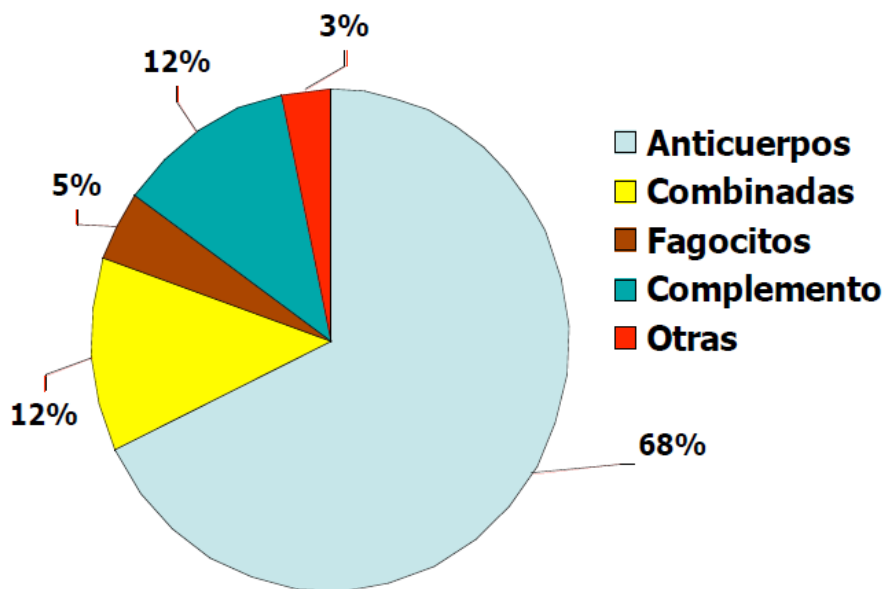


Innate immunity

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
 - By region: www.aedip.com, www.acadip.org
 - By disorder: www.aefat.es, www.angioedema-aedaf.org

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
3. **A JMF Diagnostic and Research Center**

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

Spain on the move despite the crisis

Thanks to
Eduardo López-Granados (Madrid)
Manel Juan (Barcelona)
Nuria Matamoros (Mallorca, REDIP)

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