

IPOPI Parliamentary Event

Implementing SCID newborn screening in Spain: For a life beyond “the bubble”

Monday 23 October 2017, Clara Campoamor Room, Spanish Congress (Madrid, Spain)

Hosted by Dr Jesús María Fernández MP and with the support of Dr Igea MP, Ms. Cabezas MP and Ms. Amparo Botejara MP



1 Introduction

In October 23, 2017, the Members of the Parliament Dr Jesús María Fernández (Socialist Parliamentary Group), Dr Francisco Igea (Parliamentary Group Ciudadanos), Ms. Isabel Cabezas (Popular Parliamentary Group) y Ms. Amparo Botejara (Confederal Parliamentary Group of Unidos Podemos-En Comú Podem-En Marea)¹, hosted an event to push for the implementation of newborn screening test for

¹ During the ongoing mandate, political parties in the Spanish Congress of Deputies are organised in seven different groups:

- Popular Parliamentary Group (Grupo Parlamentario Popular en el Congreso): Conservative and Christian democratic, centre-right to right-wing. Includes the Paty in the government, the People's Party (PP). 134 members on 5 December 2017.
- Socialist Parliamentary Group (Grupo Parlamentario Socialista): Social-democratic, Centre-left. 84 members on 5 December 2017.
- Confederal Parliamentary Group of Unidos Podemos-En Comú Podem-En Marea (Grupo Parlamentario Confederal de Unidos Podemos-En Comú Podem-En Marea): Left-wing. 67 members on 5 December 2017.

Combined Immune Deficiencies in Spain as a standard practice across the country. The event was jointly supported by IPOPI and the Spanish Association for Primary Immunodeficiencies (AEDIP) and was part of a wider campaign involving the patients and key healthcare professionals.

At the time when the Spanish Ministry of Health is evaluating the implementation of SCID newborn screening in the country, the roundtable was a demonstration of support from the four largest political groups to have this technology available throughout the country, with a view to its future consideration by the Interterritorial Council of the National Health System².

Although Catalonia already offers this screening and several regional initiatives have begun to position this issue on the political agenda (Murcia, La Rioja), this service is not yet included in the Common Services Portfolio of the National Health System³ (hereinafter, "the portfolio").

For this reason, patients and specialists, represented by AEDIP, IPOPI, the Spanish Association of Paediatrics (AEP), the Spanish Society of Immunology (SEI), the Spanish Society of Clinical Immunology, Allergy and Paediatrics Asthma (SEICAP), the Spanish Federation of Rare Diseases (FEDER), the Balearic, Andalusian and Catalan associations of primary immune deficits (ABADIP, ANADIP and ACADIP respectively) and the Barcelona PID Foundation, as well as representatives of governments and autonomous parliaments, joined the Members of the Parliament to promote the implementation of this technique throughout the country.

The participants agreed in urging the Ministry to expedite the evaluation process by the Spanish Ministry of Health so that the inclusion of SCID newborn screening can reach the Interterritorial Council for discussion and hopefully approval as soon as possible.

The roundtable coincided with the tabling by Dr Igea MP of a parliamentary question to the Ministry of Health, recalling that in March 2017 the General Director of Public Health, Ms. Elena Andradas, had explained that the MoH was studying the introduction of SCID newborn screening. Dr Igea further enquired as to whether there were any results obtained by the network of evaluation agencies of health technologies, as well as the timeline foreseen by the Government for the inclusion of SCID newborn screening in the portfolio.

It needs to be noted that, should Spain implemented this screening test in the portfolio soon, it could become a pioneer in the European Union, being the first country to make this test available to all children born in the national territory as a standard procedure.

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- Parliamentary Group Ciudadanos (Grupo Parlamentario Ciudadanos): Liberal, center to centre/right-wing. 32 members on 5 December 2017.
 - Parliamentary Group of Republican Left (Grupo Parlamentario de Esquerra Republicana): Catalan nationalist group, Left-wing. 9 members on 5 December 2017.
 - Basque Parliamentary Group EAJ-PNV (Grupo Parlamentario Vasco EAJ-PNV): Christian democratic and Basque nationalist group, Centre-right. 5 members on 5 December 2017.
 - Mixed Parliamentary Group (Grupo Parlamentario Mixto): 19 members on 5 December 2017.

² The Interterritorial Council of the National Health System acts as the standing body for health care coordination, cooperation, communication and information amongst health care services in the autonomous regions and between them and the central government. It aims to promote cohesion within the National Health System by protecting the rights to health protection and health care of all citizens throughout the Spanish territory.

³ The services offered by the National Health System to citizens are the included in the Portfolio of Common Services. It was established in Act 16/2003, 28 May 2003, on the cohesion and quality of the National Health System and in Royal Decree 1030/2006, 15 September 2006, which establishes the common services portfolio of the National Health System and the procedure for its update.

Within the scope of their authority, autonomous regions may establish their respective regional portfolios of services, which must necessarily include all the basic services that all National Health System users must be guaranteed. Autonomous regions may include other techniques, technologies or procedures not stipulated in the common portfolio. None of these supplementary services are financed by the National Health System; therefore, they must provide the additional necessary resources.

2 Opening Remarks

The event was opened by Dr Jesús María Fernández, Member of the Spanish Congress and spokesperson at the Health Commission (Socialist Parliamentary Group), who welcomed the initiative promoted by IPOPI and AEDIP.

Dr Fernández stressed that SCID newborn screening meets the classic principles of early diagnosis of a disease: it is a serious disease which can lead to morbidity and mortality, early diagnosis techniques are available, and it can be treated with existing technologies

On a more political level, he recalled that the Parliament should continue to work on issues that matter to people, in this case to prevent children from dying in Spain.

He referred to the regional context mentioning the initiatives taken in some autonomous regions such as Catalonia, where all babies born from 1st January 2017 already receive SCID screening, as well as other autonomous regions whose regional parliaments have demanded the implementation of SCID newborn screening in the region (Murcia, Andalusia, Extremadura, etc.). This reflects, said Dr Fernández, the richness of a federal country and that healthcare policy relies on the regions.



He concluded by urging the MoH to take the lead on this topic.

3 Patient testimonials

The opening remarks were followed by testimonials from relatives and representatives of individuals affected by SCID. These included the President of AEDIP and the mother of a baby lost to SCID at early age

Mr. Carlos Jiménez, President of the Spanish national Association for Primary Immunodeficiencies (AEDIP):

The president of AEDIP explained what is SCID, highlighting the fatal consequences if treatment is not provided at an early stage.

He briefly mentioned the steps taken since, in 2008, screening was first implemented in Wisconsin (USA), to show that Spain does not lag behind. He mentioned in this regard the pilot project carried out in the Hospital 'Virgen del Rocío' of Seville (Andalusia), which received several awards and was published in various scientific journals. Mr. Jiménez recalled that Spain could become a pioneer in the EU, if SCID newborn screening was implemented in the short term.



AEDIP's president also presented the milestones that have taken place in the interest of the implementation of SCID newborn screening, including the creation of a working group in 2016 and the subsequent preparation of a consensus document, the presentation of three non-legislative proposals in the Congress (two by the Parliamentary Group Ciudadanos, one by the Popular Parliamentary Group), and the administrative request to the MoH. He reminded that the work will not be over until SCID newborn screening is approved by the Interterritorial Council of Health and fully implemented by the autonomous regions.

Mr. Jiménez wrapped up by highlighting the psychological dimension of SCID for the patients and their families. He showcased the example of Vera (a baby-girl diagnosed at the age of two-months old in her city, Zaragoza, and who underwent a transplant in Barcelona) to explain the consequences in terms of the economic costs, personal difficulties and in short, the anguish of the families facing this disease.

Ms. Francisca Pulido Agüero, mother of two patients with SCID:

Ms. Pulido shared her experience as a mother of two children with SCID to illustrate how early diagnosis can make a crucial difference.

Only fifteen days after the birth, her first son, Javier, suffered a urine infection and high fever. "There began his illness and our ordeal. He always had fever, diarrhoea, he always had something. Endless consultations of doctors, primary care, hospitals. Nobody gave us an answer, nobody knew what he had. He was a healthy child for them. We knew that something was happening. We were going crazy".

When Javier was five months-old, he was hospitalised with pneumonia and a cytomegalovirus. The diagnosis of a primary immunodeficiency was then confirmed. Ms. Pulido, expressed how valuable it was for them to receive information on the disease and the treatment by the medical professionals.

The baby underwent preventive treatment and a bone marrow transplant in the Hospital 'Ramón y Cajal' (Madrid), followed by chemotherapy. Although the treatment was working, Javier died because of the cytomegalovirus. Despite this, Ms. Pulido was grateful that at least her son was diagnosed.

When Ms. Pulido was pregnant with her second son, the amniocentesis showed that the new baby also suffered from SCID. Unlike Javier, his little brother Angel was diagnosed and treated on time. Angel is now 19 years old; he has been raised very healthy and has had a very normal life, as his mother shared. Angel studies and works in a hospital, which means that his immune system is healthy.

"The possibility we are discussing today is that Javier would not have died. No more children should die", concluded Ms. Pulido.



4 The voice of medical professionals

Dr Olaf Neth, 'Virgen del Rocío' Hospital, Seville (Andalusia) introduced the work of the pilot study carried out at the Hospital Virgen del Rocío, which he coordinated and during which 10,000 babies have been screened.

To add on what Mr. Jimenez had said regarding SCID being the most severe form of immunodeficiency, Dr Neth further stressed that SCID is a paediatric emergency and that children suffering from this disease are usually asymptomatic.

He brought to the attention of the stakeholders and policymakers in the room the case of a baby born in Cadiz, who died a few months later. "From diagnosis to therapy, we lost time, money and most importantly, a life".

He insisted that SCID meets all the criteria for screening and that it is one of the few rare diseases for which there is a curative treatment. He highlighted the example of the USA, where it is currently being screened in 48 of the 50 states.



Dr Neth also emphasized that although there is an estimated prevalence of 1 child affected every 35.000 to 40,000 babies in Spain, the exact figure is unknown because there is no screening implemented at national level. At the Virgen del Rocío hospital in Seville, fourteen children were diagnosed in four/five years.

According to Dr Neth, the economic cost of implementing the screening test for SCID would be about two million five hundred thousand Euros per year in Spain, less than 6 Euros per sample. In other words, SCID newborn screening is cost-effective, if considering the 7.7 Euros per screening as a threshold.

He also explained the process from SCID newborn screening to diagnosis to demonstrate that, should SCID newborn screening be in place, a baby born with SCID could be diagnosed and screened within the 3 or 4 months of life.

He closed his presentation by stressing that “SCID newborn screening is a reality, as Catalonia has proved at regional level and Norway will do soon for the whole country. It is a fast and reliable technique for which Spain starts with a

good experience and an important multidisciplinary collaboration. In short, it is a moral imperative”.

5 Regional good practices

Ms. Consuelo Cano Hernández, Member of the Regional Assembly of the Region of Murcia⁴, started her presentation by highlighting that SCID newborn screening embodies the respect for health that the Constitution consecrates in its first article.

Ms. Cano further stressed the need for prevention before agreeing with the other speakers in emphasizing some of the comments about the fact that SCID meets the screening criteria, that it saves infants, it is accepted internationally and has been tested in Catalonia, Andalusia and other Spanish regions.

⁴ Author of the motion that was approved by the regional Assembly of Murcia demanding the implementation of SCID newborn screening in the region (See introduction)

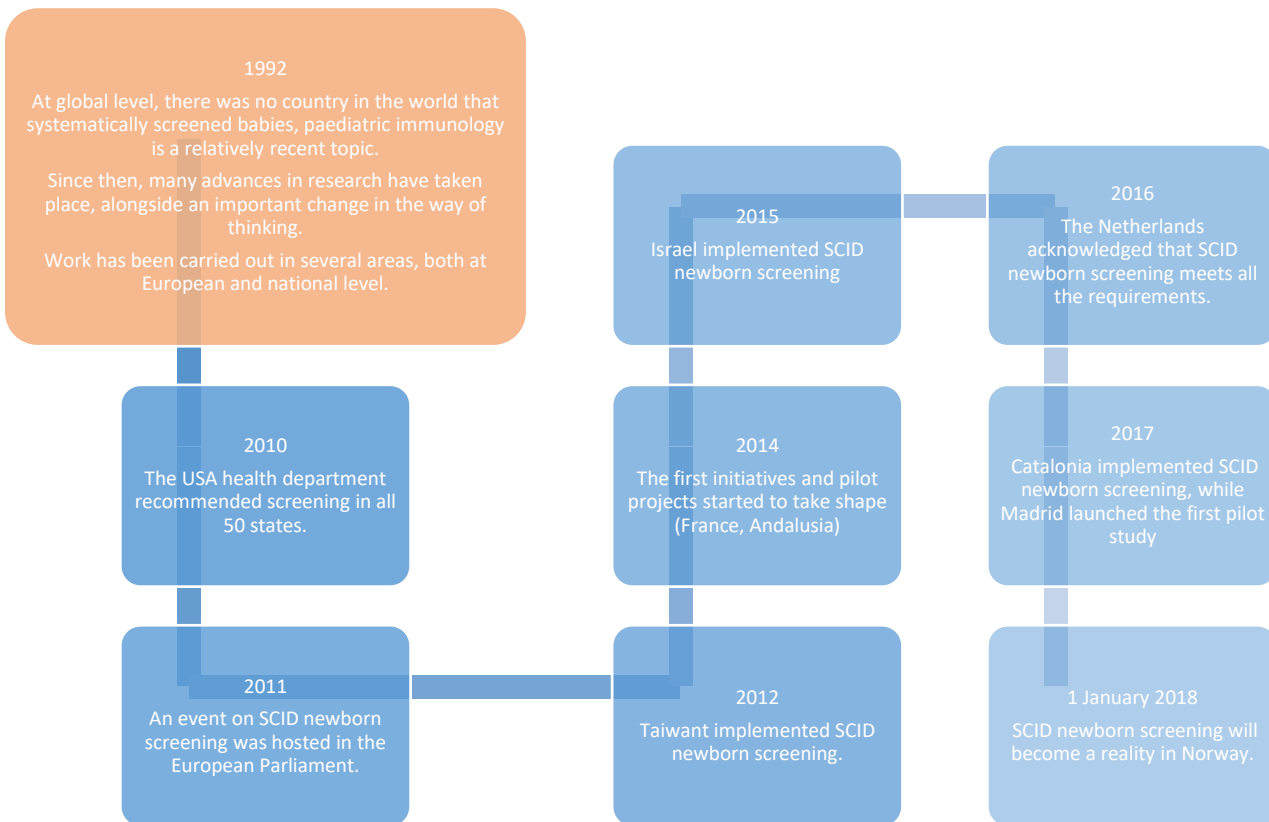
She mentioned the specific case of her region, Murcia, where around 14,000 babies are born every year (16,000 if counting the children from Melilla). It does not seem a break for the national healthcare budget, she said. Ms Cano explained that this measure was a live-saving test that would be cost effective in the medium and long term and called upon national politicians and decision-makers to avoid short-term thinking.

It is an unavoidable moral imperative that must reach the interterritorial council, hopefully its next meeting, in order not to delay it anymore. "It is unbelievable that, if screening is available, it is not more immediate. If from the autonomous regions we push the Spanish Ministry of Health, it's a matter of time that we have it implemented".



6 Intervention by IPOPI

After introducing IPOPI, Ms. Leire Solís, Public Health and Advocacy Manager at IPOPI guided the participants through the main milestones in SCID newborn screening at international level.



The experience acquired in those countries already offering SCID newborn (e.g., USA, Taiwan, Israel and Norway) screening was also highlighted. In this framework, the relevance of SCID screening in terms of management (allowing to know the number of children suffering from the disease) and prevention of vaccines that can be contraindicated, was also underlined.

The conclusion was that these milestones and evidence proof what was shared previously by other speakers: that SCID is a paediatric emergency that can be diagnosed, treated and cured and that unnecessary suffering to babies and their families can be avoided.



7 A movement that has already begun



Mr Ricardo Pérez Alamillo, Parliamentary Advisor, spoke on behalf of Dr Francisco Igea, Member of the Spanish Congress and spokesperson at the Health Commission (Parliamentary Group Ciudadanos), but also as nurse specialised in paediatric oncology, to refer to the screening of SCID as a test that "we should have from here to the next months".

He also recognized the work of the organizations that promote the implementation of this screening in Spain: "you are the locomotive. You need to keep pushing; We rarely deal with such important issues".

8 Open floor Discussion

Ms. Jose Drabwell, IPOPI President



Ms Drabwell thanked, on behalf of IPOPI, the members of Spanish Congress for making the event possible and for the political momentum given to the topic through initiatives such as the parliamentary question presented by Ciudadanos or the non-legislative propositions. She also praised speakers such as Ms. Pulido and Dr Neth for contributing to making SCID newborn screening a reality.

She welcomed the fact that political groups joined their efforts demonstrating that this is a cross-party concern and wished a swift appraisal by the Ministry of Health, so very soon all babies born in Spain could be screened for SCID.

Dr Luis Ignacio González, Immunodeficiencies Unit of the Hospital '12 de Octubre' (Madrid)

Dr González took the floor to explain that the potential claims of positive positives could be easily solved by the existing diagnostic techniques which allow to detect a false positive in 2, 3 hours, so it does not represent a real risk.

SCID is a disease that is frustrating for parents but also for healthcare workers, he shared with the audience. Children with SCID, unlike other pathologies, do not have a roadmap; in this case the uncertainty is present day by day. Against this background, early diagnosis allows that patient to arrive at the transplant with the best possible molecular diagnosis. "The sooner the better".

Dr María África González-Fernández, President of the Spanish Society of Immunology (SEI)

She thanked the initiative and especially AEDIP for taking the lead. Although, in her words, "practically everything has been said," she emphasized that the children suffering from SCID can be cured for life, something that does not happen in other diseases that can be detected at birth. She further recalled that a branch of clinical immunology is necessary in hospitals. Dr González-Fernández closed her intervention by reinstating the support of the Spanish Society for Immunology for the inclusion of SCID newborn screening as a standard practice and reemphasised the scientific reasoning behind the request.

Ms. María Elena Escalante, Delegate of Spanish Federation of Rare Diseases (FEDER) in Madrid

She emphasized the "very high importance" of the question addressed for which she thanked and congratulated AEDIP as "they are an example for other organisations". Ms Escalante also expressed FEDER's support and enthusiasm about the initiative.

Dr María José Mellado, President of the Spanish Association of Paediatrics (AEP)

These children born with SCID need a multidisciplinary approach, she stated, but primary care is also very important. She stressed that SCID is one of the few rare diseases that can be cured and hence the implementation of SCID newborn screening will have a very important impact on public health: not only

it is a proven, efficient and effective test, but addresses a human cost that is priceless. Dr Mellado also expressed the support and commitment of the Spanish Association of Paediatrics to the inclusion of SCID in the panel of diseases all newborns across the country should be screened for.

Dr Jesús María Fernández, Member of the Congress and spokesperson at the Health Commission (Socialist Parliamentary Group)

Dr Fernández simply added on the previous comment that “That the four political groups agree on everything happens very rarely”.

Ms. Carlota Villar Amer, Vice-president of Barcelona PID Foundation and ACADIP spokesperson

She congratulated the organisers and participants for the work being done; it is absolutely necessary, both economically and morally, it cannot be delayed anymore and must be implemented in all the autonomous regions.

9 Conclusion and closing remarks

Ms. Isabel Cabezas, Member of the Congress and deputy spokesperson at the Health Commission (Popular Parliamentary Group)



Ms. Cabezas stated that the Ministry of Health has the obligation to include new services in the portfolio of common services for all regions, should this be proven effective. She considered that this was the case for SCID newborn screening and hoped that the Ministry had taken note of it.

Ms Cabezas then mentioned the non-legislative proposition tabled by the Popular Parliamentary Group, in parallel to the two propositions the Parliamentary Group Ciudadanos: "I can guarantee that this initiative will be approved unanimously".

The spokesperson for the Popular Parliamentary Group at the Health Commission explained how on health-related issues, such as this one, there are no political signs at the Spanish Congress Committee for Health; the heel test gives hope, life, and the government cannot look the other way.

Ms. Amparo Botejara, member of the Congress and spokesperson at the Health Commission (Confederal Parliamentary Group of Unidos Podemos-En Comú Podem-En Marea)

She welcomed the fact that all political parties agreed, which “shows that it is a very clear question; all requirements are clearly answered”.

She called on the Ministry of Health to swiftly assess the implementation of the screening test for SCID at national level and to diligently discuss it with the regions in an interterritorial council. In her opinion, this should be done in the coming months and would like to meet the participants again in a year time to analyse the progress made in this time frame.

It is not acceptable that citizens in one autonomous region have access to SCID newborn screening while others do not, is a break of equity, she concluded. She invited the other members of the Parliament to meet again in one year to analyse if this service has been implemented in all autonomous regions.

Annex I - Relevant background

The roundtable, a milestone in a framework of political developments

On February 27th, 2017, the Parliamentary Group Ciudadanos had tabled a non-legislative proposition on the extension of the portfolio to include SCID newborn screening⁵. A few days later, the Popular Parliamentary Group registered another proposition along the same lines as the one presented by Ciudadanos⁷.



On March 22nd, 2017, the Member of the Congress, Dr Francisco Igea (Parliamentary Group Ciudadanos) addressed an oral question in the Congress to the General Director of Public Health on the “heel test” for SCID. The General Director responded that there is evidence of the benefits of this screening and that the Ministry of Health was already evaluating clinical efficacy and cost-effectiveness. She added that, if the results were positive (and the Interterritorial Council approves it), SCID could enter the portfolio of common services of the NHS.

In July 2017, the senator and coordinator of Health Policy of the Popular Party, Mr Jesús Aguirre, together with the parliamentarian Ms. María de la O Redondo, asked the regional Government of Andalusia to implement SCID newborn screening in the Andalusian health system.

On September 28th, 2017, the regional Assembly of Murcia unanimously adopted a motion tabled by the Ms. Consuelo Cano (PSOE), demanding that SCID newborn screening be provided in the hospitals of the region.

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http://www.congreso.es/portal/page/portal/Congreso/Congreso/Iniciativas?_piref73_2148295_73_1335437_1335437.next_page=/wc/servidorCGI&CMD=VERLST&BASE=IW12&PIECE=IWC2&FMT=INITXD1S.fmt&FORM1=INITXLUS.fmt&DOCS=10-10&QUERY=%28I%29.ACIN1.+%26+%28CRIBADO%29.OBJE.

6

http://www.congreso.es/portal/page/portal/Congreso/Congreso/Iniciativas?_piref73_2148295_73_1335437_1335437.next_page=/wc/servidorCGI&CMD=VERLST&BASE=IW12&PIECE=IWC2&FMT=INITXD1S.fmt&FORM1=INITXLUS.fmt&DOCS=8-8&QUERY=%28I%29.ACIN1.+%26+%28CRIBADO%29.OBJE.

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http://www.congreso.es/portal/page/portal/Congreso/Congreso/Iniciativas?_piref73_2148295_73_1335437_1335437.next_page=/wc/servidorCGI&CMD=VERLST&BASE=IW12&PIECE=IWC2&FMT=INITXD1S.fmt&FORM1=INITXLUS.fmt&DOCS=9-9&QUERY=%28I%29.ACIN1.+%26+%28CRIBADO%29.OBJE.

Annex II – Participants

Name and surname	Position and institution/organisation
<i>Amaya Erce</i>	RPP Healthcare
<i>Amparo Botejara</i>	Member of the Spanish Congress and spokesperson at the Health Commission (Confederal Parliamentary Group of Unidos Podemos-En Comú Podem-En Marea)
<i>Beatriz Gómez</i>	El Mundo health section (newspaper)
<i>Carlos Jiménez</i>	President of the Association for Primary Immunodeficiencies (AEDIP)
<i>Carlos Pulido Agüero</i>	Patient's relative
<i>Carlota Villar Amer</i>	Vice-president of Barcelona PID Foundation and spokesperson of the Catalan Association of Primary Immune Deficits (ACADIP)
<i>Carmen Blanco Rodríguez</i>	Parliamentary assistant, Popular Parliamentary Group at the Spanish Congress
<i>Carmen Castilla Alba</i>	President of the Andalusian Association of support to Primary Immune Deficiency (ANADIP)
<i>Consuelo Cano Hernández</i>	Member of the Regional Assembly of the Region of Murcia (Spanish Socialist Workers' Party – PSOE)
<i>David Jiménez González</i>	Patient
<i>Dr Elena Seoane</i>	Representative of the Spanish Society of Clinical Immunology, Allergology and Paediatric Asthma (SEICAP)
<i>Francisca Pulido Agüero</i>	Patient's relative
<i>Dr Francisco Igea</i>	Member of the Spanish Congress and spokesperson at the Health Commission (Parliamentary Group Ciudadanos)
<i>Isabel Cabezas</i>	Member of the Congress and deputy spokesperson at the Health Commission (Popular Parliamentary Group)
<i>Dr Jan Ramakers</i>	Paediatric Immunology Unit, Son Espases Hospital, Mallorca (Balearic Islands)
<i>Dr Jesús María Fernández</i>	Member of the Spanish Congress and spokesperson at the Health Commission (Socialist Parliamentary Group)



<i>Jose Drabwell</i>	IPOPI President
<i>Dr Juana Gil Herrera</i>	Immunology Service, 'Gregorio Marañón' Hospital (Madrid)
<i>Kit Greenop</i>	RPP Healthcare
<i>Leire Solís</i>	Public Health and Advocacy Manager at IPOPI
<i>Dr Luis Ignacio González</i>	Immunodeficiencies Unit of the Hospital '12 de Octubre' (Madrid)
<i>Dr Luis M. Allende Martínez</i>	Immunology Unit of the Hospital '12 de Octubre' (Madrid)
<i>Dr María África González-Fernández</i>	President of the Spanish Society of Immunology (SEI)
<i>María Elena Escalante</i>	Delegate of Spanish Federation of Rare Diseases (FEDER) in Madrid
<i>Dr María José Mellado</i>	President of the Spanish Association of Pediatrics (AEP)
<i>Dr Olaf Neth</i>	'Virgen del Rocío' Hospital, Seville (Andalusia)
<i>Pablo García Rojo</i>	Member of the Regional Assembly of Madrid (Spanish Socialist Workers' Party – PSOE)
<i>Dr Rafael Solana Lara</i>	General Secretary of Research, Development and Innovation in Health (Junta de Andalucía, Regional Ministry of Health)
<i>Ricardo Pérez Alamillo</i>	Parliamentary Advisor (Parliamentary Group Ciudadanos), Spanish Congress
<i>Rosa Escandell Solivellas</i>	Balearic Association Primary Immune Disorders (ABADIP)

Annex III - Coverage by media and relevant scientific organisations

Murcia.com: <http://www.murcia.com/region/noticias/2017/10/24-la-diputada-consuelo-cano-participa-en-el-congreso-de-los-diputados-en-una-jornada-sobre-el-cribado-neonatal-de-la-in.asp>

Redacción Médica: <https://www.redaccionmedica.com/secciones/parlamentarios/c-s-urge-al-gobierno-a-introducir-el-cribado-neonatal-en-la-carera-basica-8717>

EcoDiario: <http://ecodiario.economista.es/salud/noticias/8723159/11/17/El-Congreso-debatira-la-proxima-semana-una-mocion-de-Ciudadanos-para-reducir-las-desigualdades-sanitarias.html>

Spanish Society of Immunology (SEI): <http://www.inmunologia.org/grupos/home.php?UpOm5=M&Upfgym5uom=GF#3718>

Spanish Association of Pediatrics (AEP): <http://www.aeped.es/noticias/aep-participa-en-una-mesa-debate-en-congreso-los-diputados-sobre-cribado-neonatal-idcq>

Spanish Association for Primary Immunodeficiencies (AEDIP): <http://www.aedip.com/por-una-vida-mas-alla-de-la-burbuja-mesa-redonda-en-el-congreso-de-los-diputados/>

Spanish Society of Clinical Immunology, Allergy and Pediatrics Asthma (SEICAP): <http://www.seicap.es/es/mesa-redonda-en-el-congreso-de-los-diputados-por-una-vida-m%C3%A1s-alla-de-la-burbuja-47131>

Spanish Federation of Rare Diseases (FEDER): <https://www.enfermedades-raras.org/index.php/actualidad/9310-hacia-el-cribado-de-la-inmunodeficiencia-combinada-grave>

Healthcare Social Responsibility: <https://www.responsabilidadsocio-sanitaria.com/secciones/salud-sociedad/el-congreso-pide-agilizar-el-proceso-para-incluir-el-cribado-neonatal-de-la-inmunodeficiencia-combinada-grave-2827>