

IN-DEPTH ANALYSIS

Requested by the Environment, Public Health
and Food Safety Committee



Brain: New approach to brain diseases



Policy Department for Economic, Scientific and Quality of Life Policies
Directorate-General for Internal Policies
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Brain: New approach to brain diseases

Workshop Proceedings

Abstract

This report summarises the presentations and discussion of the Workshop on “The Brain – A New Approach to Brain Diseases” held on 21 November, 2018 at the European Parliament.

The purpose of the workshop was to highlight current and new approaches to the treatment of brain diseases, including diagnosis and rehabilitation. The panel of expert speakers addressed both clinical and policy issues and highlighted the need for dialogue and co-operation between scientists, industry and society.

The workshop was hosted by Ms Nessa Childers (MEP) and Mr Alojz Perterle (MEP).

This document was prepared by Policy Department A at the Request of the Environment, Public Health and Food Safety Committee.

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LIST OF ABBREVIATIONS

AFET	Committee on Foreign Affairs
DG	Directorate General
EBC	European Brain Council
EFNA	European Federation of Neurological Associations
ENVI	Committee on Environment, Public health and Food Safety
EU	European Union
FET	Future Emerging Technologies
GDPR	General Data Protection Regulation
JPND	Joint EU Programme – Neurodegenerative Disease Research
MEP	Member of the European Parliament
PET	Positron Emission Tomography
VOT	Value of Treatment

EXECUTIVE SUMMARY

The workshop on “Brain – New Approaches to Brain Disease” was organised by the Policy Department A Economic & Scientific Policy for the Committee on the Environment, Public Health and Food Safety (ENVI) Working Group Health of the European Parliament. It took place on 21 November 2018 at the European Parliament, and was hosted by Ms Soledad Cabezón Ruiz (MEP) and Mr Alojz Peterle (MEP). As Ms Cabezon Ruiz was unable to attend, Ms Nessa Childers (MEP) co-chaired the workshop on her behalf.

The purpose of the workshop was to highlight current and new approaches to the treatment of brain diseases, including diagnosis and rehabilitation. In recent years, the emergence of ground-breaking new technologies has provided hope for further advancement in the handling of these diseases. Expert speakers discussed the current status of and new approaches for the treatment of brain diseases, including recent ground-breaking new technologies that provide hope for earlier diagnosis and more effective treatments

The workshop was organised in two panels. The first panel, chaired by Ms Nessa Childers (MEP), addressed clinical approaches to brain disease, while the second panel chaired by Mr Alojz Peterle (MEP) addressed some of the policy priorities. Question and answer sessions followed each panel.

In the first panel, Professor Timothy Lynch (University College Dublin) discussed the diagnosis and treatment of neurological disorders by presenting a number of case studies. His recommendations included a focus on education on brain health and increased investment in research and innovation to develop new treatments and preventatives. Dr Angela Schulz (Medical Centre Hamburg Eppendorf), examined childhood dementia using a familial case study. She emphasised the importance of early diagnosis and therapies and the need for appropriate support for research into the development of new diagnostic assays and therapies. Professor Hans Lehrach (Max Planck Institute for Molecular Genetics) considered the benefits of model-driven research into brain disease. He outlined the work of the FET Flagship Project Digitwins which uses digital models of patients to test drug development. This approach has resulted in considerable savings in human lives and healthcare costs. The Q&A session addressed issues around diagnosis, genome data and ensuing privacy/GDPR aspects.

In the second panel, Ms Monika di Luca (European Brain Council) outlined the role and work of the EBC. She called for a “big thinking” brain mission focusing on education, patient empowerment and an integrated approach to brain health and research at a scale similar to the investment in space in the 20th century. Ms Joke Jaarsma (EFNA) gave a patient perspective focusing on the “Value of Treatment” (VOT) approach. The objective of VOT is to provide policy recommendations based on current gaps in patient needs and the resulting cost and burden. Ms Jaarsma called for brain research to be included on the strategic research agenda and that prevention and management should be aspects of policy prioritisation, implementation and evaluation. The Q&A session addressed issues of inequality in policy making in terms of both medical conditions (brain disease vs cancer) and geography (eastern Europe vs western Europe); the potential of personalised medicines and the need for greater EU funding for health research to ensure the EU retained its global position. The meeting concluded that Brain Health should be pushed further up the EU policy agenda in terms of priority for research funding and education.

1. POLICY BACKGROUND

There are 165 million Europeans living with a brain disorder, and one in three people will suffer from some neurological or psychiatric disorder during their life. The EU and its Member States have made considerable investments in brain research. The direct and indirect cost to European national health budgets is estimated to be 800 billion euros per year¹.

Many neurological conditions such as stroke, dementias (such as Alzheimer's, which causes up to 70 % of dementia cases) or Parkinson's have an age component, in that the incidence of them increases with age. According to the European Commission's 2018 Ageing Report, the number of people in the EU over the age of 65 will grow to almost 51.2 % per cent by the year 2070². Consequently, the incidence of cerebrovascular disease is set to rise.

The study of the brain is the final, and most important, frontier in medicine and science. The brain is the most complex human organ, and for many years this has hampered the ability to fully understand both it and the pathogenic mechanisms of brain disorders. The first step to reducing the burden of brain disorders in Europe is developing a full understanding of the brain itself. Adopting new approaches to understanding the brain and brain disease is crucial to move this key area of science forward. Supporting neurogenetics, neuroimmunology, disease registries, big data, artificial intelligence in neurology, and neuroimaging will result in new treatments for many common brain disorders such as epilepsy, stroke, headache (including migraine), traumatic brain injury, multiple sclerosis, Parkinson's disease, and dementia (including Alzheimer's disease).

The future of brain health in the EU depends on better education about the brain both during school years and in terms of training for doctors and nurses, thus achieving better diagnoses and therapeutic choices. Much more investment in research and innovation is required to develop new treatments and preventatives, and measures should be implemented to address inequality in education, training and access to treatments between east and west Europe.

Early diagnosis and treatment have a massive positive impact on diseases with known cures but the same benefits could be replicated across many brain diseases given appropriate support for research into the development of new diagnostic assays and therapies.

Investment in research of neurological diseases will not only help increase life-expectancy and reduce suffering but will also result in significant savings for social and care services. A 2015 Deloitte report indicated that health care research accounts for just four per cent of the EUR 1.4 trillion spent on healthcare in the 28 EU Member States³.

Despite encouraging advances in diagnosis and therapy, the complexity of the brain demands a redoubling of the effort to capitalize on scientific results, which requires engagement of the scientific and clinical communities at all levels in an integrated brain mission envisaged at a scale similar to the Space Race. Future EU research priorities need to reflect this.

¹ Di Luca, Monica & Oelsen, Jes, [The Cost of Brain Diseases: A Burden or a Challenge?](#) Neuron, June 2014.

² European Commission, [The 2018 Ageing Report: Economic and Budgetary Projections for the EU Member States \(2016-2070\)](#), 2018.

³ Deloitte, [Investing in European Health R&D, A pathway to sustained innovation and stronger economies](#), 2015.

2. PROCEEDINGS OF THE WORKSHOP

2.1. Workshop Overview

The European Parliament Committee on the Environment, Public Health and Food Safety (ENVI) held the workshop *Brain – new approach to brain diseases* on Wednesday, 21 November, 2018, at the European Parliament, Brussels. The workshop was chaired by Ms Nessa Childers, MEP, and Mr Alojz Peterle, MEP. Representatives from prominent neurological research organizations, clinics and advocacy groups discussed the current status of and new approaches for the treatment of brain diseases, including recent ground-breaking new technologies that provide hope for earlier diagnosis and more effective treatments. The two panels of eminent speakers included prominent researchers and medical experts in the area of brain diseases, as well as the presidents of the European Brain Council (EBC) and the European Federation of Neurological Associations (EFNA).

2.2. First Panel: Clinical Approaches to Tackling Brain Diseases in Europe

Ms Childers, chair of the first session, welcomed the panel and delegates and set the context for the meeting by providing some timely facts about the complexity of the brain and its many disorders. There are 165 million Europeans living with a brain disorder, and it is estimated that one in three people suffer from some neurological and psychiatric disorder during their life. The direct and indirect cost to European national health budgets is 800 billion euros per year, which is five times the EU budget and more than the cost of cancer and cardiovascular disease combined. This will get worse due to the ageing population, given that many brain disorders become more prevalent with age. Ms Childers stressed not only the financial burden of brain diseases but also the far reaching societal effects. Clearly the problem is too large for any one country to address and EU-wide funding and research coordination strategies are needed. The EU has already supported brain research through the Framework Programme and the 1 billion euro Human Brain Project, as well as collaborative neurodegenerative disease research at the JPND. But Ms Childers highlighted the need for a new EU vision in brain research for the future.

2.2.1. Prof. Timothy Lynch: New approaches to brain diseases

The first panel opened with a presentation by Prof. Timothy Lynch, consultant neurologist at the Centre for Brain Health, Dublin Neurological Institute at the Mater Hospital, Vice Principal of Health Affairs and Professor of Neurology at University College Dublin, and Chief Academic Officer at Ireland East Hospital Group, who discussed the diagnosis and treatment of neurological disorders by working through a number of remarkable case studies. Professor Lynch explained the inherent difficulty in the diagnosis and treatment of neurological disorders given the complexity of the nervous system (where is the problem?), the way symptoms are presented (what is the problem and what tests are required?), and the therapeutic options (what treatments are recommended?). He emphasized the benefits of new technologies for the diagnosis and treatment of brain diseases, especially those based on imaging, omics and big data, and also the value of preventative measures (physical and mental exercise, sleep, healthy diet and happiness). His recommendations to the panel were that the future of brain health in the EU could be addressed by better education about the brain both during school years and in terms of training for doctors and nurses, and much better investment in research and innovation to develop new treatments and preventatives.

2.2.2. Dr Angela Schulz: Childhood dementia – understanding the medical challenge

The next presentation was given by Dr Angela Schulz, Functional Senior Physician and Medical Specialist in Paediatrics and Youth Medicine at the Medical Center Hamburg-Eppendorf. The presentation looked at childhood dementia, considering a group of lysosomal storage diseases collectively known as neuronal ceroid lipofuscinosis (NCL). This is the commonest form of childhood dementia and the focus of the EU-supported DEM-CHILD consortium involving 19 countries, 26 centres and more than 500 NCL patients. There are 13 types of NCL, all marked by the clinical hallmarks of dementia, retinopathy and epileptic seizures. Dr Schulz used CLN2 as a case study, describing in detail the associated brain atrophy, clinical scoring, and disease progression. She emphasized the value of early diagnosis based on key symptoms to select candidates for CLN2 disease testing, and in positive candidates the immediate initiation of treatment with cerliponase by direct delivery into the brain. Using a familial case study, she showed the remarkable benefits of this approach, which prevented the onset of symptoms. Early diagnosis and treatment has a massive positive impact in CLN2, and this could be transferred to other diseases given appropriate support for research into the development of new diagnostic assays and therapies.

2.2.3. Prof. Hans Lehrach: Model-driven research in brain diseases

The final presentation in the first panel was by Prof. Hans Lehrach, Max Planck Institute for Molecular Genetics, and considered the benefits of model-driven research into brain diseases. Empirical research focuses on simple diseases where the cause is easy to identify, but most brain diseases are inaccessible to this approach because they involve complex interacting mechanisms that can only be studied effectively using mechanistic models. An example is ModCell™, a generic mechanistic model of cellular signalling transduction, which encompasses 50 signalling pathways and 20,000 chemical reactions to find interactions between 800 genes and 300 drugs. Model-driven research requires fresh brain samples, which can now be acquired by deep brain stimulation or by the development of surrogate tissues known as brain organoids. By combining these methods with large-scale data gathering (genomics, RNA-Seq, imaging mass spectrometry) and targeted modification using tools such as CRISPR/Cas9 to replicate brain defects, dynamic brain networks can be simulated to determine the mechanisms of Parkinson's disease, multiple sclerosis and migraine, among others. This approach can be applied at a population level, for example in the 100,000 virtual brains provided by UK Biobank, in which brain scan data are linked to genome sequences. Extending this concept to medical practice, the FET Flagship Project DigiTwins⁴ uses digital models of patients for drug development and testing to determine the likelihood of patients responding positively before exposing them to potentially dangerous drugs, thus providing a way to avoid the thousands of adverse drug reactions that occur every year. Prof. Lehrach ended the presentation by setting out the savings in human lives and healthcare costs made possible by such model-driven research, and welcoming further discussion to set priorities for health research in the next EU R&D Framework Programme.

2.2.4. First panel questions and answers

Ms Childers thanked the panellists for their interesting and hopeful presentations, and opened the floor for discussion. Prof. Lynch asked whether modelling, brain banks and surrogates such as organoids were sufficient or is biopsy from a patient necessary for effective diagnosis and therapy. Prof. Lehrach noted that deep brain stimulation now provides a means to remove brain cells safely, and induced pluripotent stem cells can also be extracted and used to model childhood dementia, in addition to the

⁴ <https://www.digitwins.org/>

data provided by brain banks and models. Ms Childers asked whether neurological diseases could be diagnosed in the future using simple blood biomarkers. Prof. Lehrach responded that genome sequences provide information about predisposition and this could be combined with the advanced methods described in his presentation to facilitate diagnosis and the development of cures. Prof. Lynch noted that genome data can be a double-edged sword, for example if a patient presents their genome sequence to a physician and demands a diagnosis on that basis. There was general agreement that the availability of personalized data should be handled carefully, taking into account privacy issues, data protection/GDPR, quality of life and insurance aspects. Dr Schulz raised the issue of family planning in the case of inherited neurological diseases, based on her experience of families with multiple affected children.

2.3. Second Panel: Policy Challenges for Treating Brain Disorders

Ms Childers passed the chair to Mr Alojz Peterle for the second session, and he introduced the panellists Prof. Monica Di Luca (EBC) and Dr Joke Jaarsma (EFNA). Before handing over to the first panellist, he drew parallels between the current workshop and his role in the AFET committee dealing with a strategic partnership agreement between the EU and Japan, given that both have ageing populations and thus need to focus on age-related diseases including cancer and neurodegenerative disorders. He also highlighted the role of the regulators in facilitating the development of new diagnostics and therapeutics in both areas.

2.3.1. Prof. Monica Di Luca: Brain research in Europe – our mission for the future

Prof. Di Luca began by describing her role as President of the EBC and its mission to promote and disseminate neuroscience by bringing together the research community with patients and industry in a common dialogue, stimulating innovation and the translation of research into clinical advances. The EU is at the forefront of brain research globally (producing 16 % of all research articles in this topic) and must therefore address the complexity of brain diseases by taking responsibility to improve understanding and develop new tools and methods as well as exploiting opportunities to understand neuropathology and develop therapies that will benefit society. Prof. Di Luca highlighted achievements such as the development of revolutionary imaging techniques for the analysis of dynamic brain activity (e.g., amyloid PET scans in Alzheimer's disease), game-changing new therapies for multiple sclerosis, stroke and Parkinson's disease, the advent of optogenetics for the treatment of brain disorders using light to control cell behaviour, and the treatment of diseases in utero. However, she emphasized that the complexity of the brain demands a redoubling of the effort to capitalize on scientific results, which requires engagement of the scientific and clinical communities at all levels. This requires a big-thinking Brain Mission focusing on education, patient empowerment, and an integrated approach to brain health and research at a scale similar to the Space Race in the 20th century.

2.3.2. Joke Jaarsma: The value of treatment

Finally, Ms Jaarsma offered the perspective of patients in role as president of EFNA, an umbrella of European patient advocacy groups. She focused on the value of treatment (VOT) approach, which considers not only the socioeconomic value of effective treatment but the cost of non-treatment. The objective of VOT is to provide policy recommendations based on current gaps in patient needs and the resulting cost and burden in the context of nine categories of brain disease. Using stroke and restless leg syndrome (RLS) as case studies for well-known and poorly-understood diseases, respectively, Dr Jaarsma identified treatment gaps and considered cost-effective solutions. In the stroke case study, issues included inadequate treatment of atrial fibrillation and the low number of (and access to) stroke units.

In the RLS case study, issues included the poor recognition of the disease leading late or absent diagnosis and treatment, even though RLS is more prevalent than epilepsy, multiple sclerosis and Parkinson's disease put together, making it the second most costly brain disorder after dementia. More education is therefore needed in addition to research into the causes, diagnosis and treatment of RLS. Dr Jaarsma concluded that brain research must be included on the EU strategic research agenda and that prevention and management should be aspects of policy prioritisation, implementation and evaluation.

2.3.3. Second panel questions and answers, and closing remarks

The discussion of the second session raised important issues relating to inequality. Mr Peterle drew parallels between funding and policymaking in the fields of cancer and brain research, and noted that brain research would benefit from the prioritisation currently given to cancer. He also drew attention to the 'iron curtain' between west and east Europe in terms of cancer treatment and the panellists agreed that there was similar inequality in the treatment of brain diseases such as RLS, highlighted by the VOT focus on gaps in patient care. Prof. Lynch highlighted the inequality between west and east in terms of education about brain/mind health and disease and recommended that the west should encourage and provide education about brain/mind disorders, e.g., through organizations such as the Movement Disorder Society via their Visiting Professor and Ambassador Programmes and academic meetings. Prof. Lehrach made a plea for greater prioritisation of personalised medicine, which could save 2–10 trillion euros over 15 years, by targeting therapy more effectively. He also pointed out that health research in general was underfunded in the EU, both in comparison to other research areas such as food and energy, and as a proportion of economic output (0.1 % of GNP is spent on health research in the EU). He made the case for increased funding in research and development, and particularly the need for flagship projects in order for the EU to retain its global position. He noted that "We are all patients of the future." Further discussion focused on the concept of healthy ageing (that is, living longer is pointless if the longer life is beset by disease). Dr Schulz noted that greater collaboration between researchers working on different types of dementia (child and adult forms) could facilitate the development of new treatments, and this theme of commonality was echoed by Prof. Di Luca. Dr Schulz also touched on inequality, specifically the inequality in access to medicines in different EU Member States. Dr Jaarsma made the point that young patients were particularly affected, because they would carry the burden of neurological disease for many decades.

2.3.4. Conclusion by Co-Chairs Nessa Childers (MEP) & Alojz Peterle (MEP)

The meeting closed with general agreement by the chairs and panellists that health should be pushed further up the EU agenda in terms of priority for research funding and education, and that the MEPs would support this recommendation.

Mr Alojz Peterle adjourned the workshop by thanking the panellists and audience for their contributions and participation.

ANNEX 1: PROGRAMME



**Organised by the Policy Department A
Economic and Scientific Policies for the Health Working Group of the Committee
on the Environment, Public Health and Food Safety (ENVI) Working Group Health**

Workshop

Brain: New approach to brain diseases

**Wednesday, 21 November 2018 from 10:00 to 12:00,
Paul Henri Spaak Building, P4B001
European Parliament, Brussels**

Chairs: Ms Nessa CHILDERS (MEP) and Mr Alojz PETERLE (MEP)

The purpose of the workshop is to highlight current status and new approaches to the treatment of brain diseases, including diagnosis and rehabilitation. In recent years, the emergence of ground-breaking new technologies provide hope for further advancement in handling these diseases. The panel of eminent speakers, each of whom is acknowledged as expert in their area, will address some of the major technological breakthroughs and their potential to revolutionise current approaches to brain disease.

AGENDA

10:00 – 10:10 Opening and welcome by the Chairs Nessa CHILDERS (MEP) and Mr Alojz PETERLE (MEP)

Panel 1

Clinical Approaches to Tackling Brain Diseases in Europe

10:10 – 10:20 Neurological Disorders: Diagnosis and Treatment

Presentation by Prof. Timothy LYNCH, MB, BSc., DCH, FRCPI, FRCP, ABPN

Consultant Neurologist at the Mater Misericordiae University Hospital and Clinical Director of the Dublin Neurological Institute at the Mater Misericordiae University Hospital.

The presentation will focus on diagnosis of brain disorders including stroke, dementia, Parkinson's, epilepsy and explore new developments in treatments

10:20 – 10:30 Childhood Dementia

Presentation by Dr Angela SCHULZ

Functional Senior Physician and Medical Specialist in Paediatrics and Youth Medicine at the Medical Center Hamburg-Eppendorf (UKE).

The presentation will cover childhood dementia.

10:30 – 10:40 New Approaches to Treating Brain Disorders

Presentation by Prof. Hans LEHRACH

Max Planck Institute for Molecular Genetics, Berlin Institute for Health, Charité, Alacris Theranostics

The presentation will cover new approaches to prevention of and therapy for brain diseases

10:40 – 11:00 Questions & Answers Session

Panel 2

Policy Challenges for Treating Brain Disorders

11:00 – 11:10 Brain Research in Europe – Issues for Policy Makers

Prof. Monica DI LUCA

President, European Brain Council (EBC)

The presentation will focus on the promotion of brain research at European Level in order to improve the quality of life for people living with brain disorders across Europe. It will address the policy and regulation challenges

11:00 – 11:20 Policy Recommendations for Stroke Care

Presentation by Joke JAARSMA

President of the European Federation of Neurological Associations

The presentation will focus on improving the quality of stroke care, addressing treatment gaps, cost-effectiveness and policy recommendations for improving the burden.

11:20 – 11:50 Questions & Answers Session

Closing Session

11:50 – 12:00 Closing remarks by the Chairs Ms Nessa CHILDERS (MEP) and Mr Alojz PETERLE (MEP)

ANNEX 2: SHORT BIOGRAPHIES OF EXPERTS

Prof. Monica DI LUCA, European Brain Council (EBC)



Monica Di Luca, EBC President, is Professor of Pharmacology, Director of NeuroNest (Center of Neuroscience) and Head of Laboratory of Pharmacology of Neurodegeneration – DiSFeB at the University of Milano. Her primary research interest is related to synaptic plasticity in physiological and pathological conditions, with the primary aim to apply basic findings to the cure of neurodegenerative diseases such as Alzheimer’s and Parkinson’s Disease. She has been member of Council of several national and international scientific organizations including Federation of European Neuroscience Societies (FENS, President 2014-2016), the International Brain Research Organization (IBRO), EMBO and the European Dana Alliance for the Brain (EDAB).

Prof. Timothy LYNCH, MB, BSc., DCH, FRCPI, FRCP, ABPN, University College Dublin



Tim Lynch is a Consultant Neurologist at the Mater Misericordiae University Hospital and Clinical Director of the Dublin Neurological Institute at the Mater Misericordiae University Hospital; National Lead HSE Neurology Programme and Chief Academic Officer IEHG and Vice Principal Health Affairs UCD. Prof. Lynch is a medical graduate from Royal College of Surgeons Ireland from 1984. He subsequently did a BSc Pharmacology UCD and trained at the Richmond Hospital, Beaumont Hospital, Mater Misericordiae University Hospital and Our Lady’s Hospital for Sick Children, Crumlin. He moved to Columbia University in New York for a residency in neurology followed by a Fellowship in Movement Disorders with Prof. Stanley Fahn and did a Fellowship in Neurogenetics. Prof. Lynch was involved in genetic research of frontotemporal dementia and parkinsonism linked to chromosome 17 (Wilhelmsen-Lynch disease) and part of the team that cloned the tau gene (Nature 1998). Prof. Lynch was appointed a Consultant Neurologist at the Mater Misericordiae University Hospital in 1998; Adjunct Professor of Neurology, University College Dublin in 2006; Clinical Director of The Dublin Neurological Institute at the Mater (www.neurologicalinstitute.ie) in 2008 and recently Chief Academic Officer IEHG and Vice Principal Health Affairs UCD. Prof. Lynch has served as Chairperson, Division of Medicine; Dean of Postgraduate Education and Chairperson Medical Council at the Mater Hospital. He has published over three hundred research articles in peer-reviewed journals on a number of areas in clinical neuroscience including movement disorders, neurodegeneration, Parkinsonism, frontotemporal dementia linked to chromosome 17, the genetics of neurological disorders and CNS Whipple’s disease (H index 52). Successful grants include HRB, NIH and MJIFF.

Dr Angela SCHULZ



Dr Angela Schulz is the Functional Senior Physician and Medical Specialist in Paediatrics and Youth Medicine at the Medical Center Hamburg-Eppendorf (UKE). Her areas of expertise include neuropediatric and palliative medicine. She is a member of [Gesellschaft für Neuropädiatrie](#); European Paediatric Neurology Society; Arbeitsgemeinschaft für pädiatrische Stoffwechselstörungen; and the European Study Group on Lysosomal Diseases.

She was awarded the Science Award of the Society for Neuropaediatrics in 2005. Her publications in 2018 include:

- *Disease characteristics and progression in patients with late-infantile neuronal ceroid lipofuscinosis type 2 (CLN2) disease: an observational cohort study;*
- *Autophagic vacuolar myopathy is a common feature in CLN3 disease;*
- *Study of Intraventricular Cerliponase Alfa for CLN2 Disease;*
- *Neurodegenerative Erkrankungen des Kindesalters;*
- *An Adapted Clinical Measurement Tool for the Key Symptoms of CLN2 Disease*

Joke JAARSMA, President of the European Federation of Neurological Associations



The European Federation of Neurological Associations (EFNA) brings together European umbrella organisations of neurological patient advocacy groups, to work with other associations in the field of neurology, including the European Academy of Neurology (EAN), in what has been termed a “Partnership for Progress”.

In her working life, Joke Jaarsma was senior publisher at one of the major science publishers. She joined the Dutch Restless Legs Syndrome (RLS) patient association in 1999, and she is still active as Vice President of the Dutch group.

Having finished full-time paid employment, she decided to spend her retirement in helping give neurology patients a strong and collective voice.

Prof. Hans Lehrach, Max Planck Institute for Molecular Genetics



Hans Lehrach studied Chemistry at the University of Vienna and obtained his Ph.D. at the Max Planck Institute for Experimental Medicine and the Max Planck Institute for Biophysical Chemistry in 1974. As postdoctoral fellow at Harvard University, Cambridge (1974-1978) his research focused on RNA analysis and he carried out one of the first cDNA cloning experiments. As group leader at the EMBL, Heidelberg (1978-1987), he was among the first who initiated positional cloning experiments in mouse (Brachyury) and man (Huntington’s disease, Cystic Fibrosis etc.), he also contributed to the development of widely used research tools (e.g., the EMBL vector system together with Noreen Murray) and was one of the first who initiated the human genome project. Following this, he moved to the Imperial Cancer Research Fund, London (1987-1994) as head of Genome Analysis Department, focusing on the development of new structural and functional genome analysis technologies (e.g., development of the first array robotics in 1987). In 1994, he returned to Germany and since then he has been Director and Scientific Member at the Max Planck Institute for Molecular Genetics, with a focus on genetics, genomics and systems biology.

During the last decade, a major focus of his work has been the development of a new, truly personalised medicine on the basis of ‘virtual patient’ models, based on a deep –omics analysis of the patient. He has received several awards such as the Ján Jessenius SAS Medal of Honour for outstanding achievements in medical sciences of the Slovak Academy of Sciences (2003) and the Karl Heinz Beckurts Award for achievements in genome research (2004).

This report summarises the presentations and discussion of the Workshop on “The Brain – A New Approach to Brain Diseases” held on 21 November, 2018 at the European Parliament.

The purpose of the workshop was to highlight current and new approaches to the treatment of brain diseases, including diagnosis and rehabilitation. The panel of expert speakers addressed both clinical and policy issues and highlighted the need for dialogue and co-operation between scientists, industry and society.

The workshop was hosted by Ms Nessa Childers (MEP) and Mr Alojz Perterle (MEP).

This document was prepared by Policy Department A at the Request of the Environment, Public Health and Food Safety Committee.
