

The background of the cover is a black and white photograph of a tall, ornate building with a prominent corner tower. The building has multiple stories with windows and balconies. In the foreground, there are trees with bare branches. A diagonal green overlay covers the left side of the image, partially obscuring the building and trees.

Fundación **Weber**

"The value of health research"

ACTIVITY REPORT
2022

ACTIVITY REPORT 2022

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PRESIDENCIAL LETTER

1. PRESIDENCIAL LETTER

The year 2022 has marked the consolidation of the strategies implemented throughout 2021 regarding participation in public research calls, as well as the continued concern for patients with rare diseases following the Covid-19 pandemic and addressing essential aspects for the sustainability of the national health system, such as adherence.

Regarding the first strategy, in 2022, the implementation of the Neurodiversity Power project began, funded by the European Erasmus+ program. The project is coordinated by the Weber Foundation and involves four other partners: ACTA Center (Oradea, Romania), CATRO (Sofia, Bulgaria), BOSEV (Ankara, Turkey), and INNOWA (Valencia, Spain). Its objective is to increase awareness and understanding of neurodivergent individuals in the workplace, highlighting a growing community of people with different brain functioning, and promoting their inclusion by developing appropriate roles, environments, and leadership in companies and organizations.

In addition, the Weber Foundation is participating in two research projects funded by the Carlos III Health Institute under the personalized medicine call: Genomic Precision Medicine in Lymphoid Neoplasms and the Comprehensive Study of Genetic and Molecular Variation in a Spanish Cohort of Autism Spectrum Disorders, and the Design of Diagnostic and Therapeutic Biotype Identification Algorithms. In both cases, the Weber Foundation is responsible for conducting economic evaluations to analyze the efficiency and sustainability of different genomic screening strategies. These projects are being carried out in collaboration with the Health Economics Research Group at the University of Castilla-La Mancha.

Regarding the second strategic line, the foundation continues to raise awareness about rare diseases through the publication of Newsrare and co-organizing the Summer Course on Advances in Rare Disease Management with the University of Castilla-La Mancha. The course aimed to create a multidisciplinary space for meeting, analyzing, and discussing the recent advances in the management of rare diseases, including diagnosis, treatments, access to therapeutic innovation, success stories, and more. The course also reviewed the need and implementation of novel financing schemes to incorporate therapeutic innovation into the National Health System and analyzed the impact of European funds (academia, technology, research, etc.) in fostering future development in the field of rare diseases. During the course, the second edition of the Rare Disease Protagonist of the Year award was presented, which went to the Galician Public Genomic Medicine Foundation for the IMPACT Genomics project, a precision medicine initiative, and was accepted by Dr. Ángel Carracedo.

Within the same strategic line, the Weber Foundation has also contributed to generating proposals aimed at improving access to and financing of orphan drugs in Spain through the FINEERR project. FINEERR represents a multidisciplinary strategic reflection on the challenges of financing and access to therapies for rare diseases. The Weber Foundation brought together 40 top experts to reach consensus on specific medium-term improvement proposals to guide decision-making regarding the optimal allocation of resources for rare diseases within the National Health System.

The third strategic line addressed different conditions such as chronic cough, psoriasis, and diabetes, emphasizing the importance of tight and early disease control. Furthermore, in collaboration with OAT, the foundation explored the impact of adherence on health outcomes, patients' quality of life, and the sustainability of the healthcare system. This project is a result of collaboration with the OAT group and demonstrates the outcomes that alliances with various institutions and organizations, such as the HM Hospitals Foundation, the Efficiency-Based Medicine Chair's conferences and courses, or the University of Castilla-La Mancha and the Spanish Chapter of ISPOR for the implementation of the 6th edition of the Health Intervention Economic Evaluation and Pharmaceutical Policy Master's degree.

In summary, it has been a year of consolidation of the designed strategic lines and a greater international projection for the Weber Foundation. I would like to conclude this letter by expressing my gratitude to the entire team of the Foundation for their hard work and effort, to the experts who have assisted us in developing various activities, and to all the institutions and companies that have supported us throughout this year.



Álvaro Hidalgo Vega
President of the Weber Foundation

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THE FOUNDATION

2. 1. THE FOUNDATION

The Weber Foundation **is a non-profit organization**, created on 5 July 2017 by Weber, Economy and health with the mission of promoting health economic research with the aim of contributing to the sustainability of the National Health System and improving the quality of life for patients and equity in access to health care.

With the creation of the Weber Foundation, the Weber Group has become well recognized for research, consultancy and training in the field of Health Economics, Patient-Reported Health Outcomes and Pharmacoeconomics.

2.1 MISIÓN, VISIÓN



MISSION

The Weber Foundation's mission is to promote efficiency and equity in access to healthcare, always with the main objective of improving and humanizing healthcare in order to improve patients' quality of life and social well-being. The Foundation promotes collaboration between patient associations, foundations and institutions through research and innovation projects in Health Economics that help to develop competition policies, which are key to improving access to medical technology and innovation in the healthcare sector.



VISIÓN

The Weber Foundation is at the service of patients, working for and with them. We firmly believe that through education, knowledge and research on economic issues affecting health and healthcare, tools can be developed to support health policy decisions that improve the quality of care and the patient's life.



VALUES

The Weber Foundation is governed by the following values:

Quality: We understand that the one way to achieve the Foundation's goals is to carry out quality projects with strict scientific rigor.

Sustainability: We seek to promote the optimization of the quality of life of patients through a balance between economic resources and future viability.

Transparency: Success must be based on a relationship of trust and transparency with our partners.

2.2 GOVERNING BODIES

COMPANY BOARD

The company board of the Weber Foundation is headed by **Álvaro Hidalgo Vega**, expert in the field of health economics, professor and co-director of the Health Economics and Health Management Research Group at the University of Castilla La Mancha. Associate Professor of Pharmacoeconomics at the Instituto de Empresa. He is assisted by Renata Villoro Valdés, a health economist with extensive experience managing research projects as Vice-President; and by Alexandra Ivanova Markova as Secretary General.



President
Álvaro Hidalgo



Vice President
Renata Villoro



Secretary General
Alexandra Ivanova

ADVISORY COUNCIL

The advisory board of the Weber Foundation is chaired by Indalecio Corugedo de las Cuevas, retired Professor of Economics at the Complutense University, and is constituted by:

- D. Santiago Alfonso Zamora
- D. Cristóbal Belda Iniesta
- D. Pedro Gómez Pajuelo
- Ms. María Pilar Llamas Sillero
- D. Modesto Martínez Pillado
- Mr. Jorge Mestre Ferrándiz
- D. Juan Oliva Moreno
- Mr. Martín Ortega Carcelén
- Mr. José Luis Sánchez Chorro
- Mr. Julio Sánchez Fierro
- D^a. Marta Traperó Bertran
- D. Víctor V. Vázquez
- D. Antonio J. García Ruiz

You can access to the following link to get more information about their resumes:

2.3 1.2 GOOD GOVERNANCE AND TRANSPARENCY. VALUES

The Weber Foundation always acts with the utmost rigor, transparency and good governance, with the aim of guaranteeing its foundational purposes, ensuring effectiveness and efficiency in all the projects it undertakes, and achieving excellence in its activities and management.

In order to achieve these goals, the Foundation acts considering the following values that we share in each of our projects:

- **Quality:** We understand that the one way to achieve the Foundation's goals is to carry out quality projects with strict scientific rigor.
- **Sustainability:** We seek to promote the optimization of patients' quality of life through a balance between economic resources and future viability.
- **Transparency:** Success must be based on a relationship of trust and transparency with our partners.
- **Accessibility.** To make training and knowledge about the economic aspects affecting healthcare accessible to all.
- **Professionalism and continuous improvement:** We act with professionalism, effort and commitment to maximize our social impact. Responsibility guides our activities which are carefully planned, executed and monitored.
- **Trust:** Willingness to work collaboratively with associations, foundations and institutions, which is necessary to work in a safety and trustworthy way.
- **Technological innovation:** High capacity for adaptation and creativity to respond to changes in the environment and the incorporation of new technologies.

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The background is a complex, layered composition. It features a large, diagonal white line that divides the upper left portion of the image. Below this line, there are several black silhouettes of people in business attire, standing in a row. These silhouettes are reflected on a glossy, horizontal surface. The background is composed of various shades of green, yellow, and orange, with vertical lines and abstract shapes that suggest a modern, urban environment. The overall aesthetic is clean and professional.

ACTIVITIES 2022

MAIN AREAS OF WORK OF THE FOUNDATION IN 2022

Psoriasis

Health
Technology

Artificial
Intelligence

European
Funds

Covid-19

Health costs

Quality
of life

Social
costs

Vaccination

Health
outcomes

Adherence to
treatment

Social
return on
investment in
health

Rare
diseases

Advanced
therapies

Unmet
health needs

Humanización

Economic
evaluation and
pharmacoecono-
mics

Value
of therapeutic
innovation

Multi-criteria
decision
analysis

Genomic
medicine

● New work areas in 2022

● Permanent work areas since the Foundation's creation



3.1 RESEARCH

Strategic Reflection on Financing and Access to Therapies for Rare Diseases in Spain

Organized by: Weber Foundation

Funded by: Roche

Date: January, 2022

Rationale: In the last 20 years, there have been significant advances in the field of rare diseases, including increased awareness and recognition of these pathologies as a health priority, the approval of specific legislation, improvements in diagnosis, an increase in scientific activity, the development of new therapies, and the creation of a community that gives voice to patients, reducing their isolation.

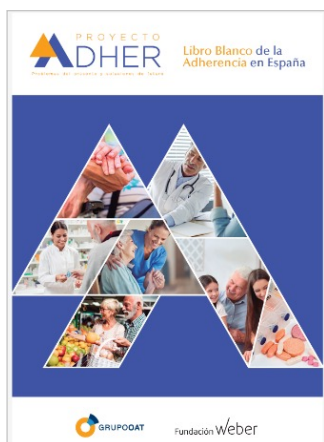
The specific regulation of orphan drugs has been very positive for the development of new treatments. Between 2000 and 2020, more than 2,300 drugs were designated as orphan drugs in Europe, and the European Medicines Agency (EMA) authorized the commercialization of more than 190 orphan drugs. However, it is worth noting that not all drugs indicated for a rare disease have to be designated as orphan drugs or approved as orphan drugs by the EMA.

Despite the progress made, there are still significant challenges in terms of financing and access to these therapies. Of the more than 3 million people who suffer from a rare disease in our country, 47% do not have access to precise treatment or consider that the treatment they are receiving is not adequate. Moreover, patients only have public funding access to less than half of the orphan drugs authorized by the EMA, and the time until reimbursement decisions can take more than 2 years. Therefore, a reflection is needed on the challenges in financing and access to therapies for rare diseases in Spain, in order to reduce the gap between drug development and use, increase equity in access to available therapies, and at the same time, introduce coherent, efficient, and long-term sustainable strategies.

The main objective of the FINEERR project was to conduct a multidisciplinary strategic reflection on the challenge posed by financing and access to therapies aimed at treating rare diseases in Spain. Specifically, it brought together the knowledge of 40 experts to agree on specific medium-term improvement proposals that would help in making optimal resource allocation decisions for rare diseases in the National Health System. This think tank on financing and access to therapies aimed at rare diseases (RDTs) was structured around a CORE Advisory Group and four thematic, multidisciplinary Working Groups (WGs), where experiences and opinions were shared on different relevant aspects of financing and access to these therapies, in order to obtain reflections and improvement recommendations.

[Access the book](#)





White Paper of Adherence in Spain

Organized by: OAT Group and the Weber Foundation

Supporters: Farmadosis, Lilly and Viatris

Date: April, 2022

Rationale: Lack of adherence to treatments, especially in chronic pathologies, is a serious health problem as indicated by the World Health Organization, as it affects the effectiveness of such treatments, the adequate evolution of the disease, the quality of life of patients and also causes an increase in healthcare expenditure.

Despite the fact that, in recent years, everything related to adherence has become more visible and there is greater awareness and a lack of clear strategies based on greater research and specific multidisciplinary actions that are implemented to solve the problems caused by a lack of adherence.

Faced with this situation, the OAT Group and the Weber Foundation have pooled their knowledge and experience to create the ADHER Project, which revolves around the development of the first White Paper on Adherence in Spain, in which the determinants and consequences of non-adherence are analyzed and measured to improve the adherence. In addition, a Delphi study has been carried out with more than a hundred experts of different profiles to determine the relevance and feasibility of implementing action measures to improve adherence to treatment, concluding by consensus in a comprehensive decalogue of the main solutions.

The White Paper on Adherence in Spain is an initiative with two objectives: 1) to provide an adequate response to the problems related to adherence on a scientific basis and in a multidisciplinary manner; and 2) to propose practical solutions to be implemented in the National Health System according to Jose Manuel Ribera Casado, president of the Scientific Committee of the OAT Group: “serves as a roadmap to carry out strategies taking into account different perspectives that not only improve adherence, also the quality of life of patients and health outcomes, thereby achieving a reduction in healthcare costs”.

This is a book of interest to healthcare professionals and other health sector managers, which highlights the importance of adherence and chronicity for the optimal treatment of patients, providing highly scientifically rigorous information on the challenges and needs for improvement, and offering comprehensive solutions. It also aims to reach the general public, so it is written in a clear and didactic way by a multidisciplinary committee.

[Access the book](#)



White Paper of Chronic Cough

Organized by: Weber Foundation

Supported by: MSD

Date: December, 2022

Rationale: Chronic cough (CC) is a relevant health problem in adults, with a major impact on quality of life and consumption of healthcare resources. Under normal circumstances, cough is a protective reflex that prevents bronchial aspiration, but in some cases, it can become prolonged, excessive and debilitating. Its management is often problematic and numerous clinical guidelines have been published. Despite this, a proportion of cases remain undiagnosed and unresolved.

This book represents an update on the evolving understanding of CC. It discusses definitions, epidemiology, pathophysiology, diagnostic and therapeutic approaches, as well as the burden of this entity on patients and healthcare systems. It also highlights gaps in the current treatment and describes the latest therapeutic options designed to address CC. This book proposes a coordinated approach between primary care physicians and the different specialists and healthcare managers

[Access the book](#)



3.2 TRAINING

6th edition. Master's Degree in Economic Evaluation of Health Interventions and Pharmaceutical Policy

Organized by: The University of Castilla-La Mancha and the Weber Foundation

Date: May, 2022

Rationale: This postgraduate programme offers the possibility of learning first-hand about the latest advances in the sector, gaining a comparative understanding of the global economic system and its effect on health policies, exchanging experiences with professionals in this field and acquiring knowledge that complements the students' professional profile. For this reason, it has a first-rate teaching staff that contributes to the achievement of its objective with the current syllabus.

Among the objectives of this master's degree, the following should be highlighted:

- To understand the global economic system and its effect on health policies in a comparative framework.
- To critically analyse new additions to the market in the field of medicines and to assess them in relation to the existing market.
- Understand the factors that regulate the economic evaluation of medicines and health technologies.
- Analyse the legal framework, as well as the different financing and pricing models in the European and national environment.
- Understand the different innovative models for managing pharmaceutical expenditure and their impact on the efficiency of the system.
- To analyse current methods and models in the evaluation of health technologies.

The methodology of the master's degree is based on face-to-face and online sessions. The lecturer develops the concepts and content and debate with the participants in class through the Moodle platform. Based on real examples, practical cases are carried out where complex situations are analysed, decisions are made and points of view are shared with the rest of the course participants.

This master's degree has an online platform, with its own virtual campus, where all the programme's activities are uploaded, making it a point of reference for all students.

[Access to the link](#)



1º Edition. Course about Clinical Management by integrated processes

Organized by: Weber Foundation

Supported by: Mediform

Date: February-June, 2022

Rationale: 90-hour online course. The overall objective of this course is to train students in an innovation model for the design, deployment and continuous improvement of and continuous improvement in the management of integrated clinical processes. Aimed at graduates in degrees related to health sciences, health service managers, those responsible for innovation, research, quality and processes, and those involved in quality improvement and clinical management teams. The programme can also be delivered in an “in company” format or edition for interested centres and institutions.

This course is accredited with 10.2 credits by the Continuing Education Commission for the Health Professions of the Community of Madrid and the National Health System.

[Access to the programme](#)



1st Edition. Evaluation of the social and economic impact of innovation in health course

Organizers: San Juan de Dios Foundation and the Weber Foundation

Date: March-May, 2022

Rationale: This course has been created in collaboration between the Weber Foundation (WF) and the San Juan de Dios Foundation (FSJD) and based on the accumulated experience of both organisations.

This course was created with the aim of covering the demand for training, both theoretical and practical application of the SROI (Social Return on Investment) methodology applied in the field of health, and specifically in health interventions. The course provides the tools for the students to be able to design and carry out an SROI analysis, as well as to interpret its results.

This course is focused on the needs of the sector, helping to incorporate improvements in health care under a social, critical and constructive approach.

[Access to the programme](#)

Formación para la Cátedra de Medicina basada en la Eficiencia

Organizers: HM Hospitals Foundation and Weber Foundation

Date: April-December, 2022

Rationale: The main goals of these workshops are the promotion and generation of evidence on the health benefits of any health activity through training, teaching and scientific dissemination activities in the fields of Health Economics through the creation of teaching programmes.

For this training we carried out a conference and three workshops:

1ST CONFERENCE “FROM REAL WORLD DATA TO REAL WORLD EVIDENCE IN ECONOMIC EVALUATION OF HEALTH DEVICES”

Organised by: HM Foundation in collaboration with HM Foundation for Efficiency-based Medicine, GIES and Weber Foundation.

Supported by: 3M and Siemens Healthineers

Date: April 27th, 2022

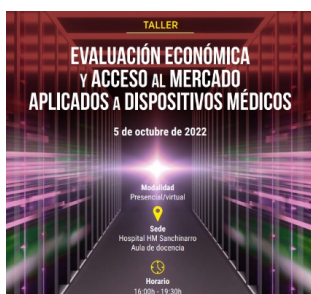
Rationale: This conference shows the technology assessment as a valuable tool for healthcare devices.

The objectives of the workshop are the following:

- To acquire a critical perspective on the role of assessment in the clinical decision-making process..
- To learn about pilot experiences on the applications of the Real-World Data in decision-making.
- Exchange knowledge and opinions with well-known experts, providing an added value of personal and professional enrichment.

[Access to the programme](#)





FIRST WORKSHOP: ECONOMIC EVALUATION AND MARKET ACCESS

Organizers: HM Foundation and Weber Foundation

Supported by: 3M

Date: October 5th, 2022

Rationale: The main objective of the workshop was to understand the context in which economic evaluation becomes a valuable tool for medical device companies, as well as to gain a critical perspective on the role of economic evaluation in health technology assessment in the clinical and funding decision-making process.

[Access to the programme](#)



SECOND WORKSHOP: GRADE METHOD

Organizers: HM Foundation and Weber Foundation

Supported by: 3M

Date: November 3rd, 2022

Rationale: The aim of this course was to introduce and provide an understanding of the fundamental aspects of the GRADE methodology for assessing the quality of evidence about economic evaluation studies of medical devices.

[Access to the programme](#)



THIRD WORKSHOP: MCDA (Multiple-criteria decision analysis)

Organizers: HM Foundation and Weber Foundation

Supported by: 3M

Date: December 1st, 2022

Rationale: The aim of this course is to introduce the fundamental aspects of introducing new criteria for the economic evaluation of medical devices (Medical Device).

[Access to the programme](#)



3.3 CONFERENCES AND SEMINARS

Presentation of the "FIRST NATIONAL REPORT ABOUT THE CARE AND ECONOMIC IMPACT OF CHRONIC HYPERPOTASSEMIA IN SPAIN"

Organised by: Weber Foundation

Supported by: Vifor Pharma

Date: February 3rd, 2022

Rationale: The Weber Foundation and Vifor Pharma will present on streaming the results of the first national report of drug consumption of the first national report on the consumption of resources and costs of chronic hyperkalaemia in both renal and cardiac patients in order to reduce the economic burden on the system.

This report aims to:

- Analyse the available evidence and produce a structured, scientifically rigorous document that reflects the current situation in the management of chronic hyperkalaemia in Spain.
- Analyse the consumption of resources and the direct and indirect costs, both in patients with chronic kidney disease and in patients with heart failure.
- To improve knowledge about the management of patients with CKD or HF and chronic hyperkalaemia.
- Carry out an economic analysis to support the need to withdraw/modify the current patiomer visa and it will help to eliminate the existing inequity in Spain compared to the rest of the European Union countries.

[Access to the report](#)





Press Conference: PRESENTATION OF THE PSOVALUE PROJECT

Organised by: Acción Psoriasis and Fundación Weber

Supported by: UCB

Date: March 1st, 2022



Rationale: The Weber Foundation and Acción Psoriasis, with the collaboration of the biopharmaceutical company UCB, presented a first preview of the results of the PSOVALUE project, which reflects an in-depth analysis of the unmet needs in psoriasis and addresses the clinical, economic and social value of achieving a sustained response in the treatment of this dermatological pathology.

The PSOVALUE project pursues three different objectives:

- To check and quantify, from different perspectives, the current unmet needs of patients suffering a moderate-severe psoriasis;
- To quantify the social value of having treatments in order to achieve greater efficacy;
- To assess the value of different biologic drugs for the treatment of moderate-severe psoriasis, using a multi-criteria decision framework that considers other relevant factors beyond efficacy and price.

[Access to the report](#)



Presentation Day: WHITE PAPER OF ADHERENCE

Organised by: OAT Group and Weber Foundation.

Supported by: Farmadosis, Lilly and Viatris.

Date: April 28th, 2022

Rationale: The presentation of this first White Paper of Adherence in Spain aims to make known the work carried out by a multidisciplinary team of experts, who analyse the determinants and consequences of non-adherence and propose measures to improve it. In addition, **a Delphi study has been carried out** to determine the relevance and feasibility of implementing action measures to improve adherence to treatment, concluding by consensus in a comprehensive decalogue of the main solutions.



This book serves as a roadmap to implement strategies considering different perspectives that not only improve adherence, also the quality of life of patients and health outcomes, thereby achieving a reduction in healthcare costs.

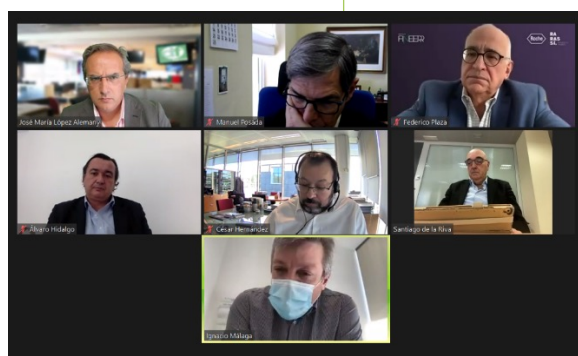
[Access to the conference](#)

FinEERR Press Conference: "STRATEGIC REFLECTION OF FINANCING AND ACCESS TO THERAPIES FOR RARE DISEASES IN SPAIN"

Organised by: Weber Foundation

Supported by: ROCHE

Date: April 28th , 2022



Rationale: More than 40 experts participate in the FINEERR Project, a document for reflection and analysis of the situation of rare diseases (RD) in our country. The 73% of the experts in the project consider the situation of funding and access to therapies for rare diseases in Spain could be improved.

Therefore, streamline the funding processes and access times is the key to improve the quality of life of patients with a rare disease.

The document "Strategic Reflection of funding and access to therapies for rare diseases in Spain" provides the following 10 conclusions:

1. Differentiation between different rare diseases
2. More empowered and participative patients
3. Comprehensive health care
4. More powerful, collaborative and attractive R&D
5. More agile and transparent decision making processes

6. Increased harmonisation of processes in the interests of territorial equity
7. Value-based financing and economic evaluation
8. Funding conditional on uncertainty
9. Digitalisation and dynamic re-evaluation
10. More than just good intentions. To implement changes, leadership and coordination at all levels are needed.

[Access to the document](#)

Discussion Day to “PRESENT RESULTS OF THE PSO VALUE PROJECT”

Organizers: Acción Psoriasis and Weber Foundation

Supported by: UCB

Date: June 9th, 2022

Rationale: Presentation of the results of the PSOVALUE project.

The Weber Foundation and Acción Psoriasis, with the collaboration of the biopharmaceutical company UCB, have organised a conference to present the complete results of the PSOVALUE project, following the preliminary results preview in March, which reflects an in-depth analysis of the unmet needs in psoriasis and addresses the clinical, economic and social value of achieving a sustained response in the treatment of this dermatological pathology.

This presentation took place at the Belgian Ambassador's Residence, and it was structured in three round tables with members of the Multidisciplinary Committee.

[Access to the conference](#)

JORNADA DEBATE PROYECTO PSO VALUE
DÍA 9 DE JUNIO DE 2022 DE 18:00h - 20:00h
RESIDENCIA DEL EMBAJADOR DE BÉLGICA Calle de Padilla, 23. 28006 Madrid

VALOR CLÍNICO Y ECONÓMICO DE LA RESPUESTA SOSTENIDA EN EL TRATAMIENTO DE LA PSORIASIS MODERADA O GRAVE

18:00-18:20 CAFÉ DE BIENVENIDA

18:20-18:30 PRESENTACIÓN DE LA JORNADA
 Sr. José de Pierpont (Presidente de Fundación Weber)
 D. Pablo Ouro (Miembro de honorarios de UCB España)
 D. Álvaro Hidalgo (Profesor Titular de la UCLM y presidente de la Fundación Weber)
 Dña. Montserrat Ginés (Vicepresidenta de Acción Psoriasis)

18:30-18:55 NECESIDADES NO CUBIERTAS EN PSORIASIS
 Modera: Dr. Pedro Herranz (Jefe del Servicio de Dermatología, Hospital Universitario La Paz, Madrid)
 Dña. Montserrat Ginés
 Dña. Paloma Morales de los Ríos (Asesora Médica Internacional, Fundación Hospital Universitario Gregorio Marañón, Madrid)

18:55-19:20 UTILIDAD DEL ANÁLISIS DE DECISIÓN MULTICRITERIO EN EL TRATAMIENTO DE LA PSORIASIS
 Modera: Dr. Lluís Puig (Miembro Honorario de Dermatología, Hospital de la Santa Creu i Sant Pau, Barcelona)
 Dr. Antonin Garcia Ruiz (Director de la Cátedra de Economía de la Salud y Área Nacional de Medicamentos, Universidad de Málaga)
 Dr. José Martínez Olmos (Profesor Adjunto Asociado de Salud Pública, Granada)

19:20-19:45 EL VALOR SOCIAL DE OBTENER UNA RESPUESTA SOSTENIDA EN EL TRATAMIENTO DE LA PSORIASIS
 Modera: D. Santiago Alfonso (Miembro de Acción Psoriasis)
 Dra. Olga Delgado (Presidenta de la SEPI, Jefe del Servicio de Farmacia del Hospital San Expanso, Palma de Mallorca)
 Dr. Jesús Balca (Farmacéutico, Hospital Universitario de Fuenfria)

19:45-20:00 ACTO DE CLAUSURA **20:00-22:00 CÓCTEL**

UN PROYECTO DE Fundación **weber** **acción PSORIASIS** CON LA COLABORACIÓN DE **patients. Driven by science.** **GOBIERNO DE ESPAÑA**

Presentation of the Report: THE PROCESS OF EVALUATION AND FINANCING OF MEDICINES IN SPAIN: WHERE ARE WE AND WHERE ARE WE GOING?

Organised by: Weber Foundation

Supported by: Abbvie

Date: June 20th, 2022

Rationale: A panel of experts discussed the keys for a greater and faster patient access to therapeutic innovation.

[Access to the conference](#)

[Access to the report](#)



EL PROCESO DE EVALUACIÓN Y FINANCIACIÓN DE LOS MEDICAMENTOS EN ESPAÑA: ¿DÓNDE ESTAMOS Y HACIA DÓNDE VAMOS?

20 de junio de 2022

12:20 - 12:30h
LA VISIÓN DEL INSTITUTO NACIONAL DE SALUD Y EXCELENCIA CLÍNICA EN EL REINO UNIDO (NICE)

12:30 - 14:00h

Inauguración
12:00 - 12:10h
Álvaro Hidalgo Vega
Profesor Titular de la UCLM y presidente de la Fundación Weber

Presentación del proyecto
12:10 - 12:20h
Néboa Zozaya González
Directora del Departamento Economía de la Salud, Weber

Ponentes

Juan Oliva Moreno Catedrático, departamento de Análisis Económico de la Universidad de Castilla La Mancha	Pedro Gómez Pajuelo Exsecretario General de la Organización Nacional de Trasplantes. Funcionario del Ministerio de Sanidad en excedencia	Miguel Ángel Calleja Hernández Jefe del Servicio de Farmacia, Hospital Universitario Virgen Macarena, Sevilla	Jorge Mestre Ferrándiz Consultor e investigador en el ámbito de la Economía de la Salud. Profesor Asociado en la Universidad Carlos III de Madrid	José Luis Trillo Mata Responsable del Servicio de Farmacia de Área de Salud del Departamento Clínico Malvarrosa Valencia
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Organizado por: **Fundación Weber** Con la colaboración de: **abbvie**

Pulse en la flecha para acceder a la inscripción ➡



Summer Course 2022: ADVANCES IN THE APPROACH TO RARE DISEASES: ACHIEVEMENTS AND CHALLENGES FOR NATIONAL HEALTH SYSTEMS

Organized by: Castilla-La Mancha University, Weber Foundation, and newsRARE

Date: September 13th and 14th, 2022

Rationale: The objective of the course was to provide a multidisciplinary space for meeting, analysis, and debate on the advances in the approach to rare diseases (RD) in recent years: in terms of diagnosis, treatments, and access to therapeutic innovation; success stories, etc.; to review the need and implementation of novel financing schemes to incorporate therapeutic innovation into the National Health System; and to analyse the impact of European funds (technology, research, etc.) to boost future development in the field of rare diseases.

The program addressed different topics related to advances in research, technology, pharmaceutical industry, and improvements in public-private collaboration and patient associationism to improve the diagnosis and treatment of rare diseases. The importance of continuing to progress in these areas to increase success stories and visibility was highlighted. Instruments such as public-private organization, obtaining and measuring health data, benefit-risk-based evaluation, and increasing attention to genetic diseases with higher relative morbidity were discussed.

[Access a summary of the participating tables](#)





Delivery of the 2nd Award for EER Protagonist of the Year: IMPACT Genomics

Organized by: Weber Foundation and newsRARE

Date: September 14th, 2022

Rationale: The aim of this award is to recognize the work of organizations, patient associations, and other institutions that, through their efforts, have contributed to improving healthcare and patient management for rare diseases, helping patients, generating better knowledge, and raising awareness among the public about orphan drugs and rare diseases.

The IMPaCT program, whose objective is to facilitate the effective implementation of Precision Medicine in the National Health System, with a focus on rare diseases, received the 2022 EER Protagonist of the Year Award. Ángel Carracedo, coordinator of IMPaCT Genomics, received the award from the Second Vice President of the Congress of Deputies and Executive Secretary of Health of the Popular Party, Ana Pascual. The IMPaCT strategic plan is divided into three pillars: Predictive Medicine, Data Science, and Genomic Medicine, and two transversal lines: ethics and internationalization, which are common to all three programs.

[Access for more information about the award ceremony and the interview of Ángel Carracedo](#)



Webinar “MULTICRITERIAL DECISION ANALYSIS (MCDA): CASE STUDIES IN PSORIASIS”.

Organised by: Acción Psoriasis and Fundación Weber

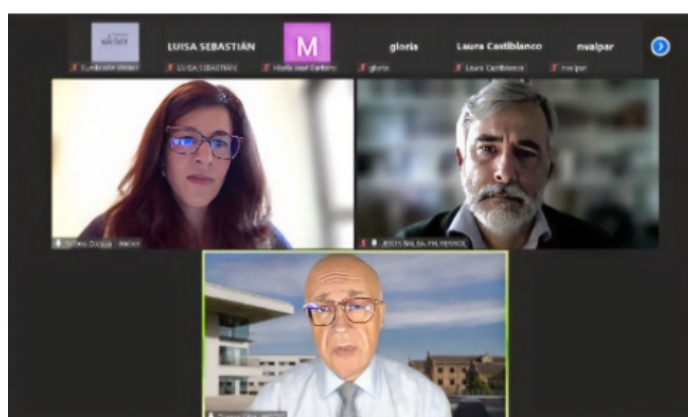
Supported by: UCB

Date: October 20th, 2022

Rationale: In this webinar we talked about the MCDA methodology, what MCDA is, in which type of medicines is more useful, what MCDA can bring compared with the standard economic evaluation.

The goal of the MCDA is to support, through a transparent, explicit and collaborative process, the decision-making process for a given health intervention, through the systematic evaluation of all the criteria or elements of value involved in the process taking into account the available scientific evidence.

To get a better understanding about the MCDA methodology, some examples of real-life application were given, but mostly applied in psoriasis.



Press conference presentation of the Report ‘SOCIAL VALUE OF STRICT AND EARLY CONTROL OF DIABETES TYPE 2 IN SPAIN’

Organised by: Weber Foundation

Supported by: UCB

Date: November 4th, 2022

Rationale: The aim of this study was to estimate the social value; in other words, the difference between the economic impact generated by a tight control of the disease, type 2 diabetes, versus a non-strict control five years after the diagnosis.

The report provided objective data of the burden of the diabetes type 2 for the Spanish healthcare system, as well as the importance of optimal control of the disease for a better use of healthcare resources, which is an additional benefit to the improvement in quality of life for patients.

The study was scientifically endorsed by the Spanish Society of Endocrinology and Nutrition (SEEN) and the Spanish Diabetes Society (SED), as well as by the Spanish Diabetes Federation (FEDE).

[Access to the report](#)



The conclusions of the report were presented by Álvaro Hidalgo, president of the Weber Foundation; Dr. Francisco Javier Escalada, president of SEEN; Joan Antoni Vallés, clinical pharmacologist at the Catalan Institute of Health, and Juan Francisco Perán, president of FEDE



Presentation of the WHITE PAPER OF CHRONIC PAIN IN SPAIN: WHERE ARE WE AND WHERE ARE WE GOING?

Organised by: Weber Foundation

Supported by: Ferrer

Date: November 30th, 2022

Rationale: In this conference were presented the main results of the White Paper on Chronic Pain in Spain. In addition, the challenges in the approach to chronic pain were analysed and also were discussed the possible solutions to overcome them. Through a holistic and realistic vision, it was explained where we are and the possible ways of improvement were assessed in order to determine where we are heading.

In this conference was presented the work carried out by the multidisciplinary team of experts and was divided into two discussion panels: 1) the care aspects of the approach of chronic pain in Spain; and 2) the socio-economic aspects of the approach of chronic pain in Spain.

This book is built for the National Health System professionals of the different specialties involved in the management of patients with chronic pain, policy makers and health management, patient associations and their representatives and anyone with an interest in the field of chronic pain.

[Access to the report](#)





3.4 DISSEMINATION

- Publication of the report: “Strategic reflection on funding and access to therapies for rare diseases in Spain” (in Spanish and English):

[Link to the report](#)

- Publication of the report “Strategic reflection on funding and access to therapies for rare diseases in Spain” at the XL+1 AES Conference (16 June 2022).

[Link to the report:](#)



- Publication of the report: “The process of evaluation and financing of medicines in Spain: where are we and where are we going?”

[Link to the report:](#)

- Presentation of the report “The process of evaluation and financing of medicines in Spain: where are we and where are we going?” at the XL+1 Jornadas AES (16 June 2022).



3.5 newsRARE PUBLICATIONS

VOL 7 – SUPLEMENT 1- FEBRUARY 2022

Promoted by: Weber Foundation

Supported by: Ipsen and UCB

Date: May 2021

Title: *Rare Diseases: Care for Rare Disease Patients and Access to Orphan Drugs after COVID-19*

In this issue we address the reflections expressed in the summer course held at the UCLM, jointly organised by the UCLM and the Weber Foundation, about the “Care for patients with Rare Diseases and access to orphan drugs after the COVID-19 pandemic”. The course showed the commitment to give visibility to RDs and provide a space for debate and reflection on strategic aspects for patients suffering from them.

The course was structured in 4 tables and each table had a specific topic: policy initiatives taken in the wake of the pandemic by COVID-19 to mitigate its impact, the social and health impact of the pandemic, the consequences of the pandemic on research and development, and the consequences of the pandemic on access to orphan drugs. He highlighted the importance of each of these issues and the interdependence between them.

Throughout all the roundtables, the need to put patients with RDs back in the focus of the National Health System (NHS) and RDs back in the focus of research was highlighted. The pandemic has meant that care for patients with rare diseases has been relegated and the research for obtaining innovation to cover the huge unmet needs in this field has been interrupted or at least slowed down. For this reason, throughout the course, all the essential aspects that should promote better care for patients with this type of pathology were discussed.

The issue is coming with an opinion article in which the president of the foundation’s Scientific Committee, Indalecio Corugedo, reflects the influence of COVID 19 in research, diagnosis and treatment of RDs and the future of orphan drugs. And with interviews with relevant professionals in the field of RDs.

[Access to the full issue](#)



VOL 7 – ISSUE 1 MAY 2022

Promoted by: Weber Foundation

Supported by: Alexion, Ipsen, Jazz Pharmaceuticals, Janssen, Roche and UCB

Date: May 2022

Title: *Rare Diseases: Rare Disease Success Stories*

The issue opens with a special article written by Silvia Calzón Fernández, Secretary of State for Health, who gives an excellent overview of the milestones and initiatives that our NHS has implemented in the field of rare diseases. She highlights the implementation of the State Register of Rare Diseases, which has become one of the first population-based surveillance systems for chronic diseases at the national level, and the progress made in the Neonatal Screening Programme to improve the early detection of these diseases.

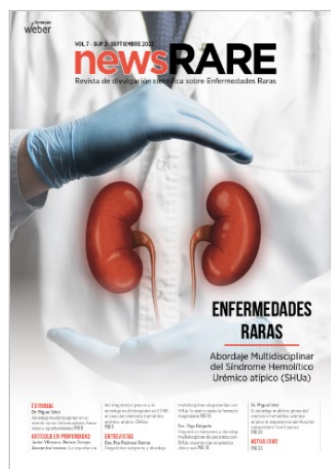
The in-depth article was elaborated by Néboa Zozaya, Director of Health Economics at Weber and Fernando Abdalla, Health Economics Consultant at Weber. They take a panoramic view of progress and review various success stories, both nationally and internationally, prompting reflection on what can be considered a success story.

In addition, the newsRARE barometer was launched to get the opinion of the different actors in the health system on success stories in rare disease patients and their environment, collecting successful experiences in RD, according to the opinion of the surveyed, and what efforts should be made to make further progress in this field.

The issue is completed by a series of interviews that, from different approaches, focus on successful experiences in the approach and treatment of rare diseases. Four specialists in neurology, rheumatology and anaesthesiology give their point of view on different rare diseases and how their management has improved in recent years, focusing on the challenges that remain. In addition, three representatives of associations give us the first-person point of view of those affected by rare diseases.

The issue also offers a range of available resources to professionals and patients, such as reviews of relevant scientific articles, news of interest or an observatory presenting the evolution of relevant indicators in the field of rare diseases until April 2022.

[Access to the full issue](#)



VOL 7 – SUPLEMENTO 2 SEPTIEMBRE 2022

Promoted by: Weber Foundation

Supported by: Alexion

Date: September 2022

Title: *Rare Diseases: A Multidisciplinary Approach to Haemolytic Syndrome Atypical uremic syndrome (aHUS)*

One of the most important missions of the Weber Foundation, and of the newsRARE project, is to contribute to the dissemination of scientific knowledge to help improve the care and quality of life of patients with Rare Diseases in Spain. This supplement was born with this purpose, which holistically reflects the need to move towards multidisciplinary approach models in the field of Rare Diseases.

This multidisciplinary vision is very relevant, since in certain cases early diagnosis and initiation of appropriate treatment can be of vital importance. A clear example of the commitment to multidisciplinary approach models is the recent creation of the Spanish Multidisciplinary Society for Systemic Autoimmune Diseases (SEMAIS) made up of twelve medical specialties, whose objective is to promote rapid diagnosis and provide multidisciplinary care for minority and/or complex pathologies. This second Supplement of the year focuses on the ultra-rare and multisystemic disease Atypical Haemolytic Uremic Syndrome (aHUS), a pathology that is included, along with other rare diseases, such as thrombotic thrombocytopenic purpura (TTP), within the thrombotic microangiopathies (TMA) and which mainly affects children and young adults, although it can appear at any time throughout life. The complexity of the diagnosis and the severity of the disease require multidisciplinary teamwork to provide effective and efficient care for the patient.

In short, this Supplement highlights the progress improving the approach of rare diseases in Spain, thanks to the possibility of learning about experiences that undoubtedly demonstrate the positive aspects of a multidisciplinary approach, in this case to HUSa.

[Access to the full issue](#)



VOL 7 – ISSUE 2 SEPTEMBER 2022

Promoted by: Weber Foundation

Supported by: Alexion, CSL Behring, CSL Vifor, Ipsen, Jazz Pharmaceuticals, Janssen, Roche and UCB

Date: May 2022

Title: *Rare Diseases: Innovative Funding Models in the field of RDs*

In this issue we study and review the different financing models in the field of RDs, both the traditional and the implementation of new financing schemes to incorporate therapeutic innovation of medicines aimed at RD in the National Health System (NHS).

The use and operational implementation of Outcome-Based Agreements in the field of pharmacotherapeutic innovation for orphan and ultra-orphan diseases in EU countries, Canada, Australia and New Zealand was also analysed and reviewed. We have then proceeded to analyse the different types of risk-sharing agreements implemented in Catalonia and to detail the economic and health results obtained from them.

In this issue, we count with the opinion of the Administration about financing and access to targeted therapies for RDs, without missing the crucial point of view of the patients.

[Access to the full issue](#)



VOL 7 – ISSUE 3 DECEMBER 2022

Promoted by: Weber Foundation

Supported by: Alexion, CSL Behring, CSL Vifor, Ipsen, Jazz Pharmaceuticals, Janssen, Roche and UCB

Date: December 2022

Title: *Rare Diseases: Elements of optimisation in EERR: European Funds*

This third, and final issue of newsRARE 2022 focuses on how European funds have supported the optimisation of the management of patients with RDs. In recent years, support in the field of RDs from European and national organisations has been remarkable.

This issue will raise awareness of this support, and the contribution of this issue of the journal is the key, as the barometer provides opinions and experiences from different perspectives, offering the possibility to better understand the barriers and solutions in the field. The bureaucratic processes for applying for this type of support are somewhat complex, and it is not always easy for any organisation or individual to access the information and comply with the requirements.

In summary, very relevant RDs projects have been launched recently and this has been possible, in part, thanks to the availability of the European funds. We are convinced that all these projects will generate important improvements in diagnosis and treatment in the field of RDs and Orphan Drugs.

[Access to the full issue](#)



3.6 COLLABORATION AGREEMENTS AND PARTNERSHIPS WITH OTHER INSTITUTIONS

- Bioinnova Consulting (Innovative public procurement project in HIV)
- HIRIS Health (Psoriasis Manifesto Project)
- Acción Psoriasis (PSOVALUE project)
- OAT Group (White Paper on Adherence in Spain)



3.7 OHER ACTIVITIES

European Project - Neurodiversity Power



It is a project funded by the Erasmus+ programme under the number 2021-1-ES01-KA220-VET-000028059.

The project is coordinated by the Weber Foundation (Madrid, Spain) and involves 4 other partners, ACTA Center (Oradea, Romania), CATRO (Sofia, Bulgaria) BOSEV (Ankara, Turkey) and INNOWA (Valencia, Spain).

With the implementation of the Neurodiversity Power project we want to raise awareness and understanding of neurodivergent people at work, to make visible a growing group of people with other forms of brain functioning in order to ensure their inclusion in the workplace in the best possible way.

The overall aim of this project is to help create or achieve a culture of neurodiversity inclusion by developing the right roles, the right environment and the right leadership in organisations.

Expected results:

- **Output 1:** Manual - Methodologies, techniques and tools to manage neurodiversity in organisations.
- **Outcome 2:** NeuroPower Curriculum - Curriculum for neurodiversity trainers.
- **Output 3:** NeuroPower Quality Label - Procedure to certify an organisation with a quality label

[Access to the information 1](#)

[Access to the information 2](#)



Personalized medicine projects

The Weber Foundation participates in two research projects funded by the Instituto de Salud Carlos III in the call for personalized medicine:

- The first one is an application to hematology: genomic precision medicine in lymphoid neoplasms.
- The second is an economic evaluation of the identification of biotypes in autism spectrum disorders: Comprehensive study of genetic and molecular variation in a Spanish cohort of autism spectrum disorders and design of diagnostic and therapeutic biotype identification algorithms.



MINISTERIO
DE CIENCIA
E INNOVACIÓN



Plan de Recuperación,
Transformación y Resiliencia



Financiado por
la Unión Europea
NextGenerationEU

Resolución de la Dirección del Instituto de Salud Carlos III O.A., M.P., por la que se aprueba la convocatoria para el año 2022 de concesión de subvenciones a Proyectos de Investigación de Medicina Personalizada de Precisión de la Acción Estratégica en Salud 2021-2023, bajo el PERTE para la Salud de Vanguardia y con cargo a los fondos europeos del Plan de Recuperación, Transformación y Resiliencia.

The Weber Foundation is in charge of reviewing the literature to analyze the economic evaluations on pharmacogenomics to serve as a basis for developing an economic evaluation methodology based on the type of test to determine the personalized treatment for the patient. Similarly, it is in charge of developing a methodology to quantify the budgetary impact of the adoption of biomarker or genetic sequencing for a hospital or a regional health system. To this end, the foundation will propose the development of Excel models that can be used in clinical practice to evaluate the efficiency and sustainability of pharmacogenetics.



IV SOLIDARITY RUN - Madrid moves for child transplantation

We participate in the IV Solidarity Race TransplantChild "MADRID MOVES FOR CHILD TRANSPLANT"

Partnership and support to Ukraine

It is important for the Foundation to show our solidarity with the Ukrainian people and thanks to all our colleagues and relatives, we collaborate in the collection of medicines and sanitary material to send them through the Ukrainian Embassy.



Weber Foundation Awards 2022

The Weber Foundation's core objective is to encourage health economic research, as well as to promote education and general knowledge on economic issues affecting health and healthcare.

The jury, consisting of members of our Advisory Board, has awarded the Premios Fundación Weber 2022 to the following competitors:

[Access to the information](#)



4



THE FOUNDATION IN THE MEDIA

THE FOUNDATION IN THE MEDIA

Sanidad
lo mejor de la sanidad

Inicio > Actualidad > Un Comité de Expertos Multidisciplinar identifica 65 necesidades no cubiertas en el...

ACTUALIDAD

Un Comité de Expertos Multidisciplinar identifica 65 necesidades no cubiertas en el abordaje de la psoriasis

1 de marzo de 2022

f t p w



..Redacción.
La Fundación Weber y Acción Psoriasis, con la colaboración de biofarmacéutica UCB, han presentado un primer avance de los resultados del **proyecto Psosvalue**. El proyecto refleja un profundo análisis de las necesidades no cubiertas en psoriasis. Asimismo, se aborda el valor clínico, económico y social que supone una respuesta sostenida en el tratamiento de esta patología dermatológica.

Access

NOTICIASDE

Inicio > Psoriasis > Un proyecto identifica 65 necesidades no cubiertas en psoriasis, sobre todo en...

Comida

Un proyecto identifica 65 necesidades no cubiertas en psoriasis, sobre todo en el proceso de toma de decisiones

Por Redacción · 1 marzo, 2022 · 0

f t p w



MADRID, 1 (EUROPA PRESS)

La Fundación Weber y Acción Psoriasis, con la colaboración de la biofarmacéutica UCB, han lanzado este martes un primer avance de los resultados del proyecto 'PSOVALUE', en el que se refleja un análisis de las necesidades no cubiertas «muy importantes» en psoriasis y se aborda el valor clínico, económico y social que supone lograr una respuesta

Access

el farmacéutico
hospitales

Un Comité de Expertos Multidisciplinar destaca la necesidad de incorporar la perspectiva de los resultados en salud que importan a los pacientes con psoriasis como base para decisiones clínicas y de gestión

02 Marzo 2022 · 0 · 0 · 0 · 0 · 0

Publicado en Actualidad Sanitaria

f t p w



La Fundación Weber y Acción Psoriasis, con la colaboración de la biofarmacéutica UCB, presentaron ayer un primer avance de los resultados del proyecto **PSOVALUE**, en el que se refleja un profundo análisis de las necesidades no cubiertas en psoriasis y se aborda el valor clínico, económico y social que supone lograr una respuesta sostenida en el tratamiento de esta patología dermatológica.

El proyecto **PSOVALUE** persigue tres objetivos diferenciados: 1) detectar y cuantificar, desde distintas perspectivas, las actuales necesidades no cubiertas de los pacientes que padecen psoriasis moderada-grave; 2) **cuantificar el valor social** que supone contar con tratamientos que logren una mayor eficacia; 3) **evaluar el valor de distintos fármacos biológicos** para el tratamiento de la psoriasis moderada-grave, a través de un marco de decisión multicriterio que contemple otros factores relevantes, más allá de la eficacia y el precio.

La jornada contó con la apertura y clausura de **Montse Ginés**, vicepresidente de Acción Psoriasis; **Ávaro Hidalgo**, presidente de la Fundación Weber; y **Pablo Duró**, director de inmunología de UCB España.

En palabras de **Montse Ginés**, vicepresidente de Acción Psoriasis: «Creemos que la atención sanitaria debe ir avanzando y por eso este proyecto pretende con todo el consenso, con toda la participación científica, hacer nuevas propuestas para la atención sanitaria. Por eso es necesario que también los pacientes se impliquen y participe su asociación».

Por su parte **Ávaro Hidalgo**, presidente de la Fundación Weber, hizo especial hincapié en la importancia de obtener una mejor


Access

Infosalus

infosalus / asistencia

Publicado 01/03/2022 14:02


Un proyecto identifica 65 necesidades no cubiertas en psoriasis, sobre todo en el proceso de toma de decisiones



Archivo - Psoriasis - AEDV - Archive
MADRID, 1 Mar. (EUROPA PRESS) -

La Fundación Weber y Acción Psoriasis, con la colaboración de la biofarmacéutica UCB, han lanzado este martes un primer avance de los resultados del proyecto 'PSOVALUE', en el que se refleja un análisis de las necesidades no cubiertas «muy importantes» en psoriasis y se aborda el valor clínico, económico y social que supone lograr una respuesta sostenida en el tratamiento de esta patología dermatológica.

'PSOVALUE' tiene tres objetivos diferenciados: detectar y cuantificar, desde distintas perspectivas (dermatología, pacientes con psoriasis, enfermería, psicología, farmacia hospitalaria, gestión, economía de la salud y política), las actuales necesidades no cubiertas de los pacientes que padecen psoriasis moderada-grave; cuantificar el valor



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THE FOUNDATION IN THE MEDIA

PRENSA **Prensa Madrid Sur**
Noticias y actualidad en el Sur de Madrid

Un plan identifica 65 requisitos de la psoriasis, especialmente en el proceso de toma de decisiones

By Redacción Prensa



Madrid, 1 de marzo. (Europa Press) – La Fundación Weber y Acción Psoriasis, en colaboración con UCB Biopharmaceuticals, dieron a conocer este martes el primer avance de los resultados del proyecto «PSOVALUE», que refleja las necesidades no deseadas “más importantes” en psoriasis y medicina. Aborda el valor económico y social de lograr una respuesta sostenible en este tratamiento dermatológico.

[Access](#)

saludadiario.es

65 necesidades no cubiertas en el abordaje de la psoriasis en España

Un comité de expertos multidisciplinar destaca la necesidad de incorporar la perspectiva de los resultados en salud que importan a los pacientes como base para decisiones clínicas y de gestión

Vote este artículo (0 votos)

Imprimir | Email | 0 Comentarios



La Fundación Weber y Acción Psoriasis, con la colaboración de la biofarmacéutica UCB, han presentado un primer avance de los resultados del proyecto PSOVALUE, en el que se refleja un profundo análisis de las necesidades no cubiertas en psoriasis y se aborda el valor clínico, económico y social que supone lograr una respuesta sostenida en el tratamiento de esta patología dermatológica.

El proyecto PSOVALUE persigue tres objetivos diferenciados: 1) detectar y cuantificar, desde distintas

[Access](#)

béninactu

Un projet identifie 65 besoins non satisfaits dans le domaine du psoriasis, notamment dans le processus de prise de décision.

Par Laura Toumon - mars 1, 2022

Partager



PARIS, 1 Mar. (Bénin Actu) – La Fondation Weber et Acción Psoriasis, avec la collaboration de la société biopharmaceutique UCB, ont lancé ce mardi une première avant-première des résultats du projet « PSOVALUE », qui reflète une analyse des besoins « très importants » non satisfaits dans le domaine du

[Access](#)

el farmacéutico

Primer Libro Blanco de la Adherencia en España

Es la primera vez que para identificar las medidas de acción más adecuadas para mejorar la adherencia se realiza un estudio Delphi específico, en el que participaron más de 130 expertos de distintos perfiles

Redacción



La Fundación Weber y Grupo OAT Group OAT, con el patrocinio de Farmadosis, Lilly y Viatris, a través del proyecto ADHER, han presentado el primer Libro Blanco de la Adherencia en España, en el que se analizan los determinantes y consecuencias de la falta de adherencia y se proponen medidas para mejorarla. Además, se ha realizado un estudio Delphi con más de un centenar de expertos de distinto perfil para conocer la relevancia y factibilidad de

[Access](#)

THE FOUNDATION IN THE MEDIA



El primer Libro Blanco de la Adherencia en España, una iniciativa para mejorar el seguimiento de los tratamientos

La Fundación Weber y Grupo OAT a través del proyecto ADHER, han presentado el primer Libro Blanco de la Adherencia en España, en el que se analizan los determinantes y consecuencias de la falta de adherencia y se proponen medidas para mejorarla.



Además, se ha realizado un estudio Delphi con más de un centenar de expertos de distinto perfil para conocer la relevancia y factibilidad de implementación de medidas de acción para mejorar la adherencia al tratamiento, contribuyendo por consenso en un decálogo integral de las principales actuaciones.

Una mala adherencia no solo tendrá repercusión en el control y manejo de la enfermedad, sino que también incrementará los costes sanitarios derivados del aumento de las consultas y hospitalizaciones, entre otros aspectos.

El Libro Blanco de la Adherencia en España es una iniciativa que tiene dos objetivos: dar una respuesta adecuada a los problemas relacionados con la adherencia con una base científica y de forma multidisciplinar y promover actuaciones prácticas para poder implementar en el Sistema Nacional de Salud que según José Manuel Ribera Casado, presidente del Comité Científico del Grupo OAT: "vino como tope de vela para llevar a cabo estrategias teniendo en cuenta diversas perspectivas que no solo mejoran la adherencia, sino también la calidad de vida de los pacientes y los resultados en salud, consiguiendo con ello una reducción de los costes sanitarios".



Access



El primer Libro Blanco de la adherencia en España apelará al "activismo" para frenar este problema mundial

Junto al documento, en el que han participado más de un centenar de profesionales, organizaciones, sociedades científicas e instituciones, se ha previsto una serie de medidas divulgativas e informativas para sensibilizar y concienciar a sanitarios y pacientes.

Conoce más en nuestro portal para profesionales sanitarios: www.organonconnect.es
También estamos en www.organon.com/espana



Access



29 de abril, 2022

Para promover la adherencia hay que contar con los profesionales sanitarios, pacientes, Administración, industria y sociedades científicas



Presentación del Libro Blanco de la Adherencia.

Grupo OAT y Fundación Weber presentaron un acto en Madrid, el primer Libro Blanco de la Adherencia en España.

PHARMAMARKET

Grupo OAT y Fundación Weber presentaron ayer en un acto en Madrid, el primer Libro Blanco de la Adherencia en España, un trabajo desarrollado por un grupo multidisciplinar de expertos que se engloba dentro del Proyecto ADHER. José Manuel Ribera, presidente del comité científico del Grupo OAT, explicó que los objetivos que se han perseguido a la hora de editar este ejemplar son "informar, estudiar, transmitir mensajes y conseguir que la adherencia avance".

La falta de adherencia a los tratamientos, sobre todo en patologías crónicas, es un grave problema de salud tal como lo indica la Organización Mundial de la Salud, ya que afecta a la efectividad de dichos tratamientos, a la adecuada

NOTICIAS RELACIONADAS

Las farmacias españolas han empezado a dispensar Parlovid, el tratamiento oral frente a la COVID-19

Ases y Cofares dialogan para mejorar el acceso de la población a medicamentos y productos de salud

Access



Claves para mejorar la adherencia a los tratamientos en España

Un 50% de los pacientes no cumple adecuadamente con su tratamiento, con casos especialmente preocupantes como en afectados por depresión / La falta de adherencia contribuye a unas 200.000 muertes prematuras y tiene un impacto de hasta 125.000 millones de euros cada año en Europa en términos de hospitalizaciones, atención en urgencias y visitas ambulatorias evitables

3 de mayo de 2022



Un incorrecto control de los medicamentos prescritos puede acarrear numerosos efectos secundarios. / PHARMAY

Una mala adherencia no solo tendrá repercusión en el control y manejo de la enfermedad, sino que también incrementará los costes sanitarios derivados del aumento de las consultas y hospitalizaciones, entre otros aspectos.

La Fundación Weber y Grupo OAT, con el patrocinio de Farmadocia, Lilly y Viatris, a

Access

THE FOUNDATION IN THE MEDIA

Sanidad
lo mejor de la sanidad

El aumento de 10 puntos porcentuales en las tasas de adherencia supondría un ahorro de 500 millones en costes sanitarios

2 de mayo de 2022

f t p e

...Redacción.
La **falta de adherencia** es una de las principales causas del fracaso terapéutico que afecta a la efectividad de los tratamientos, a la adecuada evolución de la enfermedad y a la calidad de vida de los pacientes. Asimismo, provoca un aumento en el gasto sanitario. En España, se estima que un aumento de 10 puntos porcentuales sobre las tasas de adherencia de cuatro enfermedades supondría ahorros de más de 500 millones de euros en costes sanitarios directos, y evitaría miles de muertes. Por ello, la Fundación Weber y Grupo OAT, a través del **proyecto Adher**, han presentado el primer **Libro Blanco de la Adherencia en España**. Un documento que analiza los determinantes y consecuencias de la falta de adherencia. El manual cuenta con el patrocinio de Farmadosis, Lilly y Viatris.

[Access](#)

[im] Farmacias

"La adherencia es lo que falta para tener buenos resultados en salud"

La jornada de presentación del primer Libro Blanco ha concluido con un llamamiento a la colaboración con todos los actores del sistema sanitario y a la necesidad de innovar no solo tecnológicamente sino también en la gestión.

Repton, Rousselot, and other logos are visible.

28/04/2022

f t p e

"La adherencia es lo que falta para tener buenos resultados en salud". Jesús Vázquez Castro, director General de Asistencia Sanitaria y Aseuramiento del Servicio Madrileño de Salud, ha afirmado talante el

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THEOBJECTIVE
PUBLICADO

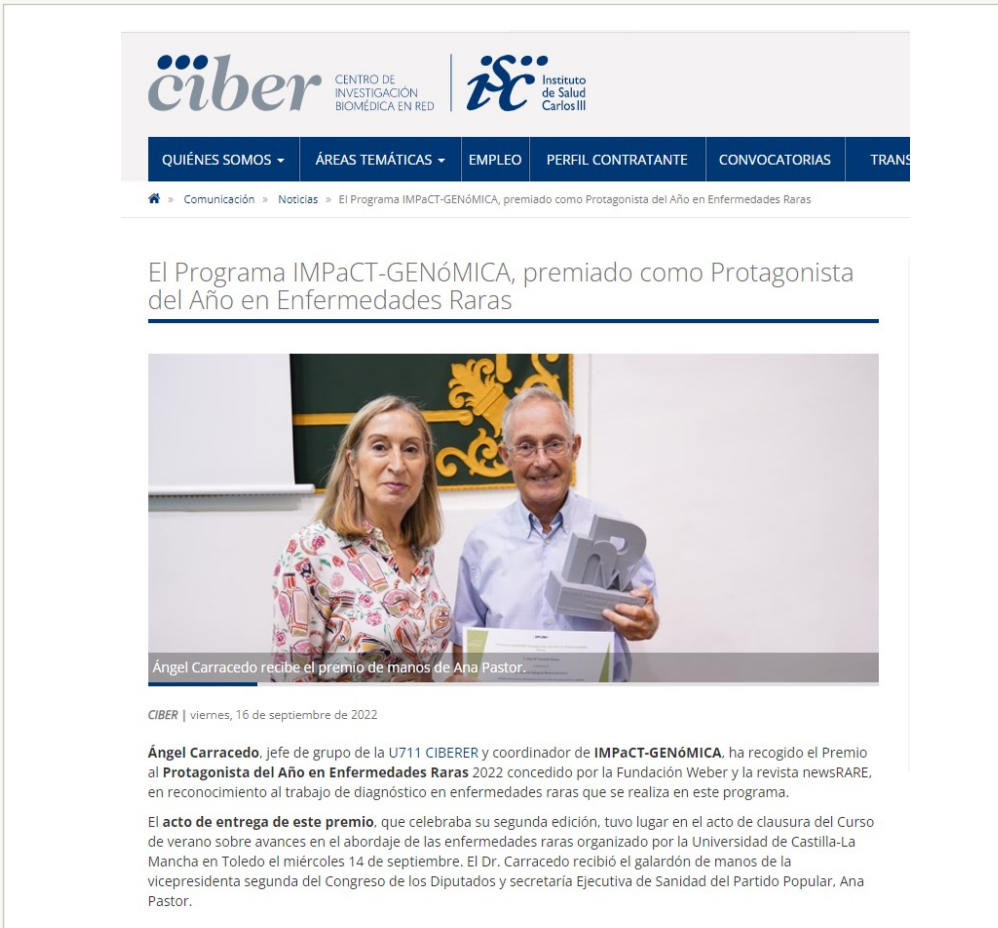
España

El colapso del sistema deja a los españoles sin la mitad de los medicamentos de la UE

Los pacientes españoles tardan 517 días en poder acceder a los fármacos autorizados en Europa, 337 días más que lo que marcan las normas europeas


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THE FOUNDATION IN THE MEDIA



The screenshot shows the CIBER website header with logos for CIBER (Centro de Investigación Biomédica en Red) and ISCIII (Instituto de Salud Carlos III). The navigation bar includes links: QUIÉNES SOMOS, ÁREAS TEMÁTICAS, EMPLEO, PERFIL CONTRATANTE, CONVOCATORIAS, and TRANS. The breadcrumb trail reads: Comunicación > Noticias > El Programa IMPaCT-GENÓMICA, premiado como Protagonista del Año en Enfermedades Raras.

El Programa IMPaCT-GENÓMICA, premiado como Protagonista del Año en Enfermedades Raras



Ángel Carracedo recibe el premio de manos de Ana Pastor.

CIBER | viernes, 16 de septiembre de 2022

Ángel Carracedo, jefe de grupo de la U711 CIBERER y coordinador de IMPaCT-GENÓMICA, ha recogido el Premio al **Protagonista del Año en Enfermedades Raras 2022** concedido por la Fundación Weber y la revista newsRARE, en reconocimiento al trabajo de diagnóstico en enfermedades raras que se realiza en este programa.

El **acto de entrega de este premio**, que celebraba su segunda edición, tuvo lugar en el acto de clausura del Curso de verano sobre avances en el abordaje de las enfermedades raras organizado por la Universidad de Castilla-La Mancha en Toledo el miércoles 14 de septiembre. El Dr. Carracedo recibió el galardón de manos de la vicepresidenta segunda del Congreso de los Diputados y secretaria Ejecutiva de Sanidad del Partido Popular, Ana Pastor.

[Access](#)


The screenshot shows the redacción médica website header with a search icon and a 'Suscríbete' button. The navigation bar includes links: PROFESIONALES, POLÍTICA, FORMACIÓN, EMPRESAS, ESPECIALIDADES, AUTONOMÍAS, Podcast, Opinión, La Revista, and VIRICO.

El empleo en la pharma española registra su mayor aumento en cuatro años

El número de empleados en plantas de producción farmacéuticas es de 36.338, un 4,2 por ciento más que en 2019

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La innovación farmacéutica genera ahorros sanitarios y sociales

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Los avances en farmacología impulsan el aumento de la supervivencia en cáncer

En el Día Mundial contra el Cáncer, Farmaindustria subraya el impacto de los fármacos en la lucha contra la enfermedad

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Casi el 80% de la población, dispuesto a vacunarse en una farmacia

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THE FOUNDATION IN THE MEDIA

Empresas
ConSalud

NACIONALINTERNACIONALECONOMÍA EHEALTH RSC ANUARIO

Oncología, la gran favorita de la industria en investigación

En la actualidad, la industria farmacéutica tiene en desarrollo más de 1.360 tratamientos contra el cáncer

[Access](#)

Empresas
ConSalud

NACIONALINTERNACIONALECONOMÍA EHEALTH RSC ANUARIO

La industria farmacéutica se vuelca en la lucha contra el cáncer

De ellos, 145 son para varios tipos de leucemia, que representan más del 3% de todos los nuevos casos de cáncer; y 141 para cáncer de pulmón, uno de los tumores con las tasas de mortalidad más altas



La industria 'farma' a la vanguardia en economía circular

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invertia | EL ESPAÑOL

EMPRESAS

Del ahorro sanitario al empleo de calidad: diez claves por las que la industria farmacéutica es un sector estratégico

Los últimos años muestran que las farmacéuticas forman parte importante de la solución en crisis como la del coronavirus.

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EL GLOBAL
El medio del medicamento y la farmacia

INDUSTRIA

Diez claves que avalan a la industria farmacéutica como un sector estratégico para España

Desde Farmaindustria insisten en que, este sector, debe contribuir a la reactivación económica y a reforzar el modelo productivo del país para el futuro

Por **El Global** - 21 junio 2022

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THE FOUNDATION IN THE MEDIA



Disponible el primer Libro Blanco de la Adherencia en España

Mayo, 2022

La Fundación Weber y Grupo OAT, a través del proyecto ADHER, han elaborado el primer Libro Blanco de la Adherencia en España, un documento en el que se analizan los determinantes y consecuencias de la falta de adherencia y se proponen medidas para mejorarla.

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La UCLM acoge un curso de verano sobre el abordaje de las enfermedades raras en los sistemas nacionales de salud

[Access](#)

RADIO AND TELEVISION

Debate with Álvaro Hidalgo, president of the Weber Foundation in the TVE programme "Las Claves".

[Access](#) (1h 22 min)

← Tweet



Las Claves
@LasClavesTVE

...

Álvaro Hidalgo, profesor de Economía de la Salud: "El modelo que tenemos en España es mayoritariamente público y de gestión directa. Es evidente que la sanidad es un bien preferente y su financiación debe ser pública, pero la provisión puede ser privada o pública"

#LasClaves21



11:46 p. m. · 17 jun. 2022

SOCIAL NETWORKS (RRSS)



SOCIAL NETWORKS (RRSS):

