

Fundación **Weber**

"The value of health research"

ACTIVITY REPORT  
**2023**









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LETTER FROM THE PRESIDENT

## 1. LETTER FROM THE PRESIDENT

Throughout 2023, the Weber Foundation has initiated a process of internationalization and outreach to patient associations. The presence of the Weber Foundation increased significantly in the European Union, thanks to the project "Neurodiversity Power - Neurodiversity Management Toolkit", which is led by the Weber Foundation and funded by the Erasmus+ program. This project involves 4 other partners, which are ACTA Center (Oradea, Romania), CATRO (Sofia, Bulgaria) BOSEV (Ankara, Turkey) and INNOWA (Valencia, Spain) and aims to increase awareness, visibility and understanding of neurodivergent people in the workplace by creating tools that facilitate real inclusion, avoid any form of harassment and adopt a different but equally effective way of brain performance if these tools are well implemented. This project marks the Weber Foundation's first achievement in a competitive public call for proposals, which has made a significant change in the Foundation's ability to compete in highly demanding and internationally competitive environments.

Another of the Foundation's challenges identified by the Advisory Board in 2022 is the need to increase public funding projects. In addition to the project financed by the European Union, there are projects financed by the Carlos III Health Institute and the Ministry of Health. With regard to the former, the Weber Foundation is positioning itself as a benchmark in economic evaluation and budgetary impact in personalized and precision medicine projects. In this line is the research project "Comprehensive study of genetic and molecular variation of a Spanish cohort of autism spectrum disorders and design of genetic diagnostic algorithms and therapeutic biotypes. Cohort ESTEA" financed by the Instituto de Salud Carlos III in which the Weber Foundation will carry out the economic evaluation and budget impact models. In the same sense, the projects carried out by the Weber Foundation for the Ministry of Health stand out, especially the document evaluating the performance of the Spanish National Health System (SNS) in the face of the COVID-19 pandemic, the purpose of which was to provide useful information to guide decision-making in order to strengthen and unite the SNS and make it more resilient in the face of future pandemic threats. In this way, the Foundation has managed to internationalize and obtain public clients, strategic objectives that we will continue to promote in the year 2024.

The Foundation's other strategic line for 2023 has been to continue to deepen projects led with patient associations with the signing of framework agreements with EUPATI-Spain to promote and monitor the impact of citizen participation in the pharmaceutical R&D cycle and with the Spanish Patients' Forum with the aim of promoting biomedical research and participatory medicine and strengthening associationism. We continue to make progress in 2023 in projects with other patient associations, especially with the Spanish Association Against Cancer (AECC) and the project to build the cancer indicator in Spain, which aims to generate a composite indicator that makes visible and quantifies the different dimensions relevant to cancer disease, in order to compare the state of these over time and between the different Autonomous Communities.

Finally, the Weber Foundation has begun to promote another strategic line that we have started to work along 2023 and that will be the focus of our actions throughout 2024, which is innovation and its application to the economic evaluation of health technologies. In this field, the Weber Foundation is a new partner of the MAD e-Health cluster led by the Madrid City Council with the aim of creating a dynamic ecosystem that drives an economy focused on technologies for the well-being of the elderly. We believe that from the Foundation we must develop tools to work with data, produce tools that implement artificial intelligence solutions to generate greater efficiency in internal processes and develop new products and projects that carry value for patients and for the Spanish Health System.

In short, the year 2023 has been a year of consolidation of the activities that we have been developing in previous years and the promotion of strategic objectives such as internationalization and the implementation of projects in competitive calls for proposals funded by Spanish and European Public Administrations. For the year 2024 we will advance in the digitalization of the Foundation, its processes and projects, continuing with internationalization and the incorporation of artificial intelligence and foresight in the analysis of the challenges of our health system.



Álvaro Hidalgo Vega  
President of the Weber Foundation



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THE FOUNDATION

## 2. THE FOUNDATION

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The Weber Foundation, **is a non-profit entity**, born on July 5, 2017 driven by Weber, Economics and Health, with the mission to promote health economic research with the aim of contributing to the sustainability of the National Health System and improving the quality of life of patients and equity in access to health care.

With the creation of the Weber Foundation, the Weber Group has become a benchmark 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 health care, always with the main objective of improving and humanizing health care in order to improve the quality of life of patients and social welfare. 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.



### VISION

The Weber Foundation is at the service of patients, working for and with them. We firmly believe that, through training, knowledge and research on economic aspects that affect health and health care, tools can be developed to support and back up decisions on health policies that will improve the quality of care and the lives of patients.



### VALUES

The Weber Foundation is guided by the following values:

**Quality:** We understand that the only way to achieve the Foundation's objectives 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 collaborators.

## 2.2 GOVERNMENTAL BODIES

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### PATRONAT

The Advisory Council of the Weber Foundation is chaired by **Álvaro Hidalgo Vega**, an expert in the field of health economics, professor and member of the Area of Fundamentals of Economic Analysis at the Faculty of Legal and Social Sciences of the University of Castilla-La Mancha. He is assisted by Alexandra Ivanova Markova as Secretary General.



Chairman  
**Álvaro Hidalgo**



General Secretary  
**Alexandra Ivanova**

#### ADVISORY COUNCIL

The advisory council of the Weber Foundation is chaired by Indalecio Corugedo de las Cuevas, retired Professor of Economics at the Complutense University, and is made up of the following persons:

- D.<sup>a</sup> Amaia Casteig Blanco
- D. Antonio J. García Ruiz
- D. Cristóbal Belda
- D. Jorge Mestre Ferrándiz
- D. José Luis Sánchez Chorro
- D. Juan Oliva Moreno
- D.<sup>a</sup> María del Mar Luque Fernández
- D.<sup>a</sup> Marta Traperó Bertran
- D. Modesto Martínez Pillado
- D. Pedro Gómez Pajuelo
- D. Santiago Alfonso Zamora
- D. Víctor V. Vázquez

You can access a brief CV at the following link:



### 2.3 GOOD GOVERNANCE AND TRANSPARENCY. VALUES

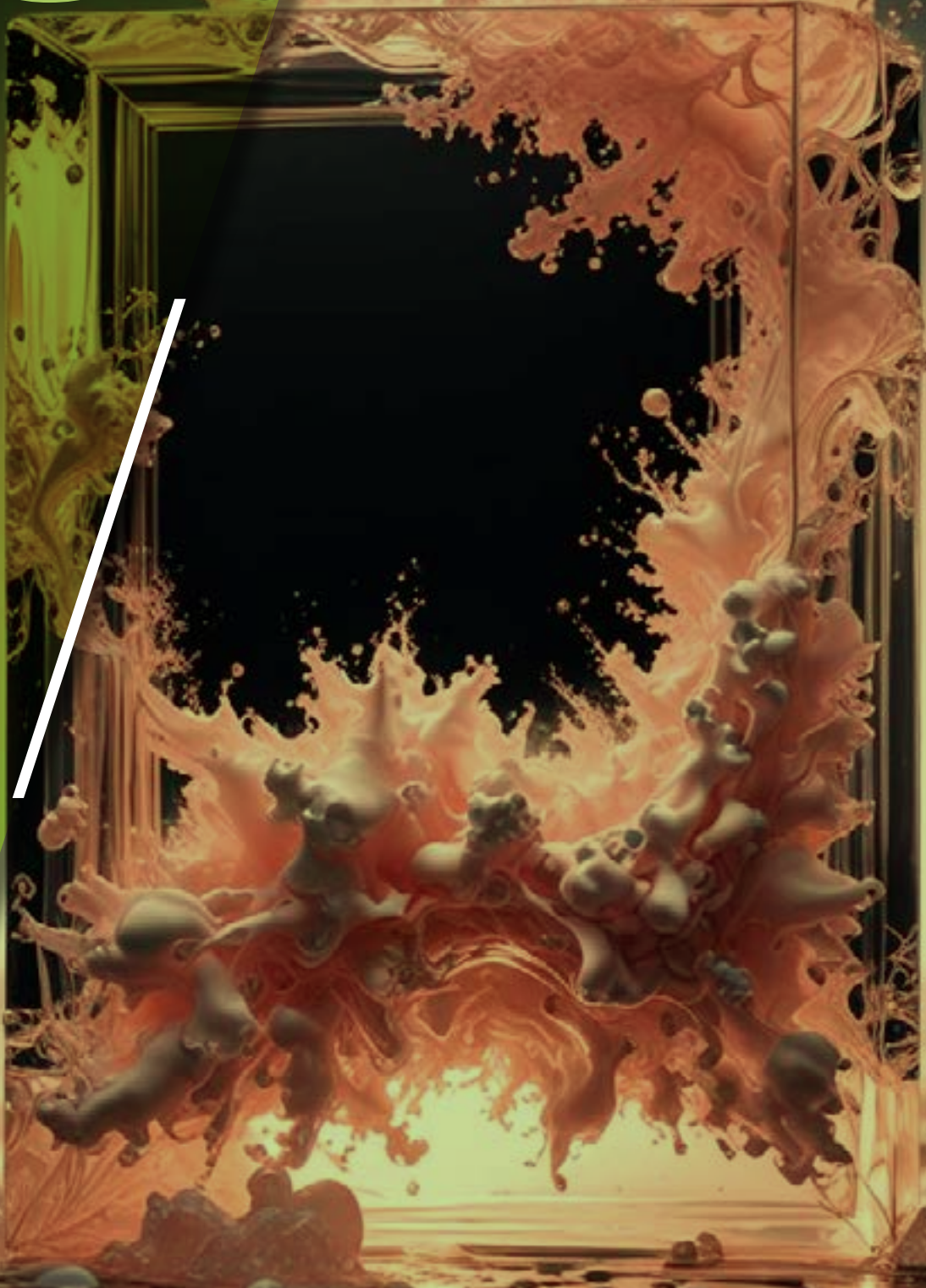
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The Weber Foundation always acts with the utmost rigor, transparency and good governance, with the aim of guaranteeing its foundational purposes, ensuring effectiveness and efficiency in all the projects it carries out, and achieving excellence in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

In order to achieve these objectives, the Foundation acts taking into account the following values that we share in each of our projects:

- **Quality:** We understand that the only way to achieve the Foundation’s objectives 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 collaborators.
- **Accessibility:** To make training and knowledge on the economic aspects that affect 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:** Predisposition to work collaboratively with associations, foundations and institutions, necessary to work in a safe and trustworthy dynamic.
- **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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ACTIVITIES 2023

**MAIN AREAS OF WORK OF THE FOUNDATION IN 2023**

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● New areas of work in 2023 ● Permanent areas of work since the creation of the Foundation





### 3.1 ESEARCH

#### **Report: ANETA Project: Strategic analysis for the implementation of advanced therapies in Spain**

**Realized:** Weber Foundation

**Supporter:** Novartis

**Year:** 2023

**Rationale:** The main objective of the ANETA project “Strategic Analysis for the Implementation of Advanced Therapies in Spain” is to contribute to the appropriate approach to advanced therapies in Spain. Specifically, this think tank aims to promote a multi-disciplinary strategic reflection by some thirty key agents and opinion leaders on the organizational and social challenge posed by the management of advanced therapies in Spain at all levels, in order to help the National Health System to better face the new scenario posed by advanced therapies, suggesting measures of action to address the various existing challenges.

The project was implemented through the formation of a CORE Advisory Committee, composed of 7 experts, from which the general vision was derived, and four technical working groups, from which the proposals for improvement were drawn.

[Link to the report](#)

#### **ATLAS of acute myeloid leukemia (AML): A comprehensive look at the management and burden of AML in adults in Spain**

**Made by:** Weber Foundation

**Supporter:** Astellas

**Year:** 2023

**Rationale:** This atlas outlines the magnitude of the AML problem, the therapeutic approach, the economic and social burden, the unmet needs and the future challenges facing this disease.

[Link to Atlas](#)





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**Report: The assessment and funding processes of drugs in Spain and other OECD countries: Where are we and where are we going?**

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**Made by:** Weber Foundation

**Supporter:** Abbvie

**Year:** 2023

**Rationale:** The objective of this project was to analyze in depth the process of evaluating and financing drugs in Spain and in other countries in the region and to ascertain the views of the main agents of the Spanish health system on how it works, in order to offer ideas for improvement.

On the one hand, an exhaustive review of the drug evaluation and financing processes in Spain and in 13 other OECD countries has been carried out in order to detect the best international practices. Thus, the work offers detailed, structured, updated and comparable information, in Spanish, on the different parts of the evaluation process, providing 9 comparative tables between countries.

[Link to Report](#)

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**Report: ANEMIA ASSOCIATED WITH CHRONIC RENAL DISEASE: Health care and economic impact in Spain**

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**Made by:** Weber and Weber Foundation

**Supporter:** GSK

**Año:** 2023

**Background:** Background: Chronic kidney disease (CKD) is a prevalent disease with a significant impact on public health. Among its complications, anemia is one of the most frequent and relevant, affecting the quality of life of patients and generating an important economic impact on the health system. The aim of the report “ANEMIA ASSOCIATED WITH CHRONIC RENAL DISEASE. Health care and economic impact in Spain” is to analyze the health care and economic impact of anemia in CKD in Spain. The report was based on a retrospective observational study using a database of patients with CKD in Spain. The direct and indirect costs associated with anemia in this population were analyzed. The results show that anemia in CKD is a common complication, present in a high percentage of patients, with a significant impact on the quality of life of patients with CKD.



significant impact on the quality of life of patients, with symptoms such as fatigue, weakness and difficulty in performing daily activities. The costs associated with anemia in CKD are high, both in terms of direct costs (pharmacological, hospitalizations, etc.) and indirect costs (loss of work productivity, etc.), varying according to the severity of CKD and the type of treatment. This report provides valuable information on the impact of anemia in CKD in Spain. It is a useful tool for decision making by health managers, health professionals and patients

[Link to the report](#)

**Communication in the 53rd Congress of the Spanish Society of Nephrology: ECONOMIC BURDEN OF ANEMIA ASSOCIATED WITH CHRONIC RENAL DISEASE IN SPAIN**

**Carga económica de la anemia asociada a la Enfermedad Renal Crónica en España**

Resumen de los datos clave:

- Carga económica anual:** 6.963.729 millones de euros.
- Pacientes con ERC y anemia:** 27.206.
- Coste medio por paciente:** 255.204 euros.
- Costes directos:** 3.305.817 millones de euros.
- Costes indirectos:** 3.657.912 millones de euros.

El informe detalla el impacto económico de la anemia en pacientes con Enfermedad Renal Crónica (ERC) en España, considerando tanto los costes directos (farmacológicos, hospitalizaciones) como los indirectos (pérdida de productividad). Se concluye que la anemia tiene un impacto económico considerable, siendo el coste por paciente en pacientes dializados casi ocho veces mayor que en pacientes no dializados.

Made by: Weber Foundation

Date of the congress: November 11 to 13, 2023

Lugar de celebración: Palma de Mallorca

**Background:** The aim of this communication was to estimate the economic burden of anemia associated with CKD in Spain from a social perspective.

An economic analysis was carried out with a prevalence-based approach, from a social perspective, with a time horizon of one year. The analysis focused on two subgroups: patients with CKD and anemia in stages 3 to 5 not dialyzed (ND) and dialyzed patients. It is concluded that patients with CKD and anemia have a considerable economic impact (almost 7 billion euros), with the cost per patient in dialyzed patients being eight times higher than in ND patients. Determining and quantifying the high social and health care impact of this complication will make it possible to dimension the efforts and seek the efficiency of our health care system.

[Link to communication](#)





### 3.2 TRAINING

#### Workshops: Number needed to treat (NNT): Old but current concept?



**Organized by::** Weber Foundation

**Supporter:** UCB

**Date:** 2023

**Rationale:** Beyond what the NNT is and how it is calculated, these workshops aim to provide an understanding of the context of NNTs as a useful tool to optimize the application of NNTs and cost per NNT in decision making in hospital practice.

#### **Objectives:**

- Understand the context in which NNTs become a valuable tool for the analysis of incremental clinical benefit and economic evaluation of drugs.
- Acquire a critical perspective on the role of efficiency in the assessment of health technologies in the clinical and financing decision-making process.
- Calculate and interpret NNT in the field of medicines in different contexts. case studies with published reports and articles.
- Translating theoretical knowledge into practice: Cost per NNT and budget distribution.

In 2023 these workshops were held for the Hospital Pharmacy services of several hospitals in different geographical areas:

#### ■ MADRID

**Hospital Pharmacy Service of the Hospital Clínico San Carlos Organized by: Weber Foundation**

**Supporter:** Weber Foundation

**Apoya:** UCB

**Date:** May 8, 2023

**Lugar:** Hotel EXE Madrid

**Hospital Pharmacy Service of the Hospital Universitario Rey Juan Carlos de Alcalá de Henares, Madrid.**

**Organized by:** Weber Foundation

**Supporter:** UCB

**Date:** May 17, 2023

**Venue:** Hospital Rey Juan Carlos

■ **SEVILLE**

**Hospital Pharmacy Service of the Virgen de la Macarena University Hospital**

**Organized by:** Weber Foundation

**Supporter:** UCB

**Date:** May 10-11, 2023

**Venue:** Hospital Universitario Virgen de la Macarena

■ **PALMA DE MALLORCA**

**Hospital Pharmacy Service of the Hospital Universitario de Son Espases**

**Organized by:** Weber Foundation

**Supported by:** UCB and Farupeib (FUIB)

**Date:** May 18, 2023

**Venue:** M d'ica Balear

■ **CATALONIA**

**Hospital Pharmacy Service of Hospitals of Catalonia**

**Organized by:** Weber Foundation

**Supported by:** UCB and the Catalan Society of Clinical Pharmacy

**Date:** May 31, 2023

**Venue:** Academy of Medical Sciences of Catalonia and the Balearic Islands

■ **VIGO**

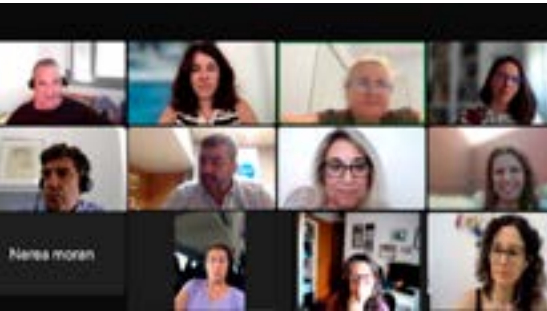
**Hospital Pharmacy Service of the Álvaro Cunqueiro Hospital in Vigo**

**Organized by:** Weber Foundation

**Supporter:** UCB

**Date:** September 21, 2023

**Place:** Álvaro Cunqueiro Hospital in Vigo



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### **Workshop: PSOVALUE patients. Psoriasis Action**

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**Organized by:** Acción Psoriasis

**Supported by:** UCB and Weber Foundation

**Date:** September 26th

**Rationale:** The objective of the workshop is to provide a comprehensive update on this dermatological condition, addressing both the medical aspects and the needs and experiences of patients. The workshop presented the evolution of the latest treatments and therapies, providing detailed information on their effectiveness and applicability in the management of psoriasis.

In addition, the social value of a PASI90 or PASI100 response in psoriasis was explored, highlighting that the social value is a concept that goes beyond the clinical benefit: it includes the personal, family, work and social spheres, and it was also explained how the social value is calculated from the economic impact of the disease.

A fundamental part of the session was the detailed explanation of the content of the Psoriasis Manifesto, a document that summarizes 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 purpose of this workshop is not only to inform, but also to generate a space for dialogue, mutual support and collaboration between health professionals and patients, to empower the patient and offer a comprehensive view of psoriasis that leads to better therapeutic approaches and a better quality of life for all those affected.

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### **Patient education and training program related to the basic principles of applied health research**

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**Organized by:** Eupati and Weber Foundation

**Rationale:** After years of joint collaboration, on February 20, 2023, a framework collaboration agreement was signed between the Weber Foundation and Eupati Spain in order to support access to therapeutic innovation and contribute to improving the well-being of all citizens.

Among the year's collaborative activities, those related to improving patient participation throughout the pharmaceutical cycle stand out, given their greater protagonism and involvement in the decision-making processes. This new form of patient participation entails the need for patients to become increasingly aware of regulatory processes and emerging R&D advances.



Among the different activities that have been carried out within this framework of collaboration, this year 2023 has seen the launch of a training and capacity-building program aimed at patients and related to the basic principles of applied health research. Two training workshops have been organized as part of this program:



**First workshop: Optimizing patient participation in drug-related decision making**

**Organized by:** Eupati and Weber Foundation

**Supporter:** Takeda

**Date:** April, 2023

**Rationale:** In order to update the regulation of health technology assessment (HTA), the Council and the European Parliament adopted the EU HTA Regulation to be better prepared for new innovations and to address Member States’ concerns about the availability and affordability of innovative medicines. This regulation paves the way for mandatory joint clinical evaluation, as well as for joint scientific and patient consultation and horizon scanning. It aims to harmonize methodological standards and foster collaboration between European HTA bodies.

From 2025, all new oncology medicines and advanced therapies will be assessed jointly, while final HTA assessments and subsequent reimbursement decisions will remain in the hands of each member state. And from 2030, all medicines will have to be assessed through the centralized EU regulatory assessment.

In view of the new scenario of participation that is opening up for patients, EUPATI and the Weber Foundation, with the support of Takeda, held a workshop with the aim of explaining the roadmap for patient participation in HTA/IPT initiatives. The aim of the workshop was to deepen the understanding of what is and what will be the participation and role of patient associations in the evaluation of health technologies.



**Second workshop: Citizen influence on health policies: The role of patient associations**

**Organized by:** Eupati and Weber Foundation

**Supported:** Alexion

**Date:** November 6, 2023

**Rationale:** The joint clinical assessments to be carried out from 2025 onwards at European level will enable the various actors in the system, including patients, to

be more involved in the process and to communicate more closely with the EU Coordinating Group.

In line with the previous workshop in April, on this occasion the aim was also to explain to various patient associations the recent regulatory changes in the evaluation of health technologies at national and European level, so that they can be better prepared to participate in the decision-making processes in terms of training, planning and organization.



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### **Mundipharma KAM Training Program**

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**Organized by:** Weber Foundation

**Supporter:** MUNDIPHARMA

**Date:** February 16, 2023

**Rationale:** The Weber Foundation launched the 2nd edition of in-company training for Mundipharma's KAMs. The main objective of the course is to learn the basic concepts and the main tools of health technology assessment and the disciplines that support it. The first module, Introduction to the pharmaceutical environment in Spain, was given by Álvaro Hidalgo, Pedro Gómez Pajuelo and Andrés Navarro.

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### **Course on clinical management by integrated processes**

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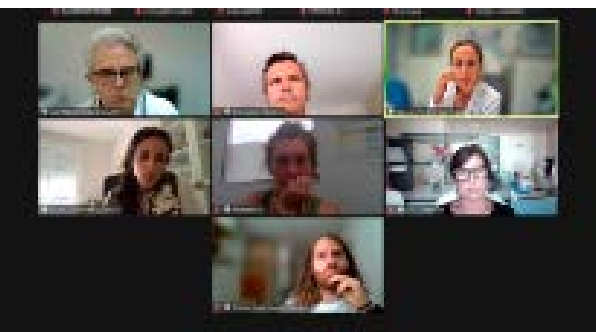
**Organizers:** Weber Foundation

**Date:** April 10, 2023

**Rationale:** It is a planned and automated course taught in e-learning mode. The student studies at his own pace within the duration of the course (6 months from the moment the enrollment is formalized).

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





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### **KAM Mundipharma Training Program: Module II**

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**Organized by:** Weber Foundation

**Supporter:** MUNDIPHARMA

**Date:** July 10, 2023

**Rationale:** The Weber Foundation launched the 2nd edition of in-company training for Mundipharma's KAMs.

The objective of the second module was to improve knowledge of the environment, the specific challenges of hospital pharmacy, and to master knowledge of relevant pharmaceutical products. The course aims to help professionals understand the environment, activities and needs of hospital pharmacy, enabling them to better manage in this area.

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### **In-company workshop for Grünenthal on: New approaches and methodologies in the economic evaluation of medicines in Spain**

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**Organizer by:** Weber Foundation

**Supported by:** Grünenthal

**Date:** October 2-3, 2023

**Rationale:** In the workshop, Álvaro Hidalgo outlined the difference between effectiveness and efficiency, highlighting the crucial role of Real-World Data (RWD) and Real-World Evidence (RWE) as key drivers of innovation in the sector. It also explored the integration of Patient-Reported Outcomes (PRO) and Physician-Reported Outcomes (PREM) into the payer decision-making process. In addition, it delved into multi-criteria decision analysis and its application in access to innovation in the pharmaceutical field. As part of the workshop activities, a critical reading session was conducted and metrics and methods for measuring progress and effectiveness in the field of pharmaceutical innovation were examined.

Cursos y Talleres





### 3.3 ONFERENCES AND SEMINARS

#### Webinar: Social Value in Psoriasis Patients: Utility in Real Life



**Organized by:** Weber Foundation

**Supporter:** UCB

**Date:** January 12, 2023

**Rationale:** Following the previous webinar on MCDA in psoriasis held in October 2022, the webinar on social value in patients with psoriasis was held on January 12. This methodology favors not only the efficient use of the resources available to the NHS, but also knowledge of the benefits and importance of patient participation in pharmaceutical management and promotes greater health for the population as a whole. To facilitate understanding, some examples of real-life application were given, especially as applied to psoriasis.

[Access the webinar](#)



#### Expert meeting with Diario Farma: Reflections on the elements of value in the process of evaluation and financing of medicines in the NHS

**Organized by:** Weber Foundation

**Supporter:** Abbvie

**Date:** February 16, 2023

**Rationale:** A group of experts met, Carlos Martín Saborido, Member of the Advisory Board of the General Director of the Common Portfolio The meeting was moderated by Olga Delgado, president of the Spanish Society of Hospital Pharmacy; Mariana Bastos, member of the Board of Directors of the Spanish Society of Hematology and Hemotherapy; Elisenda de la Torre, representative of EUPATI and president of Reu+; Álvaro Hidalgo, president of the Weber Foundation; and María Costi, director of Market Access at Abbvie. Under the moderation of José María López Alemany, director of Diariofarma, a meeting was held with the aim of





reflecting on the elements of value in the process of evaluating and financing medicines in the NHS following the report *El proceso de evaluación y financiación de los medicamentos en España: ¿dónde estamos y hacia dónde vamos?* which has analysed these processes in 13 OECD countries. Among the aspects addressed in the report, three issues were selected for analysis, namely how to give greater weight to efficiency criteria, the importance of separating evaluation and financing and, finally, the relevance of providing the processes with greater participation of all the agents involved.

[Access the news of the meeting](#)

[Access the report](#)



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### 1st Meeting of the Committee of Experts for the project: Construction of the cancer indicator in Spain

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**Organized by:** Weber Foundation

**Supporter:** AECC

**Date:** May 16, 2023

**Rationale:** This project aims to generate a composite indicator that makes visible and quantifies the different dimensions relevant to oncological disease, in order to compare the state of these over time and between the different Autonomous Communities. The aim is also to generate a consensus and involve the different stakeholders. The strategic objective is to guarantee territorial equity in cancer prevention and treatment.



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**Regional meeting in Catalonia to present the results of the Report on the Social Value of a strict and early control of DM2 in Spain**

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**Organized by:** Weber Foundation

**Supporters:** Lilly y el Correo

**Date:** June 1, 2023

**Rationale:** The results of the Report on the Social Value of strict and early control of DM2 in Spain were presented. This is the first of 5 regional meetings to be held throughout 2023.

In order to learn in detail how DM2 is addressed in our healthcare system, Diálogos in La Vanguardia brought together a multidisciplinary group of experts with the aim of contrasting points of view and identifying possible lines of improvement and contributing to making visible a disease that is increasingly being seen in younger people, a high percentage of whom are undiagnosed, and which is closely related to lifestyles.

Álvaro Hidalgo, as president of the Weber Foundation, presented the report and the results, and then the moderator, Enric Freire, a journalist from La Vanguardia specialising in health, gave way to the representative of the Catalan Department of Health, Dr. Ignasi Carrasco, director of the Health Care Area of the Catalan Health Service, and the rest of the experts: Dr. Antonio Pérez, director of the Nutrition Service Unit of the Santa Creu i Sant Pau Hospital. Ignasi Carrasco, director of the Healthcare Area of the Catalan Health Service, Dr. Antonio Amor, specialist in endocrinology and nutrition at the Hospital Clinic and Teresa Millán, director of Corporate Affairs at Lilly.

[Access the new of the meeting](#)



### Regional meeting in Andalusia to present the results of the Report on the Social Value of a strict and early control of DM2 in Spain

**Organized by:** Weber Foundation

**Supported by:** Lilly and Joly Group

**Date:** June 7, 2023

**Rationale:** As part of the series of meetings to present the results of the Report on the Social Value of strict and early control of DM2 in Spain, the second of the regional meetings that have been held was held in Seville on June 7.

María Merino participated in this meeting on behalf of the Weber Foundation and presented the conclusions of the study developed by Vivactis Weber and Lilly on the social value of strict control of the disease, whose main objective was to estimate the difference between the economic impact generated by strict and early control of the disease and non-strict control in the five years following diagnosis.

This meeting was attended and participated in by Diego Vargas, manager of the Andalusian Health Service, who explained the current situation in Andalusia regarding the prevalence and impact of DM2 in his community, and María Asunción Martínez, director of the Andalusian Comprehensive Diabetes Plan, as well as professional experts such as Dr. Francisco Tinahones; Ana María Álvarez, representative of FEDE in Andalusia and Anadis Diabetes Seville and Teresa Millán, director of Corporate Affairs at Lilly.

The meeting was moderated by Mr. Ramiro Navarro, editor-in-chief, health section, Joly Group.

#### Access to the news of the meeting

[Diario de Sevilla](#)

[Diario de Jerez](#)

[Diario de Cádiz](#)

[Europa Sur](#)

[Huelva Información](#)

[El diario de Córdoba](#)

[Málaga Hoy](#)

[Diario de Almería](#)

[Granada Hoy](#)



**Webinar: Presentation of the results of the Report on the Social Value of a strict and early control of DM2 in Spain**

**Organized by:** Weber Foundation

**Supporters:** Lilly and Weber

**Date:** June 30, 2023

**Rationale:** The aim of the webinar is to present the results of the report on the social value of strict and early control of patients with DM2 in Spain.

In this webinar, moderated by María Merino, the experts who had participated in the preparation of the report, Jose Luis Trillo, Dr. Antonio Pérez, Sara Artola, Joan Antoni Valles Collol, and Juantxo Remón Virto on behalf of the patients, took part.

[Access the report](#)

**Summer Course 2023: NEW STRATEGIES AND TRENDS IN THE MANAGEMENT OF RARE DISEASES**

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

**Date:** September 19 and 20, 2023

**Rationale:** Within the activities that have been carried out in the Summer Course 2023 of the University of Castilla-La Mancha, the Weber Foundation together with the magazine newsRARE organized, once again this year, a space for meeting, analysis and multidisciplinary debate.





The main focus of the seminar will be on new strategies and trends in the management of rare diseases (RDs). These new preventive, diagnostic and therapeutic strategies allow adaptation to the characteristics of patients with RD, thus moving towards a medicine based on efficacy and results (Value-Based Healthcare).

During the event, the importance of early diagnosis and neonatal screening was discussed in order to improve the approach to RDs. In addition, the new developments and legislative implications, both national and European, that therapeutic advances entail were discussed.

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

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**3rd Rare Disease (RD) Protagonist of the Year Award: CIBERER Biobank (CBK), transversal platform for biomedical research in Rare Diseases (EERR).**

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**Centro de Investigación Biomédica en Red de Enfermedades Raras (CIBERER)**

**Organized by:** Weber Foundation and newsRARE

**Date:** September 20, 2023

**Rationale:** The purpose of this award is to recognize the work of organizations, patient associations and other institutions that, through their work, have contributed to improving the health care and management of patients with RDs, helping patients, generating better knowledge and raising public awareness in the field of orphan drugs and rare diseases.

The Centro de Investigación Biomédica en Red de Enfermedades Raras (CIBERER) won the 3rd Rare Disease Protagonist of the Year Award with the CIBERER Biobank (CBK) project, a cross-cutting platform for biomedical research in RDD.

The CIBERER's main pillar is to promote scientific research, development and innovation in RDD in order to answer key questions and find therapeutic solutions to improve the quality of life of patients. To achieve these objectives, the CIBERER has a series of platforms that support scientific research, including the CBK. It is a public, non-profit biobank dedicated to the collection and management of biological samples from patients with RD. Its primary objective is to support diagnostic and therapeutic research in the field of RDs by facilitating access to high quality human biological samples.

In addition to guaranteeing quality standards, the CBK maintains a close relationship with patients, respecting the ethical and legal considerations of donors. It acts as a



platform that coordinates three key elements in the management of human biological samples: clinicians, researchers and donors, with the aim of promoting translational research in RD. The CBK's catalog includes various types of samples and, since its creation in 2011, it has managed to accumulate a collection of 1,084 samples from 84 RDs, establish 22 processing services for R&D and obtain quality accreditations (such as ISO 9001:2015). In addition, it has strengthened collaborations with public administrations in 2022, resulting in a significant increase in the number of donors and biological samples, as well as greater participation in outreach activities.

The results obtained highlight the advantages of the collaborations established with patient associations. It has been shown that the scientific and technical capabilities of the CBK are fundamental for the proper management of biological samples, which is essential for obtaining solid results in research related to RD. Patient associations can contribute to the development of research projects not only through funding, but also by donating samples. Close collaboration between the CBK, patient associations and donors has led to a better understanding of the needs and concerns of donors, which has helped to guide research towards obtaining optimal results. Overall, this working strategy has proven to be fruitful, and it is intended to be continued in the future.



[Access to the award ceremony and the interview with Carmen Aguado](#)

### Regional meeting in Galicia to present the results of the Report on the Social Value of a strict and early control of DM2 in Spain

**Organized by:** Weber Foundation

**Supported by:** Lilly and La Voz de Galicia

**Date:** September 22, 2023

**Rationale:** As part of the series of meetings to present the results of the Social Value of Tight and Early Control of Type 2 Diabetes in Spain Report, the 3rd regional meeting was held in A Coruña (Galicia) on September 22nd. In this meeting, to analyze the results of the Report on the Social Value of a strict and early control of type 2 diabetes in Spain, and to address the current situation and action plans for type 2 diabetes in Galicia, they met at the Museum of the Santiago Rey Fernández-Latorre Foundation: Estrella López-Pardo, manager of Sergas; Diego Bellido, head of Endocrinology and Nutrition of the Complejo Hospitalario Universitario de Ferrol (CHUF); Gemma Rodríguez Carnero, member of the Spanish Society of Endocrinology and Nutrition (SEEN); Jose Manuel García, president of the Federation of Galician Diabetes Associations (FEGADI) and member of the board of directors of the Spanish Diabetes Federation (FEDE); Jorge Santander, director of Institutional Relations at Lilly; and Álvaro Hidalgo, president of the Weber Foundation.

The meeting was moderated by Ms. María Meizoso Dopico, health editor of La Voz de Galicia.

[Access to the news of the meeting](#)



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### **Regional meeting in Valencia to present the results of the Report on the Social Value of a strict and early control of DM2 in Spain**

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**Organized by:** Weber Foundation

**Supporters:** Lilly and El Levante

**Date:** October 13, 2023



**Background:** As part of the series of meetings to present the results of the Social Value of Strict and Early Control of DM2 in Spain Report, the 4th of the regional meetings that have been held was held in Valencia on 22 September. At this meeting, the results of the report were presented, followed by a round table debate to discuss the effects of the disease in all areas, from the social to the pharmaceutical and economic spheres. This round table was moderated by Silvia Tomás, Director of Institutional Relations of Prensa Ibérica in Valencia, and was attended by Dr. Ruth Usó, Director General of Public Health of the Regional Ministry of Health; Dr. Rosa Casañ, treasurer and representative of the Spanish Society of Endocrinology and Nutrition (SEEN) and specialist in the Endocrinology and Nutrition Service at the University Hospital of Valencia; M. <sup>a</sup> Teresa Marí, representative of Federación de Diabéticos de la Comunitat Valenciana (Fedicova) and Federación Española de Diabetes (FEDE); Dr. Teresa Millán, Director of Corporate Affairs at Lilly; and María Merino, Director of the Health Outcomes Research Department at Vivactis Weber.

[Access to the news of the meeting](#)



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**Regional meeting in Bilbao to present the results of the Report on the Social Value of a strict and early control of DM2 in Spain**

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**Organized by:** Weber Foundation

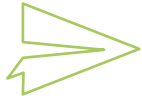
**Supporters:** Lilly and El correo

**Date:** November 29, 2023



Rationale: On November 29, as part of the series of meetings to present the results of the Report on the Social Value of Early and Strict Control of DM2 in Spain, the 5th of the regional meetings that have been held in Bilbao. At this meeting, the results of the report were presented, followed by a debate on the importance of investing in professionals and in treatment strategies which, in addition, will bring an economic return to society. This forum brought together five experts: Amelia Oleaga, head of the Endocrinology and Nutrition Service of the Basurto Hospital, Iratxe Vilariño, president of the Federation of Diabetic Associations of the Basque Country (FADE), Koldo Cámara, deputy director of Public Health of the Basque Government, Teresa Millán, director of Corporate Affairs of Lilly and çlvaro Hidalgo, president of the Weber Foundation.

[Access to the news of the meeting](#)



### 3.4 DISSEMINATION

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**Article publication: Strategic discussion on funding and access to therapies targeting rare diseases in Spain: an expert consensus paper**

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**Made by:** Weber Foundation

**Published in:** Orphanet Journal of Rare Diseases

**Date:** 2023

**Rationale:** The objective of the FINEERR project was to carry out a multidisciplinary strategic discussion on the challenge of financing and access to drugs for rare diseases in Spain, in order to reach a consensus on specific proposals for improvement in the medium term and thus support decision-making in the National Health System.

As a result of this project, an article has been produced highlighting the challenges identified, proposed solutions and specific recommendations. These findings not only offer an in-depth view of the current situation, but also provide a solid basis for implementing tangible improvements in access to treatment for rare diseases in Spain.

[Link to the article](#)

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**Publication of the article: The social value of a PASI 90 or PASI 100 response in patients with moderate-to-severe plaque psoriasis in Spain**

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**Realized by:** Weber Foundation

**Published in:** Frontiers in Public Health

**Date:** 2023

**Rationale:** A PASI 90 or PASI 100 response would have a lower economic impact and greater societal value than a PASI 75 response for patients with moderate to severe plaque psoriasis. A 1-year economic model was applied to estimate the impact of having a PASI 75, PASI 90 or PASI 100 response in four areas of analysis (quality of life, activities of daily living, work productivity and out-of-pocket expenses) and the societal value of having a PASI 90 or PASI 100 response compared to a PASI 75 response. A mixed-method approach based on the scientific literature, a patient focus group and an advisory committee with key psoriasis stakeholders was used. The model included three different scenarios: having a PASI 90 versus PASI 75 response; a PASI 100 versus PASI 90 response; and a PASI 100 versus PASI 75 response.

The annual economic impact per patient with moderate to severe plaque psoriasis who achieved a PASI 75 response was estimated at 6.139 €, mainly related to lost work productivity and reduced quality of life. Achieving a PASI 90 or PASI 100 response would reduce this impact by 3.956 € or 1.353 € respectively. The societal value of achieving a PASI 90 instead of a PASI 75 was estimated to be 2.183 € and at 4.786 € with a PASI 100 response.

[Link to the article](#)



### 3.5. NEWSRARE PUBLICATIONS

#### VOL 8 - ISSUE 1 MAY 2023

**Promoted by:** Weber Foundation

**Supporters:** Alexion, CSL Behring, CSL Vifor, Ipsen, Jazz Pharmaceuticals, Janssen, Roche and UCB

**Date:** May 2023

**Title:** Rare Diseases: Value-based Healthcare

In this issue of Value-based healthcare, we delve into value-based healthcare, which focuses on generating value for the citizen rather than counting the quantity of services provided. This approach, considered innovative by decision-makers, aims to improve the experience and health outcomes of patients with rare diseases, and to explore value-based healthcare initiatives in the field of rare diseases.

[Access to the complete issue](#)



#### VOL 8 - ISSUE 2 SEPTEMBER 2023

**Promoted by:** Weber Foundation

**Supporters:** Alexion, CSL Behring, CSL Vifor, Ipsen, Jazz Pharmaceuticals, Janssen, Roche and UCB

**Date:** September 2023

**Title:** Rare Diseases: Neonatal Screening and Early Detection of Diseases

The second issue of newsRare magazine addresses the crucial topic of newborn screening, focusing on the early detection of diseases in newborns. It explores advances in tests, technologies and policies related to the early identification of medical conditions that impact infant development. Provides in-depth analysis and case highlights on the importance and impact of newborn screening on public health.

[Access to the complete issue](#)







**VOL 8 - SUPPLEMENT 1 OCTOBER 2023**

**Promoted by:** Weber Foundation

**Supported by:** Vivactis HM3A

**Date:** October 2023

**Title:** Rare Diseases: Innovative financing, European funds and best practices

With the aim of expanding newsRARE beyond the borders of the Spanish-speaking world (Spain and Latin America) and with the collaboration of HM3A, we have launched this English supplement with the purpose of spreading the contents of newsRARE in Europe and the English-speaking world.

This international issue addressed innovative financing models, European funds and best practices for addressing national health systems.

[Access to the complete issue](#)



**VOL 8 - NUMBER 3 DECEMBER 2023**

**Promoted by:** Weber Foundation

**Supporters:** Alexion, CSL Behring, CSL Vifor, Ipsen, Jazz Pharmaceuticals, Janssen, Roche and UCB

**Date:** December 2023

**Title:** National and international policies

This issue addresses national and international policies being implemented on rare diseases to improve diagnosis, treatment and support for people affected by rare diseases.

[Access to the complete issue](#)



### 3.6 COLLABORATION AGREEMENTS AND ALLIANCES WITH OTHER INSTITUTIONS



**Weber Foundation and Eupati-Spain (February 20, 2023)** signed a framework collaboration agreement to promote and monitor the impact of citizen participation in the pharmaceutical R&D cycle, leading to the joint organization of different training activities (conferences, colloquiums, seminars, etc.), scientific dissemination, debate and strategic analysis..

[Access to the press release](#)



**Weber Foundation and SEMERGEN** initiate a strategic partnership to strengthen Primary Health Care and Health Research. This alliance promises to boost excellence in Primary Health Care and promote health research, benefiting both health professionals and patients, which will have a positive impact on the Spanish healthcare system and frontline medical care. SEMERGEN and the WEBER Foundation will work together to design strategies, promote the training of SEMERGEN associates, carry out research activities and organize seminars, courses and conferences on topics of common interest.



**Strategic collaboration for health and citizens' rights between the Weber Foundation and the Spanish Patients' Forum (FEP)**, clearly defining the role of each entity in its field of action. The FEP, with its prominent role as a national and international representative on health and patients' rights issues, brings together more than 80 organizations and represents more than 3,000 associations, being the voice of more than 42 million citizens who use the National Health System in Spain. This collaboration will provide the opportunity to leverage specialized resources, promote biomedical research and participatory medicine, and strengthen the associationism with the aim of promoting innovative programs to improve the efficiency of the healthcare system, guarantee more personalized treatments and contribute to the general wellbeing of citizens.



#### **The Weber Foundation new partner of the MAD e-Health Cluster**

The Madrid City Council leads the cluster with the purpose of creating a dynamic ecosystem that drives an economy focused on technologies for the well-being of the elderly. The aim is to make life easier for all those involved and to position Madrid as a benchmark in the e-Health sector for the elderly, among other goals.

[Access to the press release](#)



### 3.7 INTERNATIONAL PROJECTS

#### PROYECTO EUROPEO – NEURODIVERSITY POWER



As part of its commitment to social and labor inclusion, the Weber Foundation coordinates the project “Social and Labor Inclusion” to Neurodiversity Power, funded by the Erasmus+ program (reference number 2021-1-ES01-KA220-VET-000028059). This project aims to promote awareness, visibility and understanding of neurodivergent people in the work environment, developing tools that facilitate effective and sustainable inclusion.

Neurodiversity Power is a collaborative initiative involving organizations from four European countries: ACTA Center (Oradea, Romania), CATRO (Sofia, Bulgaria), BOSEV (Ankara, Turkey) and INNOWA (Valencia, Spain). Under the coordination of the Weber Foundation, this consortium is working to develop a series of resources that enable companies to manage neurodiversity in an inclusive way, avoiding any form of harassment or discrimination.

Expected outcomes of Neurodiversity Power include:

- A Methodological Manual that establishes good practices for the inclusion of neurodivergent people.
- A curricular program structured in training modules, aimed at future trainers, human resources managers and evaluators in organizations.
- A standardized procedure for the implementation of these methodologies in the work environment, which will allow companies to obtain a European Quality Seal in Neurodiversity, recognizing their commitment to inclusion,
- The creation of an online training platform, NeuroPower, for knowledge sharing and awareness of neurodiversity.

Neurodiversity Power aims to establish an inclusive methodology that supports neurodivergent individuals in the workplace, demonstrating that, with the right tools, it is possible to achieve effective performance and a respectful and diverse work environment.



### **Erasmus + 1st meeting in Oradea (Romania) of the Neurodiversity Power trip project**

**Organized by:** Weber Foundation

**Supported by:** Erasmus +

**Date:** January 18, 2023



**Rationale:** On behalf of the Weber Foundation, Álvaro Hidalgo and Marta Romero traveled to Oradea, Romania, to meet with the rest of the team working on the Neurodiversity Power project. On January 18, the second transnational meeting of the project took place with the aim of sharing the progress made so far.



### **Erasmus + 2nd meeting in Ankara (Turkey) of the Neurodiversity Power travel project**

**Organized by:** Weber Foundation

**Supported by:** Erasmus +

**Date:** May 23, 2023

**Rationale:** On behalf of the Weber Foundation, Marta Romero traveled to Ankara to meet with the rest of the project partners to strengthen collaboration and knowledge sharing between the different countries. At this meeting, the IO1 phase was concluded, ensuring the completion of all the corresponding elements, and IO2 (second part of the project) was prepared.



### **Erasmus + 3rd Sofia (Bulgaria) meeting of the Neurodiversity Power project**

**Organized by:** Weber Foundation

**Date:** November 30, 2023

**Rationale:** On behalf of the Weber Foundation, Marta Romero and Irene Barbero traveled to Bulgaria to meet with the rest of the project partners to strengthen collaboration and knowledge exchange between the different countries.

The objective of this meeting was to conclude the implementation of the IO2 phase and to start preparations for the Multiplier Events and learning/teaching/training activities. The project is now in the final stretch and two documents (handbook and curriculum) have been finalized and will soon be available and shared.





### 3.8 OTHER ACTIVITIES

#### IV Neuroscientific and Educational Conference focused on Neurological Diseases and Language Disorders

**Organized by:** Querer Foundation

**Date:** April 27, 2023



**Rationale:** The conference, organized by the Querer Foundation and the Columbus Foundation, brought together medical, educational and family professionals in a single event to demonstrate the importance of working together and promoting research for children with special needs. The latest scientific advances on diseases of neurological origin and especially on children with language disorders were presented.

Álvaro Hidalgo, on behalf of the Weber Foundation, participated in this conference in the Advanced Therapies round table, together with Dr. Lluís Montoliu, research scientist at CSIC; Dr. Ángeles García Cazorla, Neuro-pediatrician and leading researcher in the neurology department of the Hospital San Joan de Deu in Barcelona and Dr. Gloria González, director of innovation and transfer and researcher at Cima-University of Navarra and scientist at Vivet therapeutics.



These conferences are an invaluable opportunity to promote and encourage research in both the medical and educational fields.

#### XXIV COMPANY RUN-Madrid

On December 17, part of the Weber Foundation team, led by Alexandra Ivanova, participated in the XXIV edition of the companies' race, an event that unites sport and business, making this sporting event a celebration of health, companionship and teamwork.



Our team obtained great results and we hope that next year the participation of the Weber Foundation team will increase and we will improve on this year's marks.

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