

# NUESTRO CEREBRO, NUESTRO FUTURO: EL VALOR DE LA INVESTIGACIÓN CEREBRAL -DE LA BÁSICA A LA CLÍNICA- EN LA MEJORA DE LOS PACIENTES EN EUROPA

EN EL MARCO DE LA PRESIDENCIA ESPAÑOLA DEL CONSEJO DE LA UNIÓN EUROPEA

Sala Europa - Palacio del Senado, C. Bailén, 3 | Madrid | España | 28 de noviembre de 2023

## Introducción

En el marco de la presidencia española del Consejo de la Unión Europea, el [European Brain Council](#) (EBC) organiza un evento en el Senado de España el próximo mes de noviembre de 2023.

Entre su lista de prioridades, la agenda de la Presidencia española hace especial hincapié en la mejora de los resultados en materia de salud y en abordar sus retos acuciantes dentro de la Unión Europea, incluyendo la creación de un Espacio Europeo de Datos de Salud (EHDS) para mejorar las políticas sanitarias y la investigación, la prevención de enfermedades, la promoción de la salud y la lucha contra los problemas de salud prevalentes, incluidas las enfermedades mentales.

Tanto en la Unión Europea como fuera de ella, la sociedad se enfrenta a retos relacionados con la salud como nunca. Esto es especialmente notorio en el caso de los trastornos cerebrales, tanto neurológicos como mentales, que están muy extendidos, son incapacitantes y difíciles de tratar. Mejorar la salud y el bienestar de los ciudadanos se ha convertido en la prioridad principal de muchos gobiernos, y la salud cerebral no debe quedarse atrás.

De hecho, se estima que hasta mil millones de personas en todo el mundo viven con una afección neurológica y 970 millones de personas en todo el mundo vivían con un trastorno de salud mental en 2019, siendo los trastornos de ansiedad y depresión los más frecuentes. Sólo en Europa, aproximadamente el 60% de la población vive con una afección neurológica y uno de cada seis ciudadanos está afectado por un trastorno mental.

Sin embargo, aunque en el último medio siglo el campo de la neurociencia y nuestro conocimiento del cerebro han avanzado considerablemente, muchos aspectos importantes siguen siendo extremadamente elusivos. Evidentemente, sin un aumento sustancial de los esfuerzos y recursos destinados a promover la comprensión fundamental de los mecanismos que generan el correcto funcionamiento del cerebro, será imposible diseñar tratamientos que aborden la verdadera pandemia de la salud cerebral, que afecta actualmente a una parte sustancial de la población mundial. Además, Europa no puede ignorar que este campo de investigación tiene un inmenso atractivo para un número creciente de mentes jóvenes, ya que el cerebro es una de las últimas fronteras inexploradas.

Ha llegado el momento de actuar y las prioridades de la Presidencia Española son un primer paso concreto hacia una mayor concienciación y acción. Europa debe ocupar una posición central en el esfuerzo mundial por desentrañar los misterios del cerebro, tanto mediante el fomento de la investigación científica fundamental como de la aplicación práctica y clínicamente beneficiosa de los conocimientos que genera este conocimiento. Potenciar la colaboración en este ámbito puede acelerar el camino hacia una mejor comprensión del cerebro a través de la investigación básica, la innovación en la investigación clínica y los métodos de tratamiento, en definitiva en la obtención de resultados eficaces en beneficio de las personas que viven con enfermedades cerebrales o están afectadas por ellas.

Este acto demostrará lo importante que es establecer prioridades. Se analizarán elementos cruciales de la compleja cadena que va desde la neurociencia básica hasta la mejora de los resultados en los

pacientes. La investigación en este ámbito sigue siendo crucial, pero carece de financiación suficiente y a menudo se malinterpreta y descuida, lo que tiene enorme repercusión en la vida de los pacientes. Con una mayor priorización de la investigación sobre el cerebro en Europa, tenemos la oportunidad de fomentar un enfoque personalizado a la hora de desarrollar opciones terapéuticas innovadoras y aprovechar mejor los resultados relevantes para el paciente.

## Programa

Este acto trata de reunir a expertos de renombre, científicos destacados, defensores de los pacientes, representantes de la industria y responsables políticos. Se desarrollará a lo largo de una mañana y se dividirá en cuatro sesiones, cada una de las cuales abordará aspectos clave de la investigación sobre el cerebro y la salud cerebral y su futuro.

|             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|-------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 9:30-9:45   | <b>Apertura</b> <ul style="list-style-type: none"> <li>• <b>Prof. Carlos Closa</b>, Vicepresidente, Consejo Superior de Investigaciones Científicas</li> <li>• <b>Prof. Suzanne Dickson</b>, Presidenta, European Brain Council</li> <li>• <b>Prof. Juan Lerma</b>, Vicepresidente, European Brain Council</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| 9:45-10:05  | <b>Conferencia: <i>Sobre la complejidad del cerebro</i></b> <ul style="list-style-type: none"> <li>• <b>Prof. Richard Morris</b>, Edinburgh Futures Institute, Ex Presidente de la Federación de Sociedades Europeas de Neurociencia (FENS), Ganador del Brain Prize 2016</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| 10:05-10:45 | <b>Sesión 1: Cuerpo sano, cerebro sano: protegiendo nuestro activo más valioso</b> <p>El cerebro humano es complejo. Como centro de control de nuestro cuerpo, este órgano afecta directamente a todas las funciones, el pensamiento racional, las emociones, los latidos del corazón, la respiración, la ingesta de alimentos y líquidos, el sueño, etc. Un cerebro sano es el principal requisito para tener calidad de vida adecuada y un bienestar sostenible. Permite a las personas prosperar, vivir con felicidad, impulsar nuestras economías y construir un mundo para las generaciones futuras. Dar prioridad y apoyar el avance de la salud cerebral y la investigación sobre el cerebro debe considerarse una inversión en prevención, bienestar y optimización, y en la creación de un futuro mejor para todos los ciudadanos del mundo. Reconociendo la importancia de la perspectiva del paciente en el tema de la salud cerebral, comenzamos este evento escuchando la voz de personas que han vivido con una enfermedad mental o neurológica, aportando una visión extraída de su experiencia vivida.</p> <ul style="list-style-type: none"> <li>• <b>Rosa Montero</b>, Novelista</li> <li>• <b>Asier de la Iglesia</b>, Jugador profesional de baloncesto</li> <li>• <b>Dr. Usman Khan</b>, Presidente, Asociación de Enfermedades Motoras Neuronales (MND)</li> <li>• <b>Tineke Mollema</b>, Miembro de la Junta Directiva, GAMIAN-Europe</li> </ul> |
| 10:45-11:10 | <b>Sesión 2: Entender el cerebro: de los genes a los circuitos, el comportamiento y viceversa</b> <p>La segunda parte de este simposio se centrará en los avances científicos en la comprensión del cerebro humano, desde la exploración de los genes hasta la comprensión de los circuitos cerebrales y su influencia en el comportamiento. Apoyando la investigación básica y fomentando la colaboración entre investigadores, podemos esperar grandes avances en la comprensión y el tratamiento de las enfermedades cerebrales, allanando el camino para nuevos tratamientos y una mejor calidad de vida para todos.</p> <ul style="list-style-type: none"> <li>• <b>Genes, circuitos y comportamiento, por el Prof. Juan Lerma</b>, Instituto de Neurociencias CSC-UMH. Vicepresidente, European Brain Council</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |

|             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|-------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|             | <ul style="list-style-type: none"> <li>• <b>Una codificación única de los recuerdos en el cerebro humano</b>, por el <b>Prof. Rodrigo Quian-Quiroga</b>, Programa de Investigación en Neurociencias, Instituto de Investigación Hospital del Mar</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| 11:10-11:20 | <b>Pausa</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| 11:20-11:30 | <p><b>Sesión 3: El reto de atender las necesidades de los pacientes</b></p> <p>Moderada por el <b>Dr. Usman Khan</b>, Presidente, Asociación de Enfermedades Motoras Neuronales (MND)</p> <p>La tercera parte de la conferencia estará dedicada a la importancia de tener en cuenta las necesidades de los pacientes en la investigación de las enfermedades cerebrales. Para ello, es fundamental poner de relieve los retos a los que se enfrentan los pacientes, ya sea en términos de acceso a la atención sanitaria, estigmatización o búsqueda de soluciones adaptadas a sus necesidades específicas. Al situar a los pacientes en el centro de los debates, contribuimos a crear una sociedad más inclusiva y justa para todos.</p> <p><b>Conferencia: Medicina Personalizada y de Precisión en pacientes con Trastornos del Espectro Autista (cuidados e investigación)</b>, <b>Dra. Mara Parellada</b>, Coordinadora, Programa AMITEA</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| 11:30-11:40 | <p><b>Conferencia: Desarrollos tecnológicos para trastornos neurológicos graves - Enfoque en las enfermedades neurodegenerativas</b>, <b>Prof. José Obeso</b>, Director, Centro Integral de Neurociencias AC (CINAC)</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| 11:40-12:20 | <p>Mesa redonda con:</p> <ul style="list-style-type: none"> <li>• <b>Dra. Mara Parellada</b>, Coordinadora, Programa AMITEA</li> <li>• <b>Prof. Giancarlo Comi</b>, Presidente, Fundación Europea Charcot</li> <li>• <b>Dra. Paola Zaratín</b>, SSC Co-Chair, PROMS Initiative</li> <li>• <b>Stéphanie Hoffmann-Gendebien</b>, Directora General, Amylyx Pharmaceuticals EMEA</li> <li>• <b>Prof. José Obeso</b>, Director, Centro Integral de Neurociencias AC (CINAC)</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| 12:20-13:00 | <p><b>Sesión 4: Abordar los retos a nivel de la UE</b></p> <p>Moderada por <b>Frédéric Destrebecq</b>, Director Ejecutivo, European Brain Council</p> <p>La última parte de este simposio abordará la necesidad de una actuación política a escala de la Unión Europea para hacer frente a los retos relacionados con el cerebro. Un plan de acción de la UE sobre el cerebro coordinaría los esfuerzos en investigación básica y clínica, compartiría las mejores prácticas y movilizaría recursos para apoyar la investigación, mejorar la atención a la salud cerebral y promover la educación y la concienciación pública. Al apoyar esta iniciativa, el EBC y sus socios pretenden liderar la promoción de políticas innovadoras y programas eficaces para mejorar la salud cerebral en toda Europa.</p> <p>Mesa redonda con:</p> <ul style="list-style-type: none"> <li>• <b>Prof. Suzanne Dickson</b>, Presidenta, European Brain Council</li> <li>• <b>Dra. Mara Dierssen</b>, Presidenta, Consejo Español del Cerebro</li> <li>• <b>Dr. José Luis Lanciego</b>, Presidente, Comité Paneuropeo de la Organización Internacional para la Investigación del Cerebro (PERC-IBRO)</li> <li>• <b>Cristina Maragall</b>, Presidenta, Fundación Pasqual Maragall</li> <li>• <b>Dr. Francisco Colomer Sanmartín</b>, Dirección General de Planificación de la Investigación, Ministerio español de Ciencia e Innovación</li> </ul> |

|             |                                                                                                                                                                                                                                                                                                                               |
|-------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 13:00-13:15 | <b>Preguntas y respuestas del público</b>                                                                                                                                                                                                                                                                                     |
| 13:15-13:30 | <b>Palabras de clausura</b> <ul style="list-style-type: none"> <li>• <b>Excmo. Sr. D. Francisco Manuel Fajardo</b>, Secretario Cuarto de la Mesa del Senado</li> <li>• <b>Prof. Suzanne Dickson</b>, Presidenta, European Brain Council</li> <li>• <b>Prof. Juan Lerma</b>, Vicepresidente, European Brain Council</li> </ul> |

Traducción simultánea Inglés-Español disponible.

## Organizadores



El [Consejo Europeo del Cerebro \(European Brain Council \(EBC\)\)](#) es una organización sin ánimo de lucro con sede en Bruselas que engloba a sociedades científicas, organizaciones de pacientes, sociedades profesionales y socios industriales. Su misión principal es promover la salud cerebral y la investigación con el objetivo último de mejorar la vida de los 179 millones de europeos que se calcula que padecen enfermedades cerebrales.

Con el objetivo de hablar con una sola voz, EBC se erige como la plataforma para fomentar la cooperación entre sus organizaciones miembros y otras partes interesadas, promoviendo constantemente el diálogo entre los científicos, la industria y la sociedad.

Como red de actores clave en el "área del cerebro" en Europa, EBC está configurada de manera única para ser la organización a la que acudir para reforzar los lazos dentro de la comunidad más amplia a nivel europeo y mundial.

### Miembros del EBC:



Other Members/Partners include: [Industry](#) | [Associate](#) | [Observers National Brain Council](#)

## Co-Organizadores



Consejo  
Español  
del Cerebro

El [Consejo Superior de Investigaciones Científicas](#) (CSIC) es el mayor organismo público de investigación de España y uno de los más importantes del Espacio Europeo de Investigación (EEI), así como el principal agente del Sistema Español de Ciencia, Tecnología e Innovación (SECTI).

En la actualidad, el CSIC está formado por más de 13.200 personas, repartidas entre la Organización Corporativa del CSIC y los 121 institutos de investigación y tres centros nacionales, distribuidos por toda España, incluido un instituto en Roma. La actividad investigadora del CSIC se encuadra en tres áreas fundamentales, Sociedad, Vida y Materia, que abarcan la gran mayoría de las disciplinas académicas. El CSIC está representado en la UE por la Delegación del CSIC en Bruselas.

El [Consejo Español del Cerebro](#) es una Federación de Asociaciones cuyos objetivos son mejorar la calidad de vida de las personas que padecen enfermedades cerebrales, promover la Investigación clínica para combatir las enfermedades cerebrales y sus consecuencias, fomentar un mejor conocimiento de las enfermedades cerebrales en la sociedad española a través de la formación, facilitar información y promover acciones formativas e informativas contra las barreras físicas y sociales que sufren las personas que padecen alguna enfermedad del cerebro



SENADO

*Este acto, organizado en el Senado de España, forma parte del calendario oficial de reuniones de la Presidencia Española del Consejo de la Unión Europea.*

**GOLD**



**SILVER**



**BRONZE**

INSIGHTEC

pasqual  
maragall  
foundation

*Gracias a quienes nos apoyan*

# Speakers



**Prof. Suzanne Dickson**

**President, European Brain Council**

Professor Suzanne L Dickson is a neurobiologist and Professor of Neuroendocrinology at the University of Gothenburg. She graduated with a Ph.D. in Neuroendocrinology from the University of Cambridge in 1993, where she later became Senior Lecturer in Physiology. She is a leading figure in neuroendocrinology and works within many European Union and international organisations and societies to promote research, facilitate grant funding and training of Early Career Scientists. Her research into the neurobiology of appetite aims to unravel neurobiological pathways that respond to orexigenic signals, such as the hormone, ghrelin, and that drive feeding behaviours, not only food intake but also food choice, food anticipation, food reward and food motivation. This work involves mostly preclinical studies and includes behavioural tasks, viral vector mapping, chemogenetics and RNAscope. She is Secretary and Executive Board member of the European College for Neuropsychopharmacology, and also chairs ECNP's Workshop for Early Career Scientists in Europe. She also is founder and co-chair of ECNP's nutrition network and EBRA's BRAINFOOD cluster.



**Prof. Juan Lerma**

**Vice-President, European Brain Council**

Prof. Juan Lerma is a Professor at the Spanish National Research Council (CSIC). His research is related to the molecular basis of neuronal communication, specifically the mechanisms used by glutamate and its receptors in synaptic transmission and plasticity to orchestrate fundamental physiological activities and trigger brain diseases when they are deregulated. He has been Director of the Institute of Neurosciences CSIC-UMH; President of the Spanish Society of Neuroscience (SENC); President of the Pan-European Regional Committee of the International Brain Research Organisation (IBRO). Currently he is Editor-in-Chief of Neuroscience, Director of the Cajal International Neuroscience Centre (CINC-CSIC), Vicepresident of the European Brain Council and Councillor of the Society for Neuroscience (USA).



SENADO



# Speakers



**Frédéric Destrebecq**

**Executive Director, European Brain Council**

Frédéric Destrebecq is the Executive Director of the European Brain Council since October 2014. In this capacity, he is responsible for providing strategic direction and leadership while managing the day to day operations of EBC and its ongoing relationships with its member associations and other stakeholders, as well as representing the organisation in various European and national forums.

Fred holds a Master Degree in Political Science and International Relations from the Université Catholique de Louvain (Belgium). He also studied at the Institut d'Etudes Politiques (Paris) and University of Wales College (Cardiff), in the framework of the former EU Socrates exchange programme. Prior to EBC, Fred served the European Union of Medical Specialists (UEMS) as Chief Executive Officer, and previously as Director for European Affairs.



**Prof. Richard Morris**

**Federation of European Neuroscience Societies (FENS) Past President, Brain Prize Winner 2016**

Richard Morris is Professor of Neuroscience at the University of Edinburgh in Scotland and the Caro Almela Catedrático at the Instituto de Neurociencias in Alicante. He studied Natural Sciences at the University of Cambridge and did his D.Phil at the University of Sussex. His early career included a period helping to build an exhibition at the Natural History Museum and working for BBC Television, both in London, before taking up a Lectureship in Scotland. He remains active in university teaching, with his longstanding research interest being the neurobiology of cognition, particularly the role synaptic plasticity in memory formation, and how disorders in plasticity contribute to neurological disease. Beyond the lab, he set up Edinburgh Neuroscience in 2005 jointly with the clinical neurologist Charles Warlow which they directed together for its first 5 years, now one of the largest groups of neuroscientists in the United Kingdom. Outside Edinburgh, he served, by secondment, as Head of Neuroscience and Mental Health at the Wellcome Trust from 2007 to 2010, where he helped to set up the new Sainsbury-Wellcome Centre for Neural Circuits and Behaviour at UCL and the research charity MQ:Transforming Mental Health. He was a co-recipient with two prominent physiologists, Tim Bliss and Graham Collingridge, of the The Brain Prize (Lundbeck Foundation, Copenhagen), sometimes considered the "noble Prize" in neuroscience. He is an elected Fellow of the Royal Society in 1997, the Academy of Medical Sciences (1999), the Norwegian Academy of Science and Letters (2007) and of the National Academy of Sciences (USA, 2020). He was appointed a Commander of the British Empire (CBE) by the Queen in 2007. He lives in Chinchilla de Montearagón in Castilla-La-Mancha.



SENADO



# Speakers



**Rosa Montero**

**Novelist**

Rosa Montero was born in Madrid (Spain).

She holds a degree in Journalism from the Official School of Journalism in Madrid, and she studied psychology at the Complutense University of Madrid.

She has worked as a journalist since 1970 in television, newspapers, and magazines. Since 1977 she has worked in exclusivity for El País, Spain's best-selling newspaper. She has served as special correspondent for El País in various countries (India, Australia, USA, Latin America, etc.) and as editor-in-chief of the Sunday Magazine of El País from 1981 to 1982. Currently her journalism appears regularly in El País and in several major Latin American newspapers and magazines.

She published her first novel, *La crónica del desamor*, in 1979. Since then, she has published 16 novels, two collections of biographies, three interview compilations, one short story collection, and several books for children. Her books have been translated into more than twenty languages. Her most recent novels are *El peligro de estar cuerda* (2022) and *La desconocida*, a short novel written with Olivier Truc (2023).

Some of the many awards she has won for her writing are:

- National Prize for Journalism, 1980
- Primavera Prize for best novel for *La Hija del Canibal*, 1997
- Qué Leer Prize for best book of the year for *La loca de la casa*, 2003
- Grinzane Cavour Prize for best foreign book published in Italy for *La loca de la casa*, 2004
- Qué Leer Prize for best book of the year for *Historia del rey transparente*, 2006
- Cognac European Literature Festival Readers' Prize (France) for *Instrucciones para salvar el mundo*, 2011
- Madrid Critics' Prize for *La ridícula idea de no volver a verte*, 2014

She has been a visiting professor in the United States at both Wellesley College (Boston), and the University of Virginia. She has participated in hundreds of symposiums and conferences all over the world. She has received an Honorary Doctorate from the University of Puerto Rico.

In 2017, she was awarded the prestigious National Prize for Spanish Literature for career achievement.

In 2018, she was appointed Honorary Professor of Humanities at the Pontifical Catholic University of Peru, and she is an Honorary Member of the University of Málaga.

In 2019, a lecture hall was named in her honor in the School of Journalism at the Miguel Hernandez University of Elche (Alicante, Spain).

(Translation by Lisa Sagrati)



# Speakers



**Asier de la Iglesia**

**Professional Basketball Player**

I was born in 1983 in Zumárraga, Guipúzcoa. Surrounded by green mountains.

From the first time I picked up a basketball I felt that it would accompany me all my life. So, from being a game, at the age of 19 it became my profession. The cities I lived in, the bond that is created with a team, the frustrations and the achievements... From my youth I keep the best experiences and memories that this passion has given me.

The day I was diagnosed with Multiple Sclerosis, all the opportunities I had taken for granted I would have gradually faded away. Teams didn't want to sign me, they put more and more obstacles in my way to continue doing what I loved so much. The only one who had no barriers for me was myself. Despite having to leave the professional league, I decided to continue with what made me so happy and to prove to myself how far I could go. No fears. No limits.

Multiple sclerosis is a neurological, degenerative and incurable disease. This definition, which may seem devastating to many, gave me a mission in life. I felt that in my heart and in my hands was the need to improve the situation of people who, like me, had the same disease. I started selling solidarity bracelets with the phrase that helped me to face each day with a smile: "Don't wait for the storm to pass, learn to dance in the rain".

They quickly began to sell. It was the springboard to start dreaming big. Charity matches, conferences, charity events... I then decided to found the association Baila con EM, with which we have proudly and gratefully donated more than 100,000 euros to research in 2020. My dream is to make the number grow, and maybe one day, reach one million to continue sowing hope.

Today, I pick up a ball and I feel alive. Being able to continue helping makes me feel good. Having new illusions makes me smile.

That's what I think life is all about, remembering every day the wonderful reasons I have to be happy.



# Speakers



**Dr. Usman Khan**

**Chair, Motor Neurone Disease (MND) Association**

Usman is a health policy and management professional with more than 25 years experience. In the last decade he has held senior leadership roles in the UK and abroad including that as Executive Director of the European Health Management Association and the European Patients Forum. He is currently a Senior Advisor at the Good Governance Institute, a UK based consultancy and at FIPRA International, a Brussels based European public affairs consultancy. Usman holds three non-executive positions being the Chair of the Motor Neurone Disease Association, an Independent Governor at London Metropolitan University, and an NHS Independent Non-Executive Director at North Central London Integrated Care Board. Usman is also Visiting Professor in Health Management and Policy at KU Leuven, Belgium and teaches at New York University (London). He is a regular public speaker and writer on health policy matters and author most recently of Health Management 2.0 (Emerald Publishing).



**Tineke Mollema**

**Board Member, GAMIAN-Europe**

Tineke Mollema has been the coordinator of plusminus young since March 2017. She combines direct contact with fellow sufferers with contributions to national policy via the MIND Young platform. The ideal way for Tineke to work on a better future for young people with bipolar disorder. Through a recording, she became active in her own recovery process and decided to be open about her disorder and make the transition from politics to plusminus. Early detection and the prevention of stigmatization are important reasons for Tineke to actively engage young people with bipolar disorder.



SENADO



# Speakers



**Prof. Rodrigo Quian Quiroga**

**ICREA Research Professor , Hospital del Mar Research Institute**

Rodrigo Quian Quiroga is an ICREA Research Professor working at the Hospital del Mar Research Institute in Barcelona. He studied Physics at University of Buenos Aires and did a PhD in Applied Mathematics at the University of Luebeck, Germany. Before joining ICREA he was the director of the Centre for Systems Neuroscience and the Head of Bioengineering at the University of Leicester, UK. He has published more than 120 papers and 5 books (Borges and memory, The forgetting machine, Neurocience Fiction, Imaging brain function with EEG, and Principles of neural coding). He is a fellow of the UK Academy of Medical Sciences and was selected as one of the 10 UK leaders in Science and Engineering by the Royal Academy of Engineering and the Engineering and Physics Research Council.



**Dr. Mara Parellada**

**Coordinator, AMITEA Programme**

Psychiatrist. University Specialist in Child and Adolescent Psychiatry. Assistant Psychiatrist at the Child and Adolescent Psychiatry Service of the Hospital General Universitario Gregorio Marañón since 2000, she is the coordinator of AMITEA, a programme of comprehensive medical care for ASD for the entire Community of Madrid, initiated as a pilot programme and incorporated into the healthcare services of the Community, a unit declared by the Ministry of Health to be a Good Healthcare Practice Unit. Co-creator of the Dr.Tea website to familiarise patients with ASD with the healthcare environment.

Coordinator of the Regional Unit of Complex Diagnosis of ASD, in the Hospital GU Gregorio Marañón. Coordinator of the autism line of the Mental Health Strategy of the Ministry of Health and the Mental Health Plan of the Community of Madrid. She has been a trainer in ADOS-2 since 2013, and holds the position of Full Professor in the Department of Psychiatry at the Complutense University of Madrid and a visiting associate professorship at the University of California in San Francisco, USA.

A member of CIBERSAM, Centro de Investigaciones Nacionales en Salud Mental, through the Department of Child and Adolescent Psychiatry, Instituto de Investigación Sanitaria Gregorio Marañón, at HGUGM, for the past 18 years she has been leader of the group's autism research line to study the biological basis of autism spectrum disorders.

She has published over 250 articles in peer-reviewed journals and is principal investigator of several national and European public and privately funded grants studying the biological basis of autism and the overlap between autism and early onset schizophrenia.



SENADO



# Speakers



**Prof. Giancarlo Comi**

**President, European Charcot Foundation**

Giancarlo Comi, chairman of "Human Brains" scientific committee, is honorary professor of neurology at the Università Vita Salute San Raffaele and founder and director of the Institute of Experimental Neurology at the Scientific Institute San Raffaele, Milan, Italy. He is the President of the European Charcot Foundation (ECF), and since 2013 has served as vice chair of the Progressive Multiple Sclerosis Alliance and co-chair of the Industry Forum, global alliance of pharmaceutical and biotechnology companies focused on the field of multiple sclerosis. He has been holding the office of president of the European Neurology Society, of the Italian Society of Neurology and of the Italian Society of Clinical Neurophysiology. He is fellow of the European Academy of Neurology (EAN).

In recent years, Professor Comi has received the 'Gh. Marinescu' honorary award from the Romanian Society of Neurology, and has been awarded honorary memberships of the Russian Neurological Academic Society, the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS), the European Neurological Society (ENS), the Sociedad Espanola de Neurologia, the Société Française de Neurologie. He also received in 2015 the Charcot Award for MS Research from the MS International Federation (MSIF). In the past year Professor Comi was awarded the Gold Medal of 'Benemeranza Civica' from the City of Milan and has been recently conferred the honor of merit as Official by the President of Italy.

He has been principal investigator of many phase II and III multiple sclerosis clinical trials.

Prof. Comi has authored and co-authored more than 1000 articles in peer-reviewed journals, and edited several books, with an h-index of 115. He has been organizer and/or invited speaker for more than 500 conferences, both nationally and internationally. He is co-editor of Neurological Sciences and member of the editorial boards of many international journals.



**Dr. Paola Zaratina**

**SSC Co-Chair, PROMS Initiative**

Paola Zaratina is the Director of Scientific Research for the Italian MS Society and its Foundation. She has over 30 years' of experience working in Neuroscience research acquired in Public, Private and Patients' Organizations, and over 15 years of experience in drug discovery and development. Doctor Zaratina's professional education is on neuronal plasticity mechanisms underlying Multiple Sclerosis and neurodegenerative diseases. As coordinator (2018- 2021) of the EU Responsible Research Innovation H2020 MULTI-ACT project (<https://www.muliact.eu/>), Paola has led the development of a new research governance model and guidelines to engage patients as key stakeholder in multistakeholder research initiatives. Several international and national multistakeholders initiatives are applying the MULTI-ACT model (<https://www.muliact.eu/partnerships/>). Paola is the co-chair of the global Patient Reported Outcomes Initiative for Multiple Sclerosis (PROMS; <https://proms-initiative.org/>). Paola is author of more than 80 publications (1987-2023).



SENADO



# Speakers



**Stephanie Hoffmann-Gendebien**

**Head & General Manager, Amylyx Pharmaceuticals EMEA**

Stéphanie Hoffmann-Gendebien has extensive biopharma experience in developing and introducing medicines for progressive neurological diseases and other rare diseases in Europe. She has a deep understanding of the inter-connected relationships between passionate patient and medical communities, and with other stakeholders creating policy around diagnosis, support and care, and considering treatments for regulatory authorization and reimbursement. She combines this with emotional engagement and pragmatic strategies to drive positive change around healthcare, informed by an MBA and background in biochemistry. Stéphanie has held leadership roles in multiple organizations, including Genzyme and Alexion, provided consulting services around rare diseases and orphan drug development, and successfully introduced two orphan drugs in Europe. She joined Amylyx in 2021 to establish the company's first presence outside North America, as Head and General Manager for EMEA – the third European biopharma team she has built from the ground up during her career of more than 25 years.



**Dr. Mara Dierssen**

**President, Spanish Brain Council**

With a Ph.D. in Neurobiology from the University of Cantabria, she is a research director at the Centre for Genomic Regulation in Barcelona. Her main area of research is inquiring into the neurobiological mechanisms of learning and memory and their alterations in Down syndrome, a field in which she has produced trailblazing internationally recognized research into the genetic bases of intellectual impairment. She discovered impaired structural plasticity and her work was the first to show imbalanced excitatory inhibitory synapses in Down syndrome using electron microscopy. Moreover, her studies in the clinical area have led to new therapeutic avenues for people with Down syndrome.

She has received numerous awards during her career as a researcher, notably the 2008 National Prize for Thought and Science (Generalitat (Government) of Catalonia), and the "Jaime Blanco" "Jerome Lejeune" and "Ramon Trias" awards for her research in Down syndrome. She has published more than 200 peer-reviewed papers with an h index of 51 in Scopus and 63 in Google Scholar. She has also published several books on Down syndrome, and organized courses and scientific meetings, including FENS with 7000 attendants.

She has been president of the Spanish Society of Neuroscience, the International Behavioral and Neural Genetics Society and she is president of the Spanish Brain Council. She was the founder and has been president of the Trisomy 21 Research Society. She is elected member of the Academia Europaea, which brings together leading scientists and university professors from around Europe, and lately of the Royal Academy of Medicine.



SENADO



# Speakers



**Dr. José Luis Lanciego**

**President, Pan-European Committee of the International Brain Research Organization (PERC-IBRO)**

José L. Lanciego's current research focuses on gene therapy approaches for neurodegenerative diseases using non-human primate models. He is the Chair of the International Brain Research Organization Pan-European Committee, a Board Member of the European Brain Council and the International Basal Ganglia Society Council. He has published 132 papers with an h index of 46. In September 2019, he has co-founded Handl Therapeutics B.V. for pushing forward the development of novel therapies for Parkinson's disease.



**Cristina Maragall**

**President, Pasqual Maragall Foundation**

Cristina Maragall has been linked to the Pasqual Maragall Foundation since its establishment in 2008 as a member of the Board of Trustees, then as its spokesperson since 2015, and ultimately as its president since 2020.

She holds a degree in Architecture from the Polytechnic University of Catalonia and a postgraduate degree in Landscape Architecture from the Technical School of Agricultural Engineers of Barcelona. Since 2004 she has operated her architecture studio, having worked on social housing projects and urban landscape projects. She currently balances this activity with a strong commitment to the Pasqual Maragall Foundation, with the aim to change the social perception of Alzheimer's disease to improve the quality of life of affected families and focus efforts on research. Since 2018, she has been co-directing the Brain Film Fest, an international film festival about the brain promoted by the Pasqual Maragall Foundation. Additionally, she holds a position as a board member of the Fundació Catalunya Europa.

The Pasqual Maragall Foundation is a private non-profit organisation that aims to achieve a future without Alzheimer's through research and innovation.



SENADO

