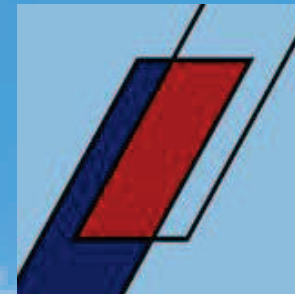


Patient Perspective in Spain

Barcelona, 22 Marzo, 2016

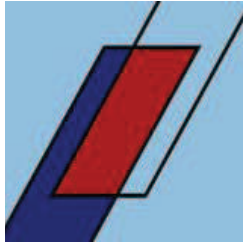
*Spain Patients Association,
a member of IPOPI*



*Laura
Miralles Payá*

 @LauraMirallesLM

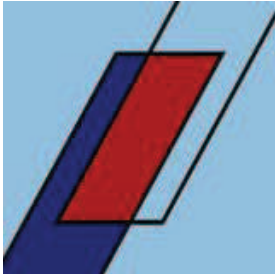




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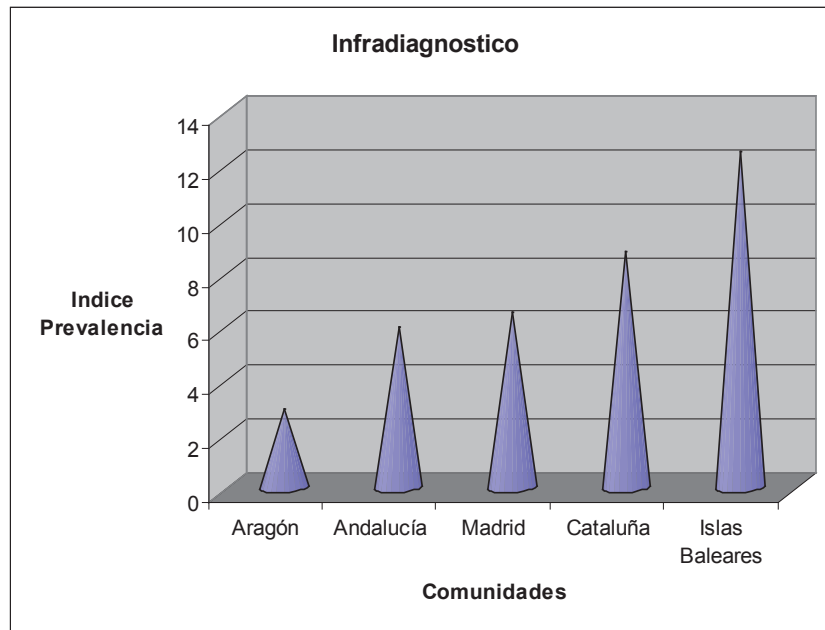
- 1. Underdiagnosis.
- 2. Lack of Immunology Services in Spain.
- 3. Lack of coordination by territories in Spain.
- 4. Difficulties in medical treatments in different regions or countries.
- 5. Changes in the Immunology Training System.
- 6. Early identification of SCID through screening of newborns, implementation required.
- 7. Research, approach in Europe.
- 8. Health management in the short term.
- 9. Mission, vision and strategic objectives of AEDIP.



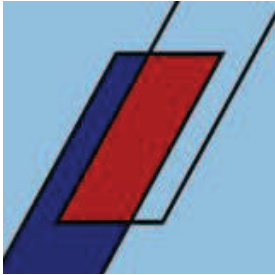
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1. Underdiagnosis.

Big differences between regions when it comes to diagnosed cases.



- We don't know how many patients are diagnosed.
- There is an IDP's Spanish Register, but is not updated. What's more, some hospitals don't record their cases.
- If we extrapolate the case of Baleares Islands to the rest of Spain, because it is the region with almost all registered cases, there should be 5.913 patients in the country. But, in fact, there are just 2.077 patients registered. It represents

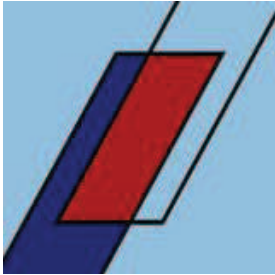


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2. Lack of Immunology Services in many hospitals of Spain.



- Doesn't exist A centralized strategy of implementation of Immunology Services doesn't exist, just some initiatives depending on each hospital.
- Many regions don't have Immunology Services in their hospitals.
- For this reason, AEDIP has concluded that it is necessary to establish one Clinical Immunology Service per 1.300.000 people.
- Not diagnosing early causes irreversible harm to patients as well as high costs to the Health Care System (it hospitalizes people many times, and leads to lots of sick leave...)

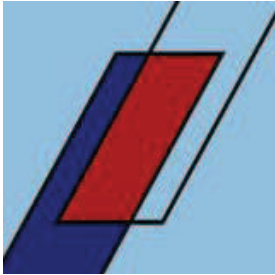


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3. Lack of coordination by territories in Spain.



- The Spanish Health Care System is decentralized into 17 regions with competence in health.
- The system is uncoordinated and it contains many inequalities.

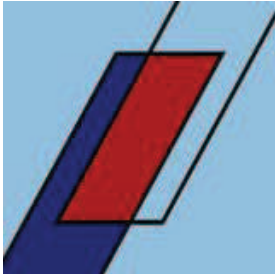


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4. Difficulties in medical treatments in different regions or countries.



- There are difficulties for patients needing intravenous treatments in a different hospital from their reference hospital. Nowadays there are high labour migration. Therefore, this is a big problem for patients.
- There is no protocol for Spanish patients needing an intravenous treatments in Europe.



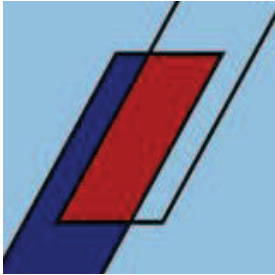
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5. Changes in the Immunology Training System.

Inclusion in laboratory without specific immunology training.

- With new rules, there are a reduction of 4 years to 2 years of training.
- On the one hand, this situation will cause an excessive increase of laboratories. On the other hand, there will be a reduction of the contents of the Immunology program.
- As a result, Spanish immunologists can't be recognized in Europe.





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6. Early identification of through screening of newborns



EXAMPLE OF EUROPEAN PASSIVITY.

About **early diagnosis of SCID (Severe Combined Immune Deficiency) through screening of newborns...**

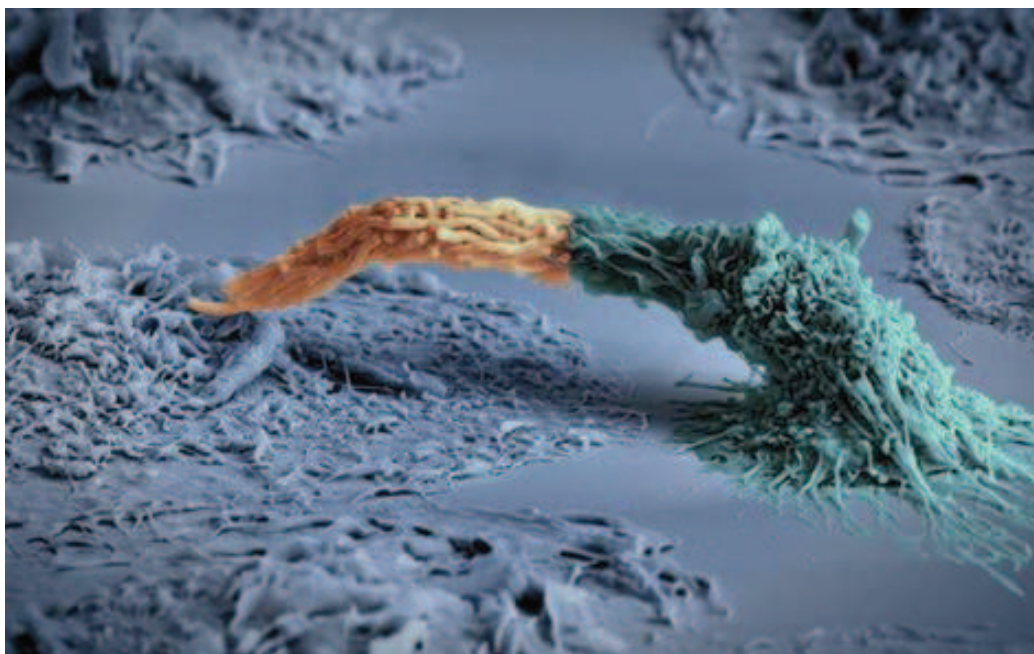
- “ There is in more than 50 percent of the states of the USA since 2008. However, in Europe, this is not done officially and universally in any state”.
- Also, if there is a timely identification, that patient may be able to get a transplant early, before suffering a serious infection."In the case of newborn screening in the USA has shown that survival increases to 90 or 95 percent. In Spain it is between 45 and 65 percent. ”

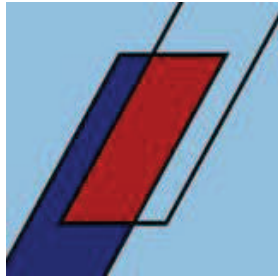


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7. Research, approach in Europe

- It is necessary to rethink the current system. The decision-making system in Europe doesn't advance, is not coordinated and doesn't take initiatives.





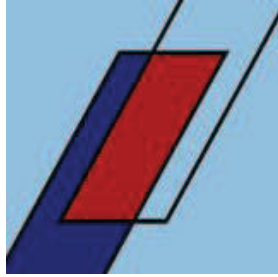
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8. Health management in the short term

Health administration.

- There is a Health management in the short term, but without overall vision and a common project.
- The focus of Health management has to be on the patient.





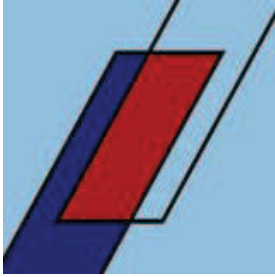
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9. Mission, vision and strategic objectives of AEDIP

- AEDIP'S MISSION

To improve the life quality of PID's patients. For this reason, they were created on the 20 th of December in 1990.



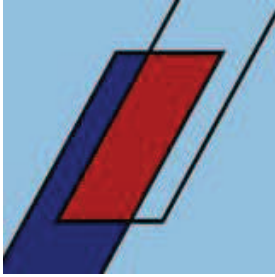


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AEDIP'S VISION

AEDIP wants to implement an early diagnosis system for IDP's standard in Spain, and an Immunology Services system that will coordinate all specialties involved in this illness, (immunologists, internists, pediatricians, pulmonologists, physiotherapists,...)





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AEDIP'S STRATEGY

$$O = (P + HP + A)$$

O = objectives

P = Patients, (IPOPI, AEDIP, ABADIP, ACADIP)

HP = Health Professionals

A = Other actors, pharmaceutical industry, scientific societies, ...



A hand is visible at the bottom right, holding the stem of a dandelion. The dandelion seed head is in the upper right quadrant. The background is a clear blue sky with a single, soft white cloud in the lower left. The text "Thank you ;)" is centered in the middle of the image.

Thank you ;)