VOL. 41 · NO.4 · AUGUST 2026

WORLD FEDERATION OF NEUROLOGY

WORLD NEUROLOGY

THE OFFICIAL NEWSLETTER OF THE WORLD FEDERATION OF NEUROLOGY

INTERNATIONAL CONGRESS ON NEUROMUSCULAR DISEASES 2026

Scientific Sessions and Teaching Courses Highlight Neuromuscular Disease Congress

More than 2,400 attendees turned out for the 19th annual event in Florence, Italy.

BY MARIANNE DE VISSER, WOLFGANG GRISOLD, AND STEVEN L. LEWIS

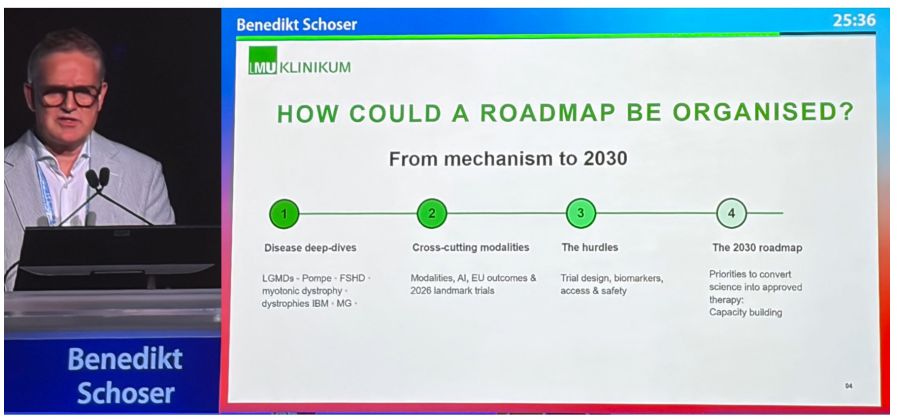
The World Federation of Neurology (WFN) Specialty Group on Neuromuscular Diseases held a successful International Congress on Neuromuscular Diseases (ICNMD) July 7-11, in Florence, Italy. The congress was hosted by Prof. Antonio Toscano and was supported by many Italian contributors.

The event started with an inspiring Patient's Day (See Patient Advocacy, Education, and Training, Page 5), followed by teaching courses, including standing-room-only hands-on sessions, and a rich scientific program with plenaries, scientific lectures, free topics, and posters. In addition, the industry symposia, supported by pharmaceutical companies, provided excellent speakers and programs.

The meeting of delegates was well organized. Fortezza da Basso, located within the 14th century walls of Florence, provided an excellent meeting site and offered space for breaks and interactions while enjoying delicious Italian ice cream.

Social meetings, such as the opening event, featured the attendance of a representative of the city of Florence and an address from a patient representative.

see **NEUROMUSCULAR** *page 4*



Prof. Benedikt Schoser outlines a roadmap for converting science into approved therapy during his presentation.

ICNMD CONGRESS: BY THE NUMBERS

The ICNMD Congress was attended by **2,464 people** from **77 countries**.
420 presenters delivered **252** presentations.
296 posters were displayed, and **519** abstracts were received.

This was the largest ICNMD. We thank the Italian hosts and the numerous committees that worked continuously on the program. The important technical congress organization was provided by ICS.

PRESIDENT'S COLUMN

WFN Activities Put a Spotlight on Brain Health

The WFN participated in ICNMD 2026, United Nations ECOSOC, WHO African Regional Committee, World Brain Day 2026, and IGAP implementation training.

BY STEVEN L. LEWIS, MD

STEVEN L. LEWIS, MD

Welcome to the August 2026 issue of *World Neurology*, the official newsletter of the World Federation of Neurology (WFN). The WFN has been busy since our last issue representing neurologists and brain health on multiple fronts. Here are some of the highlights:

The International Congress on Neuromuscular Diseases

The 19th International Congress on Neuromuscular Diseases (ICNMD 2026), the now-annual congress from the same-named WFN Specialty Group, took place July 7-11, at the Fortezza da Basso Congress Centre in Florence, Italy. The congress featured state-of-the-art science and clinical updates on diseases related to all aspects of the peripheral nervous system, from anterior horn cell to nerve root, peripheral nerve, neuromuscular junction, and muscle.

The WFN wishes to thank Prof. Antonio Toscano, congress chair, Prof. P. James B. Dyck, ICNMD chair, Prof. Wolfgang Grisold, WFN past president, along with other members of the ICNMD Congress Committee and expert faculty for their remarkable work creating this wonderful congress. See the three articles in this issue

see **PRESIDENT'S COLUMN** *page 2*

INSIDE

PATIENT ADVOCACY, EDUCATION, AND TRAINING
PAGE 5

WORKING TOGETHER TO BENEFIT NEUROEPIDEMIOLOGICAL EDUCATION, RESEARCH, AND PATIENT CARE
PAGE 9

FROM LEGACY TO COLLECTIVE ACTION IN THE PHILIPPINES
PAGE 11

THE FRAMING OF NEURASTHENIA
PAGE 17

WORLD FEDERATION OF NEUROLOGY

Editors-in-Chief
Steven L. Lewis (Editor)
Walter Struhal (Co-editor)
WFN London Office
Bedford House @ Fulham Green
69-79 Fulham High Street
London SW6 3JW
United Kingdom
Tel.: +44 (0)20 3542 1657/1658
e-mail: info@wfneurology.org

WFN OFFICERS
President: Steven Lewis (USA)
First Vice President: Riadh Gouider (Tunisia)
Acting Secretary General: Marianne de Visser (The Netherlands)
Treasurer: Morris Freedman (Canada)

ELECTED TRUSTEES
Chandrashekhar Meshram (India)
Mohammad Wasay (Pakistan)
Tissa Wijeratne (Sri Lanka)

CO-OPTED TRUSTEES
Njideka Ulunma Okubadejo (Nigeria)
Paola Guraieb Chahin (Mexico)

REGIONAL DIRECTORS
Kailash Bhatia (Europe)
Lawrence Tucker (Africa)
Christopher Chen (Asia-Oceania)
Natalia Rost (North America)
Amina Gargouri (Pan-Arab)
Renato Verdugo Latorre (Latin America)

EDITOR OF *THE JOURNAL OF THE NEUROLOGICAL SCIENCES*
John England (USA)

EDITOR OF *eNEUROLOGICALSCI*
Walter Struhal (Austria)

WORLD NEUROLOGY

WORLD NEUROLOGY, an official publication of the World Federation of Neurology, provides reports from the leadership of the WFN, its member societies, neurologists around the globe, and news from the cutting-edge of clinical neurology. Content for *World Neurology* is provided by the World Federation of Neurology and Ascend Media.

Editorial Correspondence: Send editorial correspondence to *World Neurology*, Dr. Lewis at steven.lewis@wfneurology.org or Dr. Struhal at walter.struhal@wfneurology.org.

World Neurology, ISSN: 0899-9465, is published bimonthly by Ascend Media, 401 SW Ward Road, Suite 210, Lee's Summit, MO 64081
Phone +1-913-344-1300 Fax: +1-913-344-1497

ascend media

PUBLISHING PARTNER
Ascend Media

President and CEO
Blair Johnson

Vice President of Content
Rhonda Wickham

Director of eMedia
Jena Brooks

Senior Graphic Design
Tim Nord

Senior Project Director
Amanda Nevala

PRESIDENT'S COLUMN

continued from page 1

highlighting the many facets of this highly successful program.

United Nations Economic and Social Council (ECOSOC)

The WFN, a federation of 126 neurological societies, has the privilege and responsibility of advocating for neurologists and neurological patient care globally. This includes engagement as a so-called nonstate actor (NSA) with the World Health Organization as well as with the United Nations Economic and Social Council (ECOSOC). Regarding the latter, the WFN had the privilege of attending, by invitation, the U.N. ECOSOC's 2026 **High-Level Political Forum (HLPF) on Sustainable Development**, held July 13-16, at United Nations Headquarters in New York City.

As stated by the U.N. ECOSOC, "the HLPF is the primary United Nations intergovernmental platform for reviewing progress toward the **2030 Agenda for Sustainable Development** and its 17 Sustainable Development Goals (SDGs)."

This year's forum highlighted the theme "Transformative, Equitable, Innovative, and Coordinated Actions for the 2030 Agenda for Sustainable Development and its Sustainable Development Goals (SDGs) for a Sustainable Future for All." It convened ministers and representatives of U.N. Member States and a broad cross-section of participants from the United Nations system and other stakeholders, including representatives from organizations such as the WFN. The forum featured discussions that focused on policies and actions to accelerate implementation of the 2030 agenda and its SDGs.

Along with my colleague, Prof. Alla Guekht, International League Against Epilepsy (ILAE) president and past WFN trustee, I participated in the weeklong ECOSOC event on behalf of the WFN.

We were privileged to present a statement on behalf of the WFN on the general theme of "delivering better: accelerating urgent and transformative action to achieve the SDGs by 2030." In our oral statement, we affirmed that "the 2030 agenda requires transformative, innovative, and coordinated action to protect brain health at all stages of life." We also explained that "brain health is the foundation of healthy societies and resilient communities." We noted that "neurological conditions such as stroke, epilepsy, and dementia remain leading causes of disability globally. Yet, brain health is often overlooked in high-level policy discussions."

Moreover, we asserted that "health systems, particularly in low-resource settings, require accelerated capacity building, expanding diagnostic capabilities, strengthening data systems, investing in telemedicine, and fostering community-based rehabilitation services" and "sustainable urban planning must integrate accessible, inclusive health care services to support brain health."

Finally, we concluded that "maintaining effective health care systems requires multisectoral collaboration among policymakers, administrators, and frontline providers. Professional societies like the WFN provide scientific expertise, drive global capacity building and education, and advocate for brain health priorities; the WFN (and its 126 member societies) stand ready to work with ECOSOC and other stakeholders to advance brain health for a sustainable future."

In addition to Prof. Guekht's expert in-person work at the U.N., I again remain indebted to the behind-the-scenes work of Dr. Ksenia Pochigaeva, co-chair of the WFN International Affairs/WHO Committee, for her expert drafting and honing of these statements and her availability throughout the session.

The U.N. Headquarters in New York City was the site of the United Nations Economic and Social Council's 2026 forum on sustainable development.

World Brain Day 2026

World Brain Day 2026, with the theme of "Brain Health: Access for All," took place July 22, the anniversary of the WFN's founding nearly 70 years ago. The WFN is grateful to our 126 member neurologic societies and the support from the six regional neurological associations for their involvement in this global event. The six regional associations are:

- African Academy of Neurology (AFAN)
- Asian Oceanian Association of Neurology (AOAN)
- American Academy of Neurology (AAN)
- European Academy of Neurology (EAN)
- Pan-American Federation of Neurological Societies (PAFNS)
- Pan Arab Union of Neurological Societies (PAUNS)

One of the many highlights of World Brain Day was the World Brain Day webinar, hosted by the WFN, with live

see **PRESIDENT'S COLUMN** *page 3*

ICNMD COVERAGE

Neuromuscular Disease Research, Courses Highlight Congress, **Page 1**

Patient Advocacy, Education, and Training, **Page 5**

Challenges in Supportive and Palliative Neuromuscular Care in Developing Countries, **Page 6**

Prof. Alla Guekht at the U.N. ECOSOC Forum on July 13, 2026.

WFN President Steven Lewis presenting an oral statement at the U.N. ECOSOC Forum.

PRESIDENT'S COLUMN

continued from page 2

involvement by leadership from each of the six regional neurological associations, as well as the WHO. The webinar was watched around the globe and is **available online**.

This issue of *World Neurology* features many well-illustrated articles highlighting World Brain Day events from around the globe. We look forward to publishing more World Brain Day articles in the next issue.

The WHO IGAP Implementation Meeting

The WFN attended the sub-regional WHO workshop, July 29-31, in Addis Ababa, Ethiopia. It was titled "Accelerating Implementation of the Intersectoral Global Action Plan for Epilepsy and Other Neurological Disorders (IGAP) in East Africa-Intercountry Learning Meeting." This workshop centered on five sub-Saharan African countries (Ethiopia, Kenya, South Sudan, Tanzania, and Uganda) and was organized by the WHO under the leadership of Dr. Neerja Chowdhari and Tarun Dua from the Brain Health Unit, Department of Noncommunicable Diseases, and Mental Health at WHO Headquarters. It was also supported by the WFN.

This three-day event included regional WHO representatives and Dr. Chowdhari, country health ministry and disease-based organization representatives, and people with lived experience. By the end of the intensive and pioneering workshop, attendees had strengthened skills to help catalyze the integration of IGAP in the region.

The WHO Regional Committee for Africa

The WFN participated in the 76th Session of the WHO Regional Committee for Africa (RC76) Aug. 25-27, in Addis Ababa, Ethiopia. Along with Prof. Riadh Gouider, WFN first vice president, I had the privilege of presenting two statements to the assembly on behalf of the WFN as an NSA of the WHO. One was about the African Health Workforce (Agenda Item 8) and the other was about Polio Transition and Sustainability Measures in the African Region (Agenda Item 13).

For Agenda Item 8 — the African Health Workforce — we called attention to a shortage of neurologists across most African countries, where the burden of neurological diseases is disproportionately high. We said the WFN is prepared to collaborate with WHO Member States and is committed to strengthening workforce capacity through targeted educational initiatives, such as accredited training centers and neurological education, including for primary caregivers.

For Agenda Item 13 — Polio Transition and Sustainability Measures — we highlighted that health personnel with neurological training are critical for accurately identifying and reporting acute flaccid paralysis, thereby ensuring timely detection of any polio outbreaks, including vaccine-derived cases. The WFN urged all Member States to prioritize efforts in line with the WHO recommendations for the framework for polio transition and sustainability, so that the African region can remain free from polio.

Our takeaway from the WHO Regional Committee for Africa (RC76) was that impressive work is being done by the WHO and the 47 Member States in the region. The WFN is privileged to be a part of this work.

World Congress of Neurology and WFN Update Course

The World Congress of Neurology (WCN) Congress and Science Committees are hard at work creating a high-level and diverse program for **WCN 2027** to be held Oct. 23-25, 2027, in beautiful Cape Town, South Africa. Please mark your calendars, and note that **abstract submission** is now open!

And don't forget to register for the **WFN Digital Update Course**, coming up Oct. 28-29, 2026. Thirteen world-class speakers from around the globe will provide state-of-the-art updates on major fields of neurology.

WFN Council of Delegates and Upcoming Elections

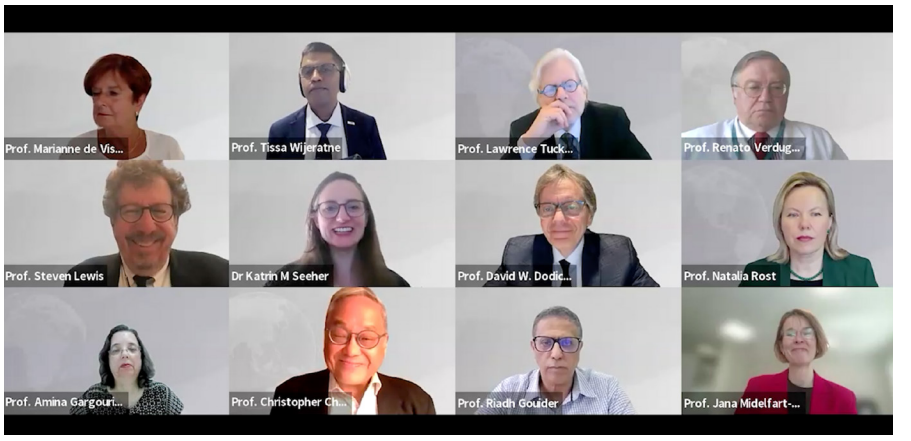
A reminder to all WFN delegates that the Annual General Meeting of the Council of Delegates (COD) will occur virtually Oct. 27, 2026. The meeting will be preceded by a three-week e-voting window for the position of secretary general and one elected trustee, and for the host site for WCN 2029. Voting will officially open on Sept. 28, running until mid-October.

To maintain a smooth and fair election, voting credentials will be sent exclusively to the authorized voting delegates submitted by each society, with voting eligibility remaining dependent on up-to-date member dues through the Oct. 9, administrative deadline. This collaborative process ensures our leadership directly reflects the shared vision of our worldwide community.

Please see the **previous issue of World Neurology** and the **Candidates Page** on the WFN website for statements from the candidates for secretary general and elected trustee.

Also, see the **WFN website** for presentations from the four member societies that are the final candidates to be the official host venue for the 30th World Congress of Neurology (WCN 2029), to be held within the Americas. These are: Argentina, Brazil, Peru, and Uruguay. The website will also include a review and analysis of the host site options by Kenes, our professional conference organizer.

In closing, thank you to all for your interest in the WFN and *World Neurology*. We look forward to more articles in upcoming issues from World Brain Day around the globe, as well as seeing the WFN delegates at the upcoming Annual General Meeting of the Council of Delegates in October. •



Leadership from the WFN, the six regional neurological associations, and the WHO at the World Brain Day webinar.

Participants at the WHO IGAP Implementation Meeting in Addis Ababa, Ethiopia.

Steven Lewis (left) with Riadh Gouider, WFN first vice president, outside the United Nations Conference Center in Addis Ababa, Ethiopia, during the WHO African Regional Committee (RC76) Meeting.

The WFN attending the WHO African Regional Committee (RC76) Meeting in August 2026.

WFN President Steven Lewis (center) presenting an oral statement at the WHO African Regional Committee (RC76) Meeting in Addis Ababa, Ethiopia.

NEUROMUSCULAR

continued from page 1

The networking event provided a pleasant atmosphere to continue neuromuscular conversations.

The WFN was represented by President Steven Lewis, Past President Wolfgang Grisold, and acting Secretary General Marianne de Visser.

The neuromuscular field is moving forward, propelled by research, revealing new immunological, genetic, and molecular findings. Many (therapeutic) innovations have entered the clinical stage and increasingly contribute to a better future for neuromuscular patients.

Providing the trajectory between research, bedside, and other aspects of neuromuscular disease that attracts eminent speakers is a significant strength of the ICNMD.

Impressions

The scientific program was introduced with an inspiring and somewhat provocative lecture by Prof. Benedikt Schoser from Munich, Germany, titled "Redefining Muscle Disease Management: A Roadmap to 2030." Prof. Schoser explained how the neuromuscular landscape is shifting from mainly supportive care to pathomechanism — targeted therapy. This is true for both acquired and hereditary neuromuscular diseases.

Of course, many hurdles still need to be overcome. These include identifying appropriate biomarkers for early diagnosis and monitoring the course of the disease. We must also assure trial readiness, including natural history data, outcome measures, patient registries, and network infrastructure.

Artificial intelligence (AI) can play an important role in diagnosis, outcome modeling, digital biomarkers, assisting target discovery, trial recruitment, and remote monitoring. However, information technology infrastructure is still lacking in many places. Data protection policy is frequently locally organized, and regulatory and ethical frameworks for clinical AI are just starting to take shape.

From left to right: Prof. Steven Lewis, WFN president, Prof. Marianne de Visser, acting WFN secretary general, and Prof. Wolfgang Grisold, WFN past president.

Prof. Schoser also warned of the threat of reduced manpower capacity if novel therapies are approved and must be administered in-hospital. He proposed moving care to the patient, which requires the use of appropriate patient-reported outcome measures and connected safety and efficacy monitoring via wearables.

Other splendid plenary lectures dealt with many topics, including:

- The paradigm shift in the treatment of chronic inflammatory demyelinating polyneuropathy (CIDP), presented by Dr. Pietro Emiliano Doneddu
- Myasthenia gravis, presented by Dr. Carolina Barnett-Tapia
- ALS, presented by Dr. Pamela Shaw

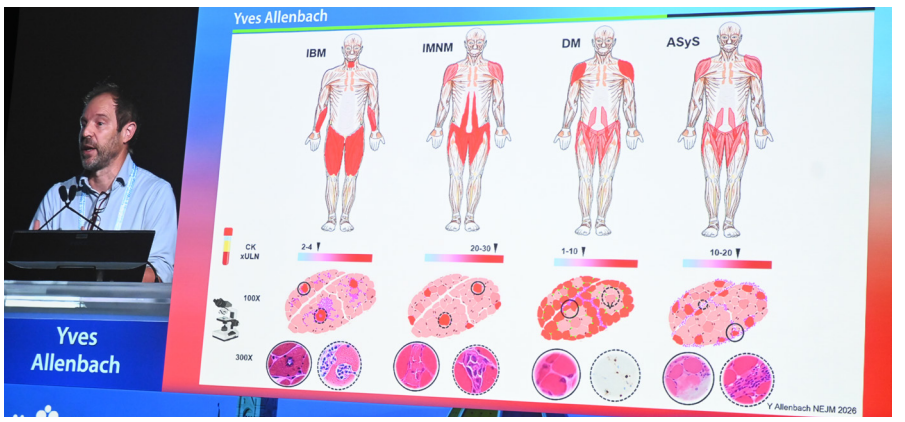
Several lectures discussed the relationship between cancer therapies and the neuromuscular system. The plenary lecture by Dr. Yves Allenbach highlighted the complex mechanism of the side effects of immune check inhibitors.

The event also featured a joint ICNMD-WFN session that included a paper by the WFN post-COVID work group. The paper, "**Prevalence and Trajectories of Post-COVID-19 Neuromuscular Conditions: A Systemic Review and Meta Analysis**," was published in the *Journal of the Neurological Sciences*. It was presented by Prof. Maurizio Leone. The same session also included news on the globally important topic of leprosy, presented by Dr. Pedro Tomaselli, and emergencies of the neuromuscular system in India, presented by Dr. Sarath Menon.

The program also included joint symposia with other societies such as the Peripheral Nerve Society (PNS), the World Muscle Society (WMS) (focusing on inequalities in access to treatments), and the WFN Autonomic Disorder Group. These symposia featured discussions on aspects of supportive and palliative care, mental health in neuromuscular diseases, aging of the neuromuscular system, and tailoring myasthenia gravis care for women. In addition, the German NervClub provided a view into the exciting world of nerve surgery, reinnervation, and rehabilitation.

On the final day of the conference, one session was devoted to the aging and senescence of the neuromuscular system, including senescence, aging of nerves, and sarcopenia.

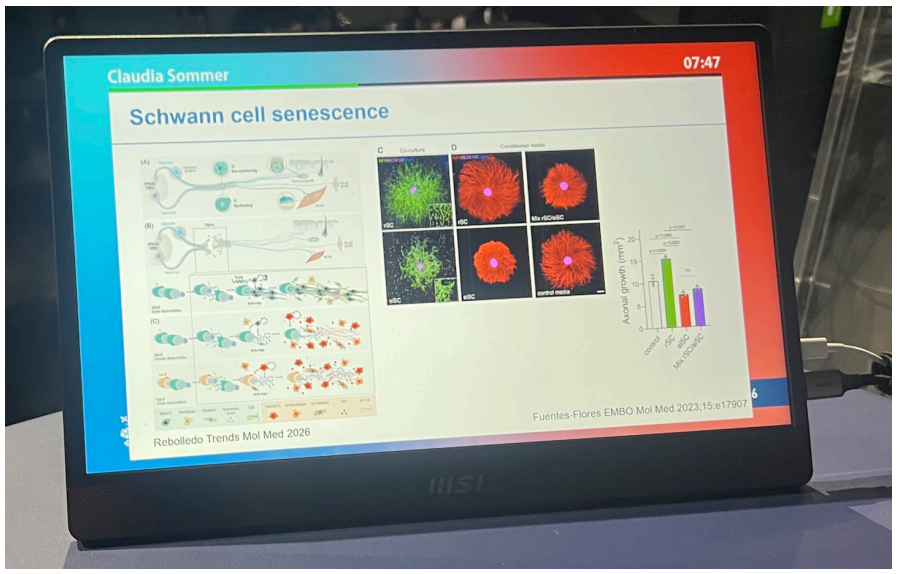
The closing ceremony featured awards for the four best posters, summarized the meeting, and announced the **next meeting**, which will take place July 5-9, 2027, in Chiba, Japan. •



Prof. Yves Allenbach delivers a lecture on the mechanism of the side effects of immune check inhibitors.

Prof. Alexander Grimm of the German NervClub gives a presentation on nerve surgery, reinnervation, and rehabilitation.

Prof. Maurizio Leone presents an update on a paper by the WFN post-COVID work group.



A look at a presentation on the aging and senescence of the neuromuscular system given on the last day of the congress.

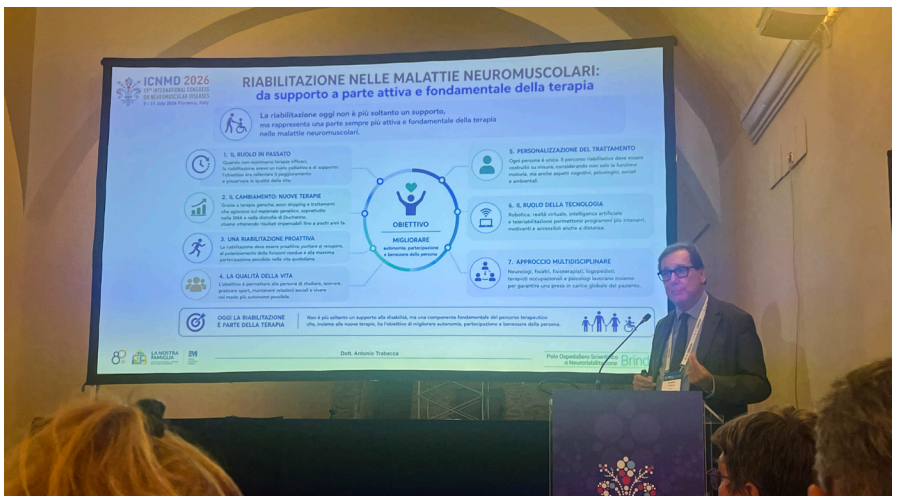
Prof. Hiroyuki Murai, 2027 congress president, announces details for next year's event in Chiba, Japan.

INTERNATIONAL CONGRESS ON NEUROMUSCULAR DISEASES 2026

Patient Advocacy, Education, and Training

Associations outline their goals on Patient's Day at the International Congress on Neuromuscular Diseases.

The opening of the Patient's Day forum at the 2026 ICNMD in Florence, Italy.



Dr. Antonio Trabacca explaining neuromuscular rehabilitation as part of the Patient's Day forum.

BY ANTONIO TOSCANO AND WOLFGANG GRISOLD

The opening of the 19th International Congress on Neuromuscular Diseases featured a dedicated session with the goal of identifying the key priorities in the management and care of neuromuscular disorders.

Patient's Day, which took place July 7, was supported by the World Federation of Neurology (WFN), the Italian Myology Association (AIM), Gruppo Italiano per lo studio del Sistema Nervoso Periferico (ASNP), and the Italian Federation of Rare Diseases (UNIAMO). It was dedicated to fostering dialogue between patient organizations and the scientific community.

UNIAMO is the representative body of the rare disease community, with more than 200 affiliated associations. It has been working for 25 years to protect and defend the rights of people with rare diseases and their families. UNIAMO engages in ongoing dialogue with institutional representatives (ministries, the Agenzia Italiana del Farmaco, Istituto Superiore di Sanità and others), scientific societies, researchers, and private stakeholders, representing the concerns of people with rare diseases.

Prof. Wolfgang Grisold, Prof. A. Toscano, and Dr. Annalisa Scopinaro opened the event, with a presentation outlining goals.

Patient's Day started with an update by experts on current therapies of major neuromuscular disorders. These included:

- Motor neuron diseases (Prof. N. Ticozzi, Milan)
- SMA (Prof. G. Ricci, Pisa, Italy)
- Peripheral neuropathies (Prof. D. Pareyson, Milan)
- Muscle diseases (Prof. T. Mongini, TURIN, Italy)
- Neuromuscular junction diseases (Prof. V. Damato, Florence, Italy)
- Metabolic myopathies (Prof. A. Toscano, Messina, Italy)
- Rehabilitation therapies (Dr. A. Trabacca, Brindisi, Italy, and Prof. G. Siciliano, Pisa, Italy)

Subsequently, the patients' associations that took part in the event presented themselves. They are:

- FSHD Italia APS
- AltroDomani
- Gli Equilibristi HIBM
- Parent Project APS
- Associazione Italiana Charcot-Marie-Tooth
- Gruppo Familiari Beta-Sarcoglicanopatie
- Famiglie SMA APS ETS
- AIGlico Associazione Italiana Glicogenosi
- Collagene VI Italia APS
- ACMT-Rete per la Charcot-Marie-Tooth ODV
- UILDM
- Consulta Malattie Neuromuscolari
- GBS|CIDP Foundation International

During the discussion, they highlighted their achievements, but also their expectations and collaborative efforts.

AIGlico Associazione Italiana Glicogenosi is very interested in ensuring that newborn screening is available in all Italian regions and recommending that physiotherapy be continuously supported for patients with neuromuscular diseases to maintain a good level of autonomy and independence. The association also advocates psychological support for patients and their caregivers as well as increasing the availability of home-based services, either for specific therapies or for physiotherapy.

ACMT Rete per la Charcot-Marie-Tooth ODV aims to promote information and training projects (annual congresses, courses for physiotherapists, and an online course on Charcot-Marie-Tooth (CMT) for health care professionals). The group also encourages meetings and exchanges between people affected by the condition (for example, National CMT Day and the "Young People" project aimed at Generation Z).

GBS-CIDP Foundation International is committed to promoting timely diagnosis, access to appropriate treatments, and qualified care. It does this via the four pillars of its mission:

- Support for patients and their families, education, research, and advocacy.
- Proposing main international programs aimed at defining shared standards of care to improve equity of access to treatment.
- Raising awareness of rare immune-mediated neuropathies.
- Promoting education for patients and health care professionals, strengthening the international network of Centers of Excellence, and consolidating collaboration with patient organizations.

Uniting the Associations

The approach of the Neuromuscular Diseases Advisory Board (Consulta Neuromuscolare) is to build a network, bringing together the efforts of the 18 different associations working in the field of neuromuscular diseases, and to make overall care more consistent across the whole national territory.

There are two levels of action. The first is regional. Regional delegates jointly carry out an assessment of the shared critical issues and the least well-met care needs. In all regions, this association calls for the establishment of a regional working table. At the central level, the members of the advisory board's governing council seek ways to resolve issues or pursue initiatives that cannot be addressed at the regional level. These include, for example, issues that need to be examined at the Ministry or National Institute of Health level.

The main objectives of Consulta Neuromuscolare are to ensure that proper multidisciplinary care is achieved and to propose the diagnostic-therapeutic-care health pathway for all regional contexts.

Patient's Day was a great success, sharing recent achievements in the diagnostic and therapeutic fields, the effectiveness of innovative therapies, and the opinions of experts and association representatives. It also highlighted short- and long-term perspectives for new common projects that can improve the quality of life of patients with neuromuscular diseases and support their families. •

Prof. Antonio Toscano is congress president of ICNMD 2026, and **Prof. Wolfgang Grisold** is past president of the WFN.

Prof. Antonio Toscano at the opening of Patient's Day at the 2026 ICNMD.

INTERNATIONAL CONGRESS ON NEUROMUSCULAR DISEASES 2026

Challenges in Supportive and Palliative Neuromuscular Care in Developing Countries

A report on a presentation from the International Congress on Neuromuscular Diseases in Florence, Italy.

ABSTRACT

Neuromuscular diseases (NMDs) are individually rare but collectively represent a substantial global health burden. Advances in molecular diagnosis and targeted therapies have transformed the management of many of these conditions. However, patients in low- and middle-income countries (LMICs) continue to face profound inequities in diagnosis, treatment, and supportive care.

This report builds on a presentation that was given at the International Congress on Neuromuscular Diseases in July 2026 in Florence, Italy. It reviews the major barriers to supportive and palliative care for patients with neuromuscular diseases in developing countries. Improving patient outcomes requires more than access to innovative therapies; it also demands the following:

- stronger health care systems
- earlier diagnosis
- multidisciplinary care
- improved education of medical students, residents, and medical specialists
- policies that integrate palliative care throughout the disease course, along with disease-directed treatment, rather than limiting it to end-of-life care

Jorge A. Bevilacqua

BY JORGE A. BEVILACQUA

Palliative care is an essential component of comprehensive health care systems; however, its availability remains severely underdeveloped and markedly inequitable across regions and income groups.[1, 2, 3, 4] Although Europe and the Americas have the greatest concentration of palliative care services, approximately 80% of the global need occurs in low- and middle-income countries (LMICs), which account for only 30% of existing services. These substantial disparities underscore the urgent need to strengthen palliative care capacity and improve equitable access, particularly in LMICs.[1]

Although medical science has advanced rapidly, health care systems have struggled to ensure equitable access to diagnosis, treatment, and comprehensive patient care. Neuromuscular diseases (NMDs) add a layer of complexity to the supportive and palliative care needs of affected patients.[5,6]

Diagnostic delay and misdiagnosis — resulting in unacceptable delays in accurate diagnosis, prognosis, genetic counseling, and appropriate care — are not unique to LMICs. However, their prevalence in these settings remains unjustifiably high. Addressing these challenges requires sustained commitment from health care systems and the implementation of coordinated strategies to improve access to appropriate care.

Approximately 40 million people per year require palliative care worldwide, 78% of whom live in LMICs. Yet only 14% of the global need for palliative care is currently met.[2] In high-income countries, the likelihood of receiving palliative care is approximately 50%, compared with only 4% in LMICs. This disparity is even greater for neurological and neuromuscular diseases.[1,2] In India, for example, only 1%-2% of the estimated 5.4 million patients requiring palliative care each year receive such care.[7,8]

A similar picture can be observed in other regions of the world. In Egypt, although multidisciplinary care is increasingly available, families pay up to 90% of medical costs out of pocket, with physiotherapy representing the second largest financial burden. Patients living in cities with access to specialized multidisciplinary care, including physiotherapy, have also been shown to maintain ambulation longer than their rural counterparts.[9] In a recent study from Latin America, out-of-pocket expenses for patients with myasthenia gravis were found to substantially exceed the minimum wage.[10]

Amyotrophic lateral sclerosis (ALS) is the neuromuscular disease most associated with palliative care. Increasing recognition of its benefits has led to recommendations for earlier and greater integration of palliative care into ALS management.[5,6,11] However, an international survey of 21 countries across six continents demonstrated significant disparities in access to ALS/motor neuron disease (MND) care.

Economic, cultural, and religious factors emerged as important determinants of access. Several resource-limited countries had virtually no public awareness of ALS and extremely limited access to patient care. Interestingly, according to the report, "these results were often a reflection of whether a country was WHO-designated high-, middle-, or low-income."[12]

These inequities disproportionately affect patients with rare neuromuscular disorders because their diseases often require lifelong multidisciplinary care and expensive interventions.[6]

The Main Critical Areas and Barriers

Several interconnected barriers create what may be termed a circle of neglect for rare NMDs in LMICs. Their low visibility at the organizational level results in limited awareness, inadequate disease registries, and insufficient inclusion in medical curricula. This contributes to a shortage of trained health care professionals and, consequently, limited investment in specialized infrastructure, logistics, and services.

These deficiencies, in turn, contribute to delays in diagnosis and treatment. Lack of diagnosis also affects the perceived prevalence of these diseases, perpetuating their neglect. Supportive and palliative care form part of this same circle. Although many of the limitations are shared with other areas of medicine, they may be particularly consequential in NMDs.

Understanding Supportive and Palliative Care

Definitions of supportive and palliative care are frequently used ambiguously and are often conceptualized primarily from an oncological perspective.[13,14] Globally, palliative care can be described as active, holistic care for individuals experiencing serious health-related suffering. It focuses on preventing and relieving physical, psychological, social, and spiritual distress without intending either to hasten or postpone death.[15]

Supportive care encompasses a broader spectrum, extending across diagnosis, rehabilitation, survivorship, secondary prevention, and end-of-life care.[4,14] Within this framework, palliative care represents one component of comprehensive supportive care; thus, supportive care encompasses palliative care.[14]

This distinction is particularly relevant in chronic hereditary neuromuscular diseases and other nononcological conditions. Patients with chronic inherited neuromuscular disorders must live with the consequences of their disease, which can impose substantial physical, emotional, and financial burdens on patients, families, and caregivers. Patients may experience one or more of the following:

- respiratory insufficiency and cardiac complications
- dysphagia and dysarthria, with consequent nutritional and communication difficulties
- immobility, chronic fatigue, and pain
- psychological and existential suffering

These challenges extend well beyond traditional neurological management and require comprehensive supportive care throughout the disease trajectory.[5,6,16]

see **DEVELOPING COUNTRIES** *page 7*

DEVELOPING COUNTRIES

continued from page 6

Systemic and Infrastructural Barriers

In most LMICs, specialized services are largely concentrated in tertiary referral centers, typically located in major cities and often far from the patients who require them.[17,9] Patients may therefore need to travel long distances to access specialized care, while primary and secondary health care systems remain poorly equipped to manage chronic neuromuscular diseases. Consequently, patients frequently reach referral centers without an adequate diagnosis and at advanced stages of disease, when therapeutic options are increasingly limited.

This creates a cascading failure: Already scarce tertiary centers become overburdened with patients with complex or advanced disease, families face catastrophic out-of-pocket expenses, and the health care system becomes increasingly inefficient.[17] Some of these pressures could be mitigated through better distribution and optimization of supportive and palliative care services closer to patients and their communities.

Diagnostic Delay and Misdiagnosis

Although approximately 15 million people worldwide live with inherited NMDs, access to precision molecular diagnosis remains highly unequal. Modern DNA sequencing enables accurate diagnosis and, increasingly, access to gene-specific therapies.[18] Nevertheless, most affected families live in LMICs, while genetic reference databases remain heavily biased toward populations of European ancestry and those from developed regions. Molecular diagnosis therefore remains inaccessible to many patients.[19,20]

As noted above, delayed diagnosis postpones appropriate therapy while potentially exposing patients to ineffective or even harmful treatments.

This challenge is directly linked to workforce limitations. Shortages of trained professionals exist across many developing countries because of factors related to training pathways, financial pressures, and increasing demand for specialized expertise. In supportive and palliative care, contributing factors include inadequate education in neuromuscular medicine, limited awareness of palliative care as a professional field, fragmentation between specialties, and insufficient multidisciplinary collaboration.[17,21,22] As a result, referrals are delayed, symptom control is inadequate, and tertiary hospitals become increasingly overburdened.

Limited Access to Therapy

Access to therapy deserves particular attention, as discussions often focus on novel, high-cost treatments. However, in LMICs, access is also limited for basic and essential interventions, including supportive and palliative care.[37]

This limitation becomes even more evident when access to modern therapies is considered. Highly effective treatments now exist for spinal muscular atrophy (SMA), Duchenne muscular dystrophy (DMD), Pompe disease, and several autoimmune conditions, including immune-mediated neuromuscular junction disorders and myopathies.[21] Yet these therapies remain inaccessible to most patients worldwide.[10,19,23]

There is a widespread perception within both the medical and patient communities that when a disease-specific therapy becomes available, supportive and palliative care become less necessary. This notion is incorrect. On the contrary, the introduction of a disease-modifying therapy increases the importance of optimal supportive care to give patients the best possible chance of benefiting from treatment.

Moreover, the existence of novel high-cost therapies may make supportive and palliative care even more relevant when advanced treatments cannot be accessed. In other words, sophisticated, high-cost therapies cannot achieve their full potential when delivered in communities lacking adequate supportive care.

Why NMDs Require a Different Approach

NMDs should not be viewed solely as rare neurological disorders. They are chronic, progressive conditions, often associated with a shortened life expectancy. They require continuous multidisciplinary management that addresses physical, psychological, social, and existential needs.[5,6]

NMDs require a model of supportive and palliative care that differs from systems derived primarily from oncology, which remain the prevailing models in many developing countries.[13,14]

NMDs differ substantially from cancer because they often follow prolonged disease trajectories, involve progressive disability rather than a predominantly terminal course, and require long-term ventilatory, nutritional, rehabilitation, and communication support. They may also present unique psychological and mental health challenges, particularly when cognitive impairment occurs in certain NMDs.[5,6,18]

Consequently, cancer-centered models should not simply be transferred to NMD without appropriate adaptation.

Promising Strategies for Improvement

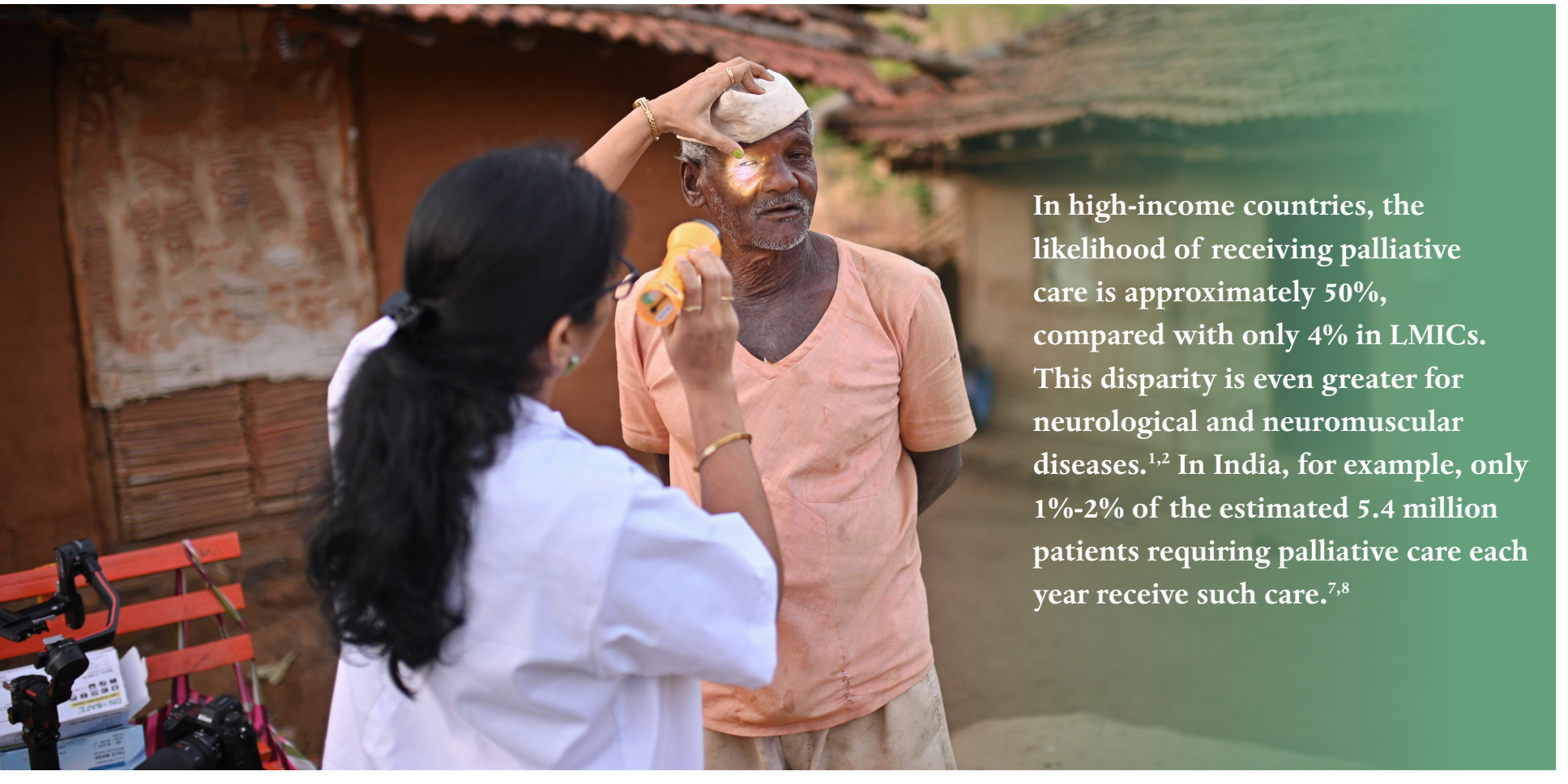
Several approaches may help overcome these challenges, including community-based models of care. Community- and home-based care can substantially improve access while reducing hospital utilization. The Kerala "Neighborhood Network" in India provides an example of a volunteer-supported model of home-based palliative care.[24] Telemedicine and wearable technologies may also provide opportunities to extend specialist expertise to underserved regions.[25]

Education and Professional Development

Education and professional development are essential to achieving sustainable improvements in neuromuscular care. Based on the author's experience in Latin America, examples of specialized educational initiatives in the neuromuscular field include the Paris Summer School of Myology (AcadeMYO).[27] This initiative subsequently inspired similar programs adapted to different regions, including the Euro Latin America Summer School of Myology (EVELAM),[28] which promotes education in rare NMDs, including the principles of supportive and palliative care and practical workshops.

Scientific societies can also contribute by organizing educational and scientific meetings, such as those promoted by the Latin American Society of Neuromuscular Disorders (SOLANE),[29] and by supporting specialized training programs such as the World Muscle Society SEED Project.[30] Collectively, these initiatives have trained

see **DEVELOPING COUNTRIES** *page 8*



In high-income countries, the likelihood of receiving palliative care is approximately 50%, compared with only 4% in LMICs. This disparity is even greater for neurological and neuromuscular diseases.[1,2] In India, for example, only 1%-2% of the estimated 5.4 million patients requiring palliative care each year receive such care.[7,8]

ICNMD FLORENCE

continued from page 7

thousands of health care professionals across Latin America and other developing regions.

Precision Diagnosis and Genomic Diversity

Regional genomic initiatives such as Latin Seq[31] and sponsored diagnostic programs demonstrate how international collaboration can expand access to molecular diagnosis while increasing the representation of diverse populations in genetic databases.[32,33] Such projects can contribute to a better understanding of the genetic profiles of patients with NMDs in LMICs, facilitating earlier diagnosis and enabling more appropriate disease management.[34,35,36]

Integrated Multidisciplinary Care

All of these approaches should ultimately converge toward what is clearly indispensable: integrated multidisciplinary care. Effective neuromuscular care requires coordinated collaboration among neurologists, rehabilitation specialists, palliative care clinicians, respiratory physicians, nutritionists, psychologists, speech and language therapists, nurses, and social workers. Depending on the context, patient associations, nongovernmental organizations, and other stakeholders can also play an important role.

Conclusion

Although remarkable therapeutic advances have transformed the outlook for several NMDs, these innovations have also widened disparities between countries with and without access to precision medicine. As a result, supportive and palliative care has become more important.

Treatment does not necessarily equal cure. Health care systems therefore have an ethical responsibility to provide integrated, patient-centered supportive care throughout the disease trajectory. Achieving this goal requires earlier diagnosis, multidisciplinary collaboration, expanded education, stronger health policies, and equitable access to both modern therapies and high-quality supportive care.

In essence, supportive care for NMDs in LMICs is a field in transition. Although it remains severely underresourced compared with high-income countries, there is growing recognition of the problem and increasing momentum toward practical, culturally adapted solutions aimed at maximizing quality of life despite resource limitations. •

Jorge A. Bevilacqua, MD, PhD, is professor at the Departamento de Neurología y Neurocirugía, Hospital Clínico Universidad de Chile.

References:

1. Connor SR, Centeno C, Garralda E, Clelland D, Clark D. Estimating the Number of Patients Receiving Specialized Palliative Care Globally in 2017. *J Pain Symptom Manage*. 2021 Apr;61(4):812-816. doi: 10.1016/j.jpainsymman.2020.09.036. Epub 2020 Sep 30. PMID: 33010338; PMCID: PMC8012880.
2. https://www.iccp-portal.org/guide/palliative-care.
3. https://www.who.int/health-topics/palliative-care.
4. Oliver D. Neuropalliative care: Defining an emerging field. *Handb Clin Neurol*. 2022;190:17-31. doi: 10.1016/B978-0-323-85029-2.00008-7. PMID: 36055714.
5. de Visser M, Oliver DJ. Palliative care in neuromuscular diseases. *Curr Opin Neurol*. 2017 Dec;30(6):686-691. doi: 10.1097/WCO.0000000000000493. PMID: 28914735.
6. Oliver DJ. Neuropalliative Care in Neuromuscular Disorders. *Continuum* (Minneap Minn). 2025 Dec;31(6):1602-1617. doi: 10.1212/cont.0000000000001638. Epub 2025 Dec 2. PMID: 41328934.
7. Khosla D, Patel FD, Sharma SC. *Indian J Palliat Care* 2012;18:149-54.
8. Mahesan A, Kamila G, Gulati S. Rare pediatric disorders in Indian health care settings with focus on neuromuscular disorders: Diagnostic and management challenges. *J Biosci*. 2024;49:15. PMID: 38200670.
9. El Sherif R, Lowes L. *Neuromuscular Disorders*, 53, Suppl. 2025, 105566, doi.org/10.1016/j.nmd.2025.105566.
10. Salutto VL, et al. *Front Public Health*. 2026 8;14:1791605. doi: 10.3389/fpubh.2026.1791605.021.
11. Oliver DJ, Borasio GD, Caraceni A, de Visser M, Grisold W, Lorenzl S, Veronese S, Voltz R. A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. *Eur J Neurol*. 2016 Jan;23(1):30-8. doi: 10.1111/ene.12889. Epub 2015 Oct 1. PMID: 26423203.
12. Kunkel J, Olivier D, Blank R. Disparities in Access to ALS/MND Care: an International Survey. *Neurology*. April 13, 2021 issue 96 (15_supplement) 4376. doi.org/10.1212/WNL.96.15_supplement.4376.
13. Taylor A, Davies A. Palliative care or supportive care? *Clin Med* (Lond). 2025 Jul;25(4):100487. doi: 10.1016/j.clinme.2025.100487. Epub 2025 Jul 14. PMID: 40669828; PMCID: PMC12320666.
14. Scotté, F.; Taylor, A.; Davies, A. Supportive Care: The "Keystone" of Modern Oncology Practice. *Cancers* 2023, 15, 3860. https://doi.org/10.3390/cancers15153860.
15. Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnaghar S, Blanchard C, Bruera E, Buitrago R, Burla C, Callaway M, Munyoro EC, Centeno C, Cleary J, Connor S, Davaasuren O, Downing J, Foley K, Goh C, Gomez-Garcia W, Harding R, Khan QT, Larkin P, Leng M, Luyirika E, Marston J, Moine S, Osman H, Pettus K, Puchalski C, Rajagopal MR, Spence D, Spruijt O, Venkateswaran C, Wee B, Woodruff R, Yong J, Pastrana T. Redefining Palliative Care — A New Consensus-Based Definition. *J Pain Symptom Manage*. 2020 Oct;60(4):754-764. doi: 10.1016/j.jpainsymman.2020.04.027. Epub 2020 May 6. PMID: 32387576; PMCID: PMC8096724.
16. Borsini, E., Montes Onganía, A., De Muria, M., Finn, B., & Golpe, R. (2023). Abordaje paliativo en enfermedades respiratorias avanzadas. *Respirar*, 15(4), 263–278. doi: 10.55720/respirar.15.4.5.
17. Baruah U, Sharma P, Thomas PT, Dhamija RK. Neuropalliative Care in India — Barriers, Challenges and Future Directions. *Ann Indian Acad Neurol*. 2023 Mar-Apr;26(2):107-111. doi: 10.4103/aian.aian_1021_22. Epub 2023 Mar 17. PMID: 37179665; PMCID: PMC10171018.
18. Deenen JC, Horlings CG, Verschuuren JJ, Verbeek AL, van Engelen BG. The epidemiology of neuromuscular disorders: a comprehensive overview of the literature. *J Neuromuscul Dis*. 2015;2:73-85.
19. Genetic Neuromuscular Disorders and Health Services Access, Utilization, and Needs in Zambia. *Pediatric Neurology*. 2023;148:173-177.
20. Wilson LA, Macken WL, Perry LD, Record CJ, Schon KR, Frezatti RSS, Raga S, Naidu K, Köken ÖY, Polat I, Kapapa MM, Dominik N, Efthymiou S, Morsy H, Nel M, Fassad MR, Gao F, Patel K, Schoonen M, Bisschoff M, Vorster A, Jonvik H, Human R, Lubbe E, Nonyane M, Vengalil S, Nashi S, Srivastava K, Lemmers RJLF, Reyaz A, Mishra R, Töpf A, Trainor CI, Steyn EC, Mahungu AC, van der Vliet PJ, Ceylan AC, Hiz AS, Çavdarlı B, Semerci Gündüz CN, Ceylan GG, Nagappa M, Tallapaka KB, Govindaraj P, van der Maarel SM, Narayanappa G, Nandeesh BN, Wa Somwe S, Bearden DR, Kvalsund MP, Ramdharry GM, Oktay Y, Yiş U, Topaloğlu H, Sarkozy A, Bugiardini E, Henning F, Wilmshurst JM, Heckmann JM, McFarland R, Taylor RW, Smuts I, van der Westhuizen FH, Sobreira CFDR, Tomaselli PJ, Marques W Jr, Bhatia R, Dalal A, Srivastava MVP, Yareeda S, Nalini A, Vishnu VY, Thangaraj K, Straub V, Horvath R, Chinnery PF, Pitceathly RDS, Muntoni F, Houlden H, Vandrovcova J, Reilly MM, Hanna MG. Neuromuscular disease genetics in under-represented populations: increasing data diversity. *Brain*. 2023 Dec 1;146(12):5098-5109. doi: 10.1093/brain/awad254. PMID: 37516995; PMCID: PMC10690022.
21. Diaz MM, Guareña LA, Garcia B, Alarcon-Ruiz CA, Seal SM, Rubinos C, Cruz-Oliver D, Carhuapoma JR. A Scoping Review of End-of-Life Discussions and Palliative Care: Implications for Neurological Intensive Care in Latin America and the Caribbean. *J Palliat Med*. 2025 Jun;28(6):829-846. doi: 10.1089/jpm.2024.0304. Epub 2024 Dec 9. PMID: 39648837; PMCID: PMC12223374.
22. Jibaja M, Godoy DA. Diagnosis and management of neuromuscular diseases in middle and low-income countries: the gap is significant. *Lat Am Neurointensive Care J*. 2025;2(2):1-12.
23. Angelini, C. Therapeutic Advances and Novel Drug Treatment Opportunities in the Neuromuscular Disorders Area. *International Journal of Neuromuscular Diseases* 2026, *1*(1), 1.
24. www.grin.com/document/310038?srsltid=AfmBOorJirN_ge5oSAzV88kKU4FjgeNX3jzDCaaMhB8nyK5plROM3vUm.
25. Torri F, Schirinzi E, Fontanelli L, Ricci G, Mancuso M, Bochicchio M, Siciliano G. Telemedicine and remote monitoring in neuromuscular diseases: Challenges and opportunities. *J Neuromuscul Dis*. 2026 Jan;13(1):43-52. doi: 10.1177/22143602251330436. Epub 2025 Jun 25. PMID: 40560121; PMCID: PMC13141847.
26. Monges S, Rosa AL. Management of neuromuscular diseases and spinal muscular atrophy in Latin America. *Gene Ther*. 2017 Sep;24(9):578-580. doi: 10.1038/gt.2017.68. Epub 2017 Jul 28. PMID: 28753203.
27. AcadeMYO - Paris Summer School of Myology https://academyo.fr/.
28. EVELAM, Euro Latin America Summer School of Myology https://evelam.org/.
29. SOLANE, The Latin American Society of Neuromuscular Diseases (SOLANE) https://websolane.org/.
30. *World Muscle Society SEED Project* https://www.worldmusclesociety.org/page/applying-for-a-seed-fellowship.
31. Latin Seq - https://latin-seq.com.
32. Bevilacqua JA, Guecaimburu Ehuletche MDR, Perna A, Dubrovsky A, Franca MC Jr, Vargas S, Hegde M, Claeys KG, Straub V, Daba N, Faria R, Periquet M, Sparks S, Thibault N, Araujo R. The Latin American experience with a next generation sequencing genetic panel for recessive limb-girdle muscular weakness and Pompe disease. *Orphanet J Rare Dis*. 2020 Jan 13;15(1):11. doi: 10.1186/s13023-019-1291-2. PMID: 31931849; PMCID: PMC6958675.
33. Bevilacqua JA, Al-Salti AM, Al Madani A, Alves da Fonseca A, Durmus H, Chai J, Alshehri A, Ribeiro MG, Sgobbi P, Nikitin SS, Vargas S, Furtado A, Thibault N, Araujo R, Daba N. Detection of gene variants associated with recessive limb-girdle muscular weakness and Pompe disease in a global cohort of patients through the application of next-generation sequencing analysis. *Front Genet*. 2024 Nov 29;15:1477291. doi: 10.3389/fgene.2024.1477291. PMID: 39678382; PMCID: PMC11638199.
34. Töpf A, Johnson K, Bates A, Phillips L, Chao KR, England EM, Laricchia KM, Mullen T, Valkanas E, Xu L, Bertoli M, Blain A, Casasús AB, Duff J, Mroczek M, Specht S, Lek M, Ensini M, MacArthur DG; MYO-SEQ consortium; Straub V. Sequential targeted exome sequencing of 1001 patients affected by unexplained limb-girdle weakness. *Genet Med*. 2020 Sep;22(9):1478-1488. doi: 10.1038/s41436-020-0840-3. Epub 2020 Jun 11. PMID: 32528171; PMCID: PMC7462745.
35. Soltani N, Shahbazi Z, Fallah MS, Karimipoor M, Bagherian H, Dabbagh Bagheri S, Shirzadeh T, Zafarghandi Motlagh F, Rabie Salehi G, Younesikhah S, Asnavandi S, Zeinali R, Majidi Z, Zeinali S. Whole-Exome Sequencing in Undiagnosed Muscular Dystrophies: A High Diagnostic Yield and Novel Insights From Iranian Families. *Hum Mutat*. 2026 Aug 3;2026:6592066. doi: 10.1155/humu/6592066. PMID: 42553504; PMCID: PMC13434219.
36. Hanaya Alsuwaidi A, Mousa M, Olbrich M, Marzouka NAD, Wohlers I, Ibrahim S, Alsafar H. National genomic projects in Asia and Africa: a review. *Hum Genomics*. 2026 Jun 30. doi: 10.1186/s40246-026-01007-9. Epub ahead of print. PMID: 42381083.
37. Carroll WM, Grisold W. World Federation of Neurology Needs Registry Survey 2021. *J Neurol Sci*. 2024;465:123124.

Working Together to Benefit Education, Research, and Patient Care

A decades-long partnership between Limoges, France, and the African Republic of Benin has contributed to neuroepidemiological advances in both regions.

BY DIEU DONNÉ GNONLONFOUN, JÉRÉMY JOST, DISMAND HOUINATO, PIERRE-MARIE PREUX

From left to right: Prof. Dismand Houinato, MD, PhD, previous director of the LEMACEN Unit in Cotonou, Benin; Prof. Jeremy Jost, MD, PhD, future director of the EpiMaCT Unit in Limoges, France; Prof. Dieu donné Gnonlonfoun, MD, PhD, current director of the LEMACEN Unit in Cotonou, Bénin; Prof. Pierre-Marie Preux, MD, PhD, current director of the EpiMaCT Unit in Limoges, France.

The academic cooperation between Limoges, France, and the Republic of Benin in neuroepidemiology and public health is the result of more than four decades of scientific, pedagogical, and human relationships.

It began in the early 1980s, around tropical neurology and epidemiology, and progressively developed into a structured partnership involving the entities from both countries. In Limoges, these included the University of Limoges, the Institute of Epidemiology and Tropical Neurology (IENT) — later renamed the Institute of Epidemiology and Global Health–Michel Dumas (IESM-MD) — and the successive Limoges research units that preceded the Epidemiology of Chronic Diseases in Tropical Zone unit (EpiMaCT). Partner entities in Benin included the University of Abomey-Calavi, the Laboratory of Epidemiology of Chronic and Neurological Diseases (LEMACEN), and, for specific training projects, the University of Parakou.

The Limoges-Benin Partnership

From the outset, this cooperation was closely linked to the development of tropical neurology as an academic field. Prof. Michel Dumas and the Limoges team played a central role in building scientific and teaching links with Benin, notably through neurological teaching and support for the training of Beninese physicians and academics.

The IENT was created in 1982 as a structure dedicated to training, research, and international cooperation in tropical neurology and epidemiology. This early orientation explains why the Limoges-Benin partnership was first rooted in neurology before progressively expanding to neuroepidemiology, chronic diseases, and broader public health.

A key feature of this cooperation has been the long-term training of Beninese academic leaders. This point is essential because the partnership wasn't only built through institutional agreements; it was also built through individuals who trained partly in Limoges and later took major responsibilities in Benin.

LEMACEN founder Prof. Dismand Houinato is a neurologist and professor of neurology at the University of Abomey-Calavi. He was trained in public health and epidemiology in Limoges, including through doctoral and HDR-level pathways, and became one of the major figures structuring chronic disease and neurological epidemiology in Benin.

The new director of LEMACEN, Prof. Dieu donné Gnonlonfoun, is a professor of neurology at the University of Abomey-Calavi. He followed part of his academic training in Limoges, including master's and doctoral training in epidemiology. This continuity between successive generations of Beninese neurologists trained in part through the Limoges partnership is one of the strongest indicators of the depth and durability of the cooperation.

Formalizing a New Agreement

In 2003, the partnership entered a new phase with the formalization of a framework agreement between the University of Abomey-Calavi and the University of Limoges. This agreement provided the institutional foundation for long-term scientific and educational cooperation. It was aimed at strengthening academic ties, fostering collaborative teaching and research initiatives, and supporting the advancement of Francophonie academic cooperation. The agreement encompassed a wide range of activities, including staff exchanges and teaching assignments, the mobility of students and academics, the sharing of scientific and pedagogical expertise and resources, and broader measures to reinforce institutional capacities within both universities.

A renewed interuniversity partnership agreement was signed in 2020. It confirmed the same strategic orientations. These included:

- collaboration in teaching
- research and development
- expertise
- staff exchanges
- student exchanges
- exchanges of university documentation
- cultural and intellectual activities

This renewal was important because it gave a contemporary institutional framework to a cooperation that had already become dense, productive, and multidimensional.

EpiMaCT

The Limoges research structures also evolved at the same time. Before EpiMaCT, the research team worked under earlier names, including NETEC (Tropical and Compared Neuroepidemiology) and NET (Tropical Neuroepidemiology). EpiMaCT was created in 2022 and now embodies the continuation and broadening of this scientific trajectory. Its focus is the epidemiology of chronic diseases in tropical settings, including neurological disorders, cardiovascular and metabolic diseases, mental and cognitive health, and cancers.

This evolution mirrors the trajectory of the cooperation with Benin: from tropical neurology to neuroepidemiology, and then to the broader epidemiology of chronic diseases and global health.

The institutional transformation of the Limoges institute also reflects this broadening scope. The IENT became the Institute of Epidemiology and Global Health-Michel Dumas (IESM-MD) in September 2025, following an administrative decision in August 2025. This change of name preserved the historical legacy of the IENT and Prof. Dumas, while making explicit the wider global health dimension that had progressively become central to its activities.

On the Beninese side, the creation of LEMACEN in 2014 was a major turning point. The Laboratory of Epidemiology of Chronic and Neurological Diseases, hosted by the faculty of health sciences at the University of Abomey-Calavi, provided a strong local institutional base for the partnership.

The Benin Connection

LEMACEN made it possible to consolidate a Beninese research environment dedicated to chronic and neurological diseases. It did so with missions in research, training, supervision of master's and doctoral students, scientific support, research project implementation, seminars, and expert activities. Its creation did not initiate the cooperation, which was already several decades old, but it gave it a more stable and visible scientific anchor in Benin.

Since 2014, the partnership has expanded considerably. Joint research has

see **WORKIING TOGETHER** *page 10*

WORKING TOGETHER

continued from page 9

been conducted in both population- and hospital-based settings covering epilepsy, dementia, stroke, and other neurological disorders. Research has also covered cancers, mental health, alcohol-related disorders, and other chronic diseases.

The thematic extension from neuroepidemiology to chronic disease epidemiology has been progressive and coherent, because many of these conditions share common methodological, health, and public health challenges. These include case identification, access to diagnosis, treatment gaps, long-term follow-up, stigma, disability, and integration into primary care and public health policy.

Training has been one of the most visible and durable outputs of the cooperation. Between 2010 and 2025, the available institutional figures report more than 20 jointly supervised master's students, 16 doctoral theses, eight ongoing university theses in cotutelle, and more than 60 joint Medline-indexed publications. Selected examples can be found in the References section.[1,2,3,4,5]

These figures show the scale and regularity of the partnership. The cooperation has not been limited to occasional exchanges; it has generated a continuous pipeline of trained students, doctoral candidates, researchers, and academic leaders.

The second edition of Appui au Développement de l'Enseignement Supérieur Français en Afrique (ADESFA), a fund from the French Ministry of Foreign Affairs for the development of French higher education in Southern and Eastern Africa, was launched in 2020. It represented a major step in structuring training. It supported the development of a joint public health master's program in neuroepidemiology involving the universities of Limoges, Cotonou, and Parakou.

The inclusion of the University of Parakou is important, because it shows that the partnership was not limited to the University of Abomey-Calavi and was already opening toward a broader Beninese academic network. ADESFA II helped strengthen local training capacities, harmonize curricula, and build a license-master-doctorate continuum in public health in Benin. It also contributed to the emergence of a new pool of students and young researchers able to work on epidemiology, neuroepidemiology, and chronic diseases.

INSPIRE UAC

This dynamic is now continuing with the Innovation Santé Publique Internationale Recherche Enseignement à l'Université d'Abomey-Calavi (**INSPIRE-UAC**) project from the French Development Agency and the French National Research Agency. This is a larger structuring project devoted to international public health innovation, research, and education at the University of Abomey-Calavi.

INSPIRE-UAC aims to strengthen public health training offerings, including neuroepidemiology across the university system, from bachelor's to doctoral level. It is also designed to reinforce the coherence of public health pathways. Although UAC is the central Beninese institution in the project, the University of Parakou is also expected to cooperate in this new phase, in continuity with its involvement in ADESFA. This is important because the long-term objective is not only to reinforce one program, but to contribute to the structuring of a national and regional training ecosystem in public health.

INSPIRE-UAC also represents a change in scale. It is no longer only a matter of individual mobility, co-supervision, or short teaching missions. The project includes curriculum structuring, professionalizing training pathways, doctoral training, digital teaching infrastructure, and pedagogical engineering. The development of a shared Moodle learning management system (LMS), pedagogical support from Limoges, and training of teachers in the use of digital tools all illustrate the movement from a bilateral academic exchange toward a more integrated educational partnership.

Capacity-building activities have also continued through international courses and targeted training. In 2025, international courses were organized in Benin on subjects including:

- epidemiology
- neuroepidemiology and vascular neurology
- epidemiology and occupational and environmental risk assessment

These activities aimed to strengthen practical skills in data collection, analysis, interpretation, and application of epidemiological methods. They also brought together neurologists, cardiologists, internists, psychiatrists, public health doctoral students, epidemiologists, and other health professionals, thereby reinforcing the multidisciplinary character of the cooperation.

The partnership has also gained institutional and political visibility. Visits to LEMACEN by French senators in 2024 and French deputies in 2025 should be seen as milestones in the recognition of the cooperation. They illustrate that the partnership is no longer only an academic or scientific relationship, but also part of a wider framework of university diplomacy, Francophone cooperation, and international development.

Similarly, the planned Fête de la Science in Cotonou in September 2026 will extend the cooperation toward public engagement, science communication, gender equity in science, career orientation and links with socioeconomic partners.

Several research projects have contributed to this progressive consolidation. They were funded by diverse sources, including the French National Research Agency, the Nouvelle-Aquitaine Region, Sanofi Global Health Unit, and IRD (the French Institute for Research and Development). Together, they show that the partnership has been supported by a succession of national, regional, private and international funding mechanisms.

EMPOWER

The most recent large-scale development is EMPOWER, funded by the European Union's Horizon Europe research and innovation program, coordinated by the University of Limoges through EpiMaCT and involving LEMACEN. The EMPOWER project focuses on people living with noncommunicable diseases (including neurological diseases), frontline health workers, and digital health tools in sub-Saharan Africa.

EMPOWER includes the University of Abomey-Calavi as a full partner, alongside institutions from Togo, Italy, Switzerland, Luxembourg, and the Université Numérique Francophone Mondiale (UNFM). This project marks another change of scale: The Limoges-Benin cooperation has become part of a wider international implementation-research consortium addressing chronic diseases and health system strengthening in West Africa.

The cooperation has grown through successive stages, from early links in tropical neurology and individual training to a structured institutional partnership. It then expanded through joint master's and doctoral training, shared research, and co-authored publications. More recently, larger projects helped structure public health training in Benin.

The partnership is now entering a new phase through major international projects. The central strength of the cooperation lies in its continuity. It has survived institutional changes, changes in research unit names, evolving scientific priorities, and successive generations of academic leaders. Its continuity is also embodied by the fact that both the founder and the current director of LEMACEN are professors of neurology who followed part of their academic training in Limoges. This creates a rare form of partnership, where institutional history, scientific trust, and human trajectories reinforce each other.

Over more than four decades, the Limoges-Benin cooperation has moved from pioneering academic exchange in tropical neurology to a comprehensive partnership in neuroepidemiology, chronic disease epidemiology, and public health. It has contributed to training, research capacity, doctoral supervision, scientific production, curriculum development, digital education, international projects, and public engagement.

The current goal of the Limoges-Benin cooperation is to support a center of excellence in public health and chronic disease epidemiology in Benin. This will be rooted in neuroepidemiology but open to the broader challenges of noncommunicable diseases and global health. •

Dieu donné Gnonlonfoun is a professor of neurology and director of the Laboratory of Epidemiology of Chronic and Neurological Diseases at the University of Abomey-Calavi in Cotonou, Benin. **Jérémy Jost** is a professor of clinical pharmacy at the University of Limoges and is affiliated with the Institute of Epidemiology and Global Health-Michel Dumas. **Dismand Houinato** is a professor and honorary director of the Doctoral School in Health Sciences at the University of Abomey-Calavi. **Pierre-Marie Preux** is a professor of epidemiology and head of the epidemiology department at the University of Limoges.

References:

1. Houinato D, Yemadje LP, Glitho G, Adjien C, Avode G, Druet-Cabanac M, Preux PM. Epidemiology of epilepsy in rural Benin: prevalence, incidence, mortality, and follow-up. *Epilepsia*. 2013 Apr;54(4):757-763. doi:10.1111/epi.12082.
2. Cossi MJ, Gobron C, Preux PM, Niama D, Chabriat H, Houinato D. Stroke: prevalence and disability in Cotonou, Benin. *Cerebrovasc Dis*. 2012;33(2):166-172. doi:10.1159/000334195.
3. Paraïso MN, Guerchet M, Saizonou J, Cowppli-Bony P, Mouanga AM, Nubukpo P, Preux PM, Houinato DS. Prevalence of dementia among elderly people living in Cotonou, an urban area of Benin (West Africa). *Neuroepidemiology*. 2011;36(4):245-251. doi:10.1159/000328255.
4. Houehanou YC, Lacroix P, Mizehoun GC, Preux PM, Marin B, Houinato DS. Magnitude of cardiovascular risk factors in rural and urban areas in Benin: findings from a nationwide STEPS survey. *PLoS One*. 2015 May 6;10(5):e0126441. doi:10.1371/journal.pone.0126441.
5. Wachinou AP, Houehanou C, Ade S, Totah T, Berger M, Solelhac G, Amidou S, Fiogbe AA, Alovokpinhou F, Lacroix P, Preux PM, Marques-Vidal P, Agodokpessi G, Houinato D, Heinzer R. Prevalence of sleep-disordered breathing in an African general population: The Benin Society and Sleep (BeSAS) study. *Lancet Respir Med*. 2022 Sep;10(9):831-839. doi:10.1016/S2213-2600(22)00046-7.

WORLD BRAIN DAY 2026

From Legacy to Collective Action in the Philippines

The 2026 ALRAN Forum marked World Brain Day with presentations, government representatives, and a challenge to view brain health as a national priority.

BY MARK ANTHONY STA. MARIA

In celebration of World Brain Day, the Philippine Neurological Association (PNA) launched the inaugural Advancing Leadership, Research, and Advocacy in Neurology (ALRAN) Forum on July 22, 2026, in Manila. More than a commemorative event, the forum was established as a permanent platform where leaders from medicine, government, academia, research institutions, civil society, patient groups, and the private sector could work together toward better neurological health for every Filipino.

The forum honored the enduring legacy of Dr. Alfredo "Alran" Bengzon, one of the founding pioneers of Philippine neurology and a leader whose influence extended far beyond clinical medicine. A neurologist, educator, institution-builder, health care executive, public servant, and former secretary of health, Dr. Bengzon demonstrated throughout his life that the most difficult health problems could not be solved within the walls of hospitals alone. His leadership connected physicians with policymakers, hospitals with universities, government with civil society, and professional excellence with compassion and social responsibility.

This spirit of connection became the premise of the ALRAN Forum. Its goal is to transform dialogue into coordinated action, including:

- identifying gaps in neurological care
- developing practical solutions
- generating evidence
- influencing policy
- strengthening health systems
- ensuring timely, equitable, and high-quality neurological services throughout the country

A portrait of Dr. Alfredo "Alran" Bengzon, for whom the ALRAN Forum is named.

Beginning with this inaugural gathering, the forum is envisioned as an annual World Brain Day event in the Philippines that will institutionalize multisectoral collaboration for brain health.

Presentations

The day's presentations revealed both the progress and the unfinished work of Philippine neurology. Speakers described the increasing burden of neurological disorders and the persistent maldistribution of neurologists, training institutions, diagnostic facilities, and treatment resources. Philippine data demonstrated major disparities between public and private hospitals, particularly in stroke diagnosis, treatment, rehabilitation, and outcomes.

Government representatives presented ongoing initiatives involving the Mental Health Act, the National Stroke Policy, regional brain and spinal care centers, the Mental Health Gap Action program, medicines access sites, benefit packages, health technology assessment, and the Philippine Brain Research Agenda. Together, these discussions emphasized that access to neurological care is determined not only by clinical expertise, but also by geography, financing, infrastructure, research capacity, referral systems, and the strength of primary health care.

Representatives from academia, business, and civil society further challenged participants to view brain health as a societal and developmental priority. The concept of "brain capital" highlighted how healthy brains, cognitive abilities, emotional resilience, and human skills contribute to national productivity and economic progress. Civil society perspectives returned the discussion to one of Dr. Bengzon's most important questions: What about the people who never make it through the hospital door? The answer required moving beyond institution-centered care toward meaningful engagement with communities, local governments, patient advocates, and organizations that understand the lived realities of underserved Filipinos.

The Philippine Neurological Association Position Statement on Brain Health, formally declaring the PNA's aspiration to serve as the national steward of brain health in the country.

Attendees listen to one of many guest speakers at the 2026 ALRAN Forum in Manila, Philippines.

Attendees of the 2026 ALRAN Forum.

PNA Position Statement on Brain Health

The forum reached its climax during the facilitated panel discussion where participants began translating the day's insights into concrete proposals. These included involving local governments and barangay health workers in prevention programs; integrating PNA regional chapters with regional councils for mental health; developing locally responsive provincial referral networks; assigning neurologist mentors to support primary health care workers; helping hospitals prepare technically sound proposals for facilities and equipment; and providing scholarships and training pathways for future neurologists from underserved regions.

The discussions culminated in the presentation of the PNA Position Statement on Brain Health, formally declaring the PNA's aspiration to serve as the national steward of brain health in the country. The statement called for a shift from reactive, disease-centered care toward lifelong brain health promotion, prevention, early recognition, timely intervention, and equitable access. Its five-point call to action committed the association to lead public awareness initiatives, advance meaningful research, embed preventive neurology into clinical practice, strengthen the capacity of health care professionals, and continually convene intersectoral partners.

The inaugural ALRAN Forum concluded not simply with a summary of discussions, but with a commitment to continuity. Each World Brain Day, the forum will bring sectors together to assess progress, strengthen partnerships, and transform knowledge into policies, programs, and measurable improvements in care. In honoring Dr. Bengzon, the PNA did more than remember an exceptional leader; it carried forward his conviction that health is a fundamental human right and that achieving it is a shared responsibility.

The ALRAN Forum in the Philippines now stands as both a tribute and a promise: an annual gathering in which leadership inspires collaboration, research guides policy, advocacy mobilizes communities, and collective action advances brain health for every Filipino. •

Mark Anthony Sta. Maria is co-chair of the ALRAN Forum 2026 for the Philippine Neurological Association.

WORLD BRAIN DAY 2026

Getting the Word Out About Brain Health in Austria

TV appearances highlight awareness and prevention as part of World Brain Day activities in Austria.

BY WALTER STRUHAL AND JULIA FERRARI

The **Austrian Society of Neurology** (ÖGN – Österreichische Gesellschaft für Neurologie) participated in the World Federation of Neurology's World Brain Day 2026 to raise awareness about neurology in Austria.

The ÖGN celebration highlighted the importance of neurological prevention, promoting brain health among the Austrian population, the significant benefits of rapid response, and the broad scope of the field, including neurorehabilitation. Adequate neurological manpower and low-threshold inclusive access are key to reducing disease morbidity and mortality in neurology.

Austria provides high-quality neurological care with continuous advancements in treatment and innovative therapies. These include a national stroke system with certified stroke and thrombectomy units, as well as specialized care for epilepsy, Parkinson's disease, neuroimmunology, neuromuscular diseases, and dementia. These treatments include novel monoclonal antibody therapies.

Equal and inclusive access to specialized services — particularly in neurointensive care, acute care, neurological rehabilitation, and outpatient care based on public insurance — is essential for the high-level service spectrum in Austrian neurology.

On World Brain Day 2026, ÖGN President Julia Ferrari and President-Elect Walter Struhal made a total of five live appearances on national public TV station ORF. Throughout the day, from morning TV to afternoon news and an evening studio talk, they promoted key points on brain health, risk factors, prevention, and inclusive access to the broad range of neurology services.

These appearances aimed to raise public awareness about brain health, prevention of neurological diseases, and early access to services. •

Prof. Julia Ferrari is president of the ÖGN and head of the Department of Neurology, Neurological Rehabilitation, and Acute Geriatrics at Barmherzige Brüder Hospital Vienna. **Prof. Walter Struhal** is president-elect of the ÖGN and head of the Department of Neurology at University Clinic Tulln-Klosterneuburg, Karl Landsteiner University of Health Sciences.

Prof. Julia Ferrari, president of ÖGN, appears on ORF (Austria's national public broadcast) Studio 2.

Prof. Julia Ferrari (left), president of ÖGN, is interviewed on ORF Studio 2, a popular TV magazine broadcast in Austria.

Prof. Walter Struhal (left), president-elect of ÖGN, appears on ORF Guten Morgen Österreich, Austria's national breakfast TV show.

Prof. Walter Struhal (left), president-elect of ÖGN, appears on ORF Aktuell nach eins, a daily, lunchtime TV news and information magazine broadcast.

WORLD BRAIN DAY 2026

World Brain Day Celebrations in India

The Indian Academy of Neurology sponsored in-person awareness programs, online seminars, and media outreach to raise awareness about brain health.

BY CHANDRASHEKHAR MESHRAM, SUDHIR KOTHARI, R. LAKSHMINARASIMHAN, AND U. MEENAKSHISUNDARAM

Highlights from India's celebrations of World Brain Day 2026.

Every year on World Brain Day, the Indian Academy of Neurology (IAN) promotes awareness of brain health to the masses. This is accomplished through a combination of in-person activities, virtual sessions, social media posts, and mass media publications by IAN members.

This year, IAN leadership including President-Elect Dr. Sudhir Kothari organized a virtual meeting with chairs and conveners from all 22 IAN subsections. Dr. Kothari briefed attendees about the need to conduct awareness activities in line with the theme of this year's World Brain Day: "Brain Health: Access for All."

Many IAN members organized in-person awareness programs for their patients. Prominent among them was a collaborative event for awareness and advocacy organized by Dr. Poornima Gauri in Pune, India. The event was called Rishton Ka Manja, where music meets brain and mind wellness.

On July 25, 2026, the Movement Disorders subsection of IAN conducted a webinar titled "Movement Disorders: Access for All." IAN members, who are experts in the management of movement disorders, spoke on various management modalities. This was followed by a panel discussion with experts. The session was well publicized on the IAN social media feeds and was well attended by IAN members as well as patients, caregivers, and the population at large.

On social media, the IAN posted a message to promote awareness of "Brain Health: Access for All." Some IAN subsection leaders gave short video messages. These simple messages were collated and published on the IAN social media platforms.

Many cities across the country noted active participation:

Nagpur, India

Nagpur Neuro Society (NNS), under the aegis of IAN, organized various activities over the week under guidance of Prof. Chandrashekhar Meshram.

The NNS hosted Walk for Brain on July 22. The event was flagged off by Dr. Meshram, World Federation of Neurology (WFN) trustee and Padma Shri awardee. Despite rainy weather, more than 200 people walked 4 km through the city, beginning at the Indian Medical Association auditorium. Walkers carried placards with messages such as "Our Brain, Our Future," "It Is Your Brain, Use it or Lose it," "Brain Health, Supreme Wealth," "Proper Diet for Healthy Brain," "Epilepsy Is Treatable: Don't Hide it," "Clean City, Healthy Brain," "Avoid Air Pollution for Healthy Brain," and "Stroke Is a Brain Attack — Reach Hospital Immediately."

Dr. Meshram explained the importance of this year's World Brain Day theme and suggested tips to preserve brain health and prevent neurological diseases. Dr. Ketan Chaturvedi, NNS secretary, Dr. Satish Lahoti, joint secretary, and other members actively participated in the event.

Beginning July 22, talks and interviews on different topics were aired twice daily for seven days on All India Radio. Topics included:

- "Brain Health: Access for All," by Dr. Meshram
- "Epilepsy," by Vasant Dangra
- "Stroke and Neurointervention," by Lahoti
- "Dementia and Parkinsonism," by Nikhil Dongre
- "Head Injury," by Jitendra Tadghare
- "Trigeminal Neuralgia," by Palak Jaiswal
- "Brain Tumors," by Pramod Giri

The information reached several hundred thousand people. Similar messages also appeared in newspapers throughout the week.

There were also several educational events held throughout the city**.** Amrit Bansod conducted an awareness activity on "Brain Health: Access for All" at the KDK College of Pharmacy and Research Institute in Nandanwan, Nagpur.

An interactive awareness session on "Ancient Brain in the Modern AI World" was conducted at JSW Kalmeshwar by Jeevan Kinkar and Paresh Korde. Participants discussed how our ancient brain is adapting to the challenges of today's AI-driven world, including digital overload, constant notifications, shrinking attention spans, and information overload. They also covered practical, neuroscience-based strategies to improve focus, productivity, and long-term brain health.

Vasant Dangara and Amarjeet Wagh conducted an awareness session on pediatric epilepsy in collaboration with Nagpur Epilepsy Association.

Nitin Virwani published an article in the newspaper to create awareness about World Brain Day in Akola, India.

Pune, India

Celebrating World Brain Day in Pune, India, Poornima Gauri of the NICHE Advocacy Foundation, along with DES Brijlal, of Jindal College of Physiotherapy, organized NeuroHarmony 2.0.

Aligning with World Brain Day's theme of "Brain Health: Access for All," NeuroHarmony 2.0 conducted various scientific sessions and advocacy programs throughout its conference July 23-26 at the NM Wadia Amphitheatre in Fergusson College in Pune, India. Interdisciplinary collaboration to improve the quality of neuro-health care was the foundation of the conference.

With the vision of redefining neuro-health care, the mission was to bridge the gaps in neuro-health care services and upgrade the knowledge, attitude, and skills of allied neuro-health care students and professionals. Through this platform, they were able to successfully connect researchers, practitioners, and students from various disciplines.

Diverse perspectives and research findings were shared. We also reached the populace through our public forum events and raised awareness and advocacy about neuro-health care. Through this conference, organizers laid the foundation for better teamwork and quality of care in neuro-health care services.

Mumbai, India

Nirmal Surya organized an awareness session on brain health through the Epilepsy Foundation on July 21. He organized a webinar on "Brain Health: Access for All." WFN President Steven Lewis and the World Brain Day Co-Chair Tissa Wijeratne participated in the activity.

Trichy, India

To mark World Brain Day 2026, M.A. Aleem published articles in newspapers. He gave a talk on brain health for school children in a program organized by the Anna Science Centre Planetarium.

Response from IAN members as well as the public was promising, and IAN plans to continue its focus on patient and public awareness to promote brain health. •

Chandrashekhar Meshram is a WFN trustee. Sudhir Kothari is president-elect of the Indian Academy of Neurology (IAN). **R. Lakshiminarasimhan** is president of the IAN. **U. Meenakshisundaram** is secretary of the IAN.

See next page for a look at the celebrations, activities and media coverage of World Brain Day 2026 in India.

WORLD BRAIN DAY 2026: INDIA

जागतिक मेंदू दिनानिमित्त जनजागृती; 'वॉक फॉर ब्रेन'मधून व्यायामाचे महत्त्व अधोरेखित

Updated: July 23, 2026 14:30 IST

नवभारत

Akola | 23 July 2026 | Page 1

विश्व मस्तिष्क दिवस | लक्षणों को पहचानकर शीघ्र उपचार जरूरी : डा. वीरवानी

किसी भी आयु में दिमागी बीमारी संभव

लोकमत

वयाच्या ५५ वर्षानंतर दरवर्षी मेंदू दोन टक्क्यांनी होतो संकुचित

व्यायामामुळे मेंदूच्या पेशींच्या वाढीला चालना

Hello Nagpur
Page No. 5 Jul 24, 2026
Powered by: erelego.com

Exercise can cut dementia risk by 30%: Dr Meshram

Regular exercise keeps body fit and brain healthy

LOKMAT NEWS NETWORK
NAGPUR

Regular exercise is essential not only for keeping the body healthy but also for maintaining good brain health. People who exercise regularly have nearly a 30 per cent lower risk of developing dementia compared to those who do not exercise.

Padma Shri Dr Chandrashekhar Meshram, Trustee of the World Federation of Neurology, said that regular physical activity can also slow the natural shrinking of the brain, which typically occurs at a rate of 1 to 2 per cent each year after the age of 55.

Dr Meshram was speaking at the closing ceremony of the 'Walk for Brain' walkathon organised by the World Federation of Neurology to mark World Brain Day. The walkathon began from the IMA Hall on North Ambazari Road and was flagged off by Dr Meshram. Several doctors, including Dr Ketan Chaturvedi and Dr Pavitra Patnaik from the Neuro Society, were present on the occasion.

Dr Chandrashekhar Meshram

Women, children, medical students and representatives of various social organisations took part in the walkathon. Carrying banners promoting brain health awareness, participants encouraged people to adopt regular exercise and a healthy lifestyle. Despite the rain, the enthusiasm of the participants remained high.

Dr Meshram explained that regular exercise helps develop new neural connections in the brain, improving memory, concentration and decision-making ability. Exercising in the morning keeps the brain more active, enhances the ability to cope with stress and makes it easier to retain new information. He urged people to make regular exercise a part of their daily routine to keep both their body and brain healthy.

The event received special support from Dr Satish Lahoti, Dr Nilesh Agrawal, Dr Tushar Patil, Dr Dhruv Batra, Dr Jitendra Tadghare, Dr Ajay Kurve, Dr Sandeep Iratwar, Dr Vasant Dangra, Dr Abhishek Wankar, Dr Vishal Dabhare, Dr Sachin Gathe, Dr Palak Jaiswal, Dr Kedar Takalkar and others.

तरुण भारत

पावसातही 'वॉक फॉर युअर ब्रेन'

जागतिक मेंदू सप्ताह प्रारंभ

मेंदू विकारामुळे दरवर्षी ११ लाख मृत्यू

आज जागतिक मेंदू दिन

पुण्य नगरी

नियमित व्यायामाने ३० टक्क्यांनी घटतो स्मृतिभ्रंशाचा धोका

पद्मश्री डॉ. चंद्रशेखर मेश्राम यांचे प्रतिपादन

जागतिक मेंदू सप्ताहानिमित्त घेण्यात आली वॉकेथॉन

Nagpur Edition
Jul 24, 2026 Page No. 02
Powered by: erelego.com

लोकमत समाचार

सिटी न्यूज़

स्वस्थ मस्तिष्क चाहिए तो पैदल चलना जरूरी

लोकमत समाचार सेवा

Nagpur Main
Page No. 5 Jul 27, 2026
Powered by: erelego.com

Planetarium organises talk on brain health

The Hindu Bureau
TIRUCHI

Anna Science Centre-Planetarium observed World Brain Day by organising an awareness talk for schoolchildren by city-based neurologist M.A. Aleem on Wednesday.

In his address, Dr. Aleem gave an overview on brain health and how mental wellness helps students improve concentration, memory power, learning, and emotional balance.

"A healthy brain is the foundation of a successful life. Many students face academic pressure, competitive exams, mobile phone addiction and anxiety caused by various factors, that can affect brain health if not managed properly," he said.

He advised students to eat nutritious food and avoid excess junk food, sugary drinks, and caffeine. He encouraged them to maintain a regular sleep schedule besides cultivating other healthy habits.

The Hindu Trichy 31.07.2026

मेंदू विकारांमुळे दरवर्षी होतात ११ दशलक्ष मृत्यू

आज जागतिक मेंदू दिन : कमी उत्पन्न असलेल्या देशांत ८० टक्के प्रमाण

सकाळ वृत्तसेवा

डॉ. चंद्रशेखर मेश्राम | डॉ. प्रमोद गिरी | डॉ. केतन चतुर्वेदी | डॉ. स्टीफन लुईस

९० टक्के पक्षाघात टाळणे शक्य

३.४ अब्जांवर नागरिक आजाराने ग्रस्त : डॉ. चंद्रशेखर मेश्राम

Nagpur Main
22/07/2026 Page No. 202

WORLD BRAIN DAY 2026

Improving Outcomes for Neurological Disorders Worldwide

Northwestern University celebrates World Brain Day.

BY CAROLINE GEBCZAK AND DYLAN R. RICE

Neurological disorders are now the leading cause of disability worldwide, affecting people in every country and health care system. More than 3.4 billion people (over 40% of the global population) were living with a neurological condition in 2021, and more than 80% of neurological deaths and health loss occur in low- and middle-income countries (LMICs).[1] As the burden of neurological disease continues to grow, improving brain health will require stronger international partnerships, research collaborations, and investments in the neurological workforce and its next generation.

With these priorities in mind, Northwestern University, based in Chicago, recently established the Center for Global Neurology, a joint effort between the **Robert J. Havey, MD Institute for Global Health** and the **Ken & Ruth Davee Department of Neurology** at Northwestern University.

Building upon six years of growth as a program for global neurology, the center was formally launched in June 2026 with Farrah J. Mateen, MD, PhD, serving as its inaugural director. The center succeeds the Program for Global Neurology founded in 2020 by Igor Koralnik, MD, whose leadership helped Northwestern establish international collaborations in neurovirology, education, and global health.

The center was created around a simple yet ambitious mission: to improve the outcomes of people living with, or at risk for, neurological disorders worldwide, with particular attention to vulnerable populations in low- and middle-income countries (LMICs). The center will serve as a multidisciplinary hub that connects clinicians, scientists, trainees, and global partners working across a variety of neurological subspecialties.

To date, the center has grown to include more than 100 members, including students, staff, residents, and fellows as well as 18 dedicated faculty members. They are all committed to addressing issues related to neurological disorders in global settings. The center faculty collaborates with colleagues in 18 countries, including 15 LMICs, spanning Africa, Asia, Europe, North America, and South America.

Faculty members are adult and pediatric neurologists, adult and pediatric neurosurgeons, physiatrists, and scientists in epidemiology and laboratory sciences. These partnerships are founded on long-term relationships, reciprocal learning, and a shared commitment to strengthening neurological care, education, research, and advocacy.

Members of Northwestern's Center for Global Neurology at the World Brain Day inaugural event in Chicago.

The center organizes its work around four interconnected themes: global brain health, global neuro-technologies, global neuro-infections, and capacity building in LMICs. Together, these themes reflect the growing recognition that neurological disorders cannot be addressed through isolated efforts alone. Instead, they require collaboration across disciplines, countries, and health systems. Examples of this work are already underway.

Dr. Mateen leads several initiatives in the Republic of Guinea, underscoring the center's commitment to sustainable partnerships and capacity building. The Guinea Epilepsy Project has over the span of 10 years developed one of the region's largest prospective epilepsy cohorts while providing access to anti-seizure medications and physician training.

Building upon this infrastructure, new collaborative studies are evaluating innovative approaches to diagnosing neuromyelitis optica (NMO). These approaches include filter paper-based aquaporin-4 antibody testing that could expand access to diagnosis in resource-limited settings. These projects are designed not simply to answer research questions, but to strengthen long-term neurological care and research capacity alongside local Guinean collaborators.

In Nigeria, Dr. Philip Gorelick, MD, MPH, and colleagues are working with Aminu Kano Teaching Hospital to evaluate scalable, low-resource stroke unit models that can improve stroke outcomes throughout sub-Saharan Africa. He also directs the Multidisciplinary NeuroAIDS Research and Training Program, which mentors early- and mid-career investigators at the University of Ibadan through research training focused on HIV-associated neurological disorders, stroke, and related conditions. These initiatives reflect the center's emphasis on

see **WBD AT NORTHWESTERN** *page 16*

From left to right: Kate Klein, administrative director of the Havey Institute for Global Health, Dr. Roxanna Garcia, center faculty member, Dr. Robert Murphy, executive director of the Havey Institute for Global Health, Dr. Sandi Lam, center faculty member, and Dr. Farrah Mateen, director of the center.

Dr. Sandi Lam discusses remote-mentored distributed care for multidisciplinary surgical treatment of epilepsy in Uganda.

WBD AT NORTHWESTERN

continued from page 15

developing sustainable research leadership alongside improvements in acute and rehabilitative neurologic patient care.

Under the leadership of Dr. Koralnik, investigators have established international collaborations examining the neurological manifestations of long COVID across Colombia, India, Nigeria, and the United States. Comparative studies from his research team have demonstrated that sociocultural factors, health care access, and differences in perceptions and reporting of mental health and cognitive symptoms may contribute to variations in the experience of long COVID across countries.[2]

The center also supports innovative investigations into neurological infections: Dr. Rafal Sobota, MD, leads studies in Blantyre, Malawi, examining molecular markers of cerebral malaria to identify biomarkers that distinguish severe disease and improve prediction of neurological outcomes. Such work illustrates how advances in laboratory science may ultimately improve diagnosis and treatment for some of the world's most disabling neurological diseases.

Beyond faculty research projects, education remains central to the center's mission. Since the inception of the Program for Global Neurology, Northwestern neurology residents participate in a month-long elective at the University Teaching Hospital in Lusaka, Zambia, where they are mentored and taught by local Zambian-based neurologists, in inpatient and outpatient settings, who generously educated Northwestern's neurologists-in-training.

Also, the McGaw Global Health Clinical Scholars Program is a two-year Northwestern University program that offers residents and fellows training in clinical care delivery in resource-limited settings worldwide. These opportunities emphasize long-term institutional partnership rather than short-term international experiences. The center also collaborates with the Roberta Buffett Institute and the Division of Multiple Sclerosis & Neuroimmunology, which have hosted the center's first four undergraduate student interns.

As the Center for Global Neurology continues to grow, it will serve as a home for students, residents, fellows, and faculty interested in global neurology. Through seminars, mentorship, collaborative grant development, and interdisciplinary programming, it aims to foster a growing community committed to advancing neurological health worldwide.

Celebrating World Brain Day 2026

The center officially celebrated its launch by hosting its inaugural World Brain Day event on July 22, 2026, joining colleagues around the world in recognizing the annual initiative led by the World Federation of Neurology (WFN).

The event brought together more than 150 members of the Northwestern University community, including faculty, trainees, students, and staff, for an afternoon dedicated to promoting brain health from a global perspective. The event featured a Pecha Kucha symposium, a dynamic presentation format originating in Japan in which speakers present 20 slides for 20 seconds each. This fast-paced style allowed participants to share a diverse range of ideas, experiences, and perspectives on global neurology and brain health.

Presentations highlighted stroke prevention, biomarkers of cerebral malaria, global neurosurgery, refugee sleep health, neurovirology, exercise and brain health, community neurology, and innovations in neurological care delivery. Together, the presentations reflected the diversity of expertise across the center's members while reinforcing the common message: Improving brain health requires collaboration across specialties, institutions, and countries.

The event featured a Pecha Kucha symposium, a dynamic presentation format originating in Japan in which speakers present 20 slides for 20 seconds each. This fast-paced style allowed participants to share a diverse range of ideas, experiences, and perspectives on global neurology and brain health.

As the inaugural event of the Center for Global Neurology, World Brain Day acted not only as a celebration of brain health for all, but also as a statement of the center's commitment to the global community.

Future Plans

Looking ahead, the Center for Global Neurology is planning several events to continue engaging the Northwestern and broader community in global health efforts. In September 2026, Northwestern will host a screening and discussion of *Medical Stories — Neuromyelitis Optica Spectrum Disorder: Blindsided Within*, a World Health Organization-recognized documentary featuring patient-advocate Sumaira Ahmed, founder of **The Sumaira Foundation**. The screening and discussion will highlight the importance of patient advocacy, public engagement, and international awareness for rare neurological diseases.

Although formally established only this year, the Center for Global Neurology builds upon years of international collaboration. As neurological disorders continue to represent one of the greatest global health challenges of our time, progress will depend upon further collaboration across borders. Northwestern's Center for Global Neurology looks forward to working alongside colleagues, institutions, and organizations — including the WFN — to advance equitable neurological care and improve brain health for populations worldwide.

For more information about the Center for Global Neurology, visit the **Northwestern University Center for Global Neurology website** or reach out via email at **centerforglobalneurology@northwestern.edu**. •

Caroline Gebczak is a clinical research coordinator, and **Dylan Rice** is a clinical research project manager in the Department of Neurology at the Northwestern University Feinberg School of Medicine. Both are coordinators for the Center for Global Neurology at the Havey Institute for Global Health.

References:

1. Steinmetz JD, Katrin Maria Seeher, Schiess N, Nichols E, Cao B, Chiara Servili, et al. Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021. *The Lancet Neurology* [Internet]. 2024 Mar 1 [cited 2026 Aug 5];23(4). Available from: https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(24)00038-3/fulltext.
2. Jimenez M, Lopez M, Miller J, Okubadejo NU, Hurtado C, Singh AK, et al. A cross-continental comparative analysis of the neurological manifestations of long COVID. *Frontiers in human neuroscience* [Internet]. 2026 [cited 2026 Aug 5];19:1760173. Available from: https://pubmed.ncbi.nlm.nih.gov/41685290/.

Attendees at the World Brain Day inaugural event.

Dr. Hrayr Attarian discusses sleep health among refugees.

JUNIOR TRAVELING FELLOWSHIP

Research on Epilepsy, Networking, and a Neurology Department Tour

My experience at the 12th European Academy of Neurology Congress in Geneva.

BY DR. MOHAMED MAHMOUD MOHAMED ABDELHAMID ABDELKAREM

It is a great honor and with gratitude that I write this report as recipient of one of this year's Junior Traveling Fellowship awards from the World Federation of Neurology (WFN).

This generous award provided me with the invaluable opportunity to travel from Egypt to attend the 12th European Academy of Neurology (EAN) Congress June 26-30, in Geneva, Switzerland.

I would like to extend my deepest appreciation to WFN President Prof. Steven Lewis, WFN Vice President Dr. Riadh Gouider, and the entire WFN Education Committee for their commitment to fostering quality neurology and brain health worldwide.

A central focus of my attendance was the opportunity to present our research paper, titled "Beyond Visual Analysis: Uncovering the Electrographic Signature of Genetic Focal Epilepsy Via AI-Driven Gamma Power Quantification."

This research addresses the critical clinical gap in diagnosing focal cortical dysplasia (FCD) type II in pediatric epilepsy. High-field MRIs often fail to detect the microscopic cytoarchitectural disruptions caused by somatic mTOR-pathway mutations, leaving these highly epileptogenic lesions hidden. Furthermore, the tangential dipoles generated deep within the sulci often suffer from volume conduction, making standard EEG visual analysis insufficient.

Through this presentation, I shared our computational quantification approach, demonstrating how analyzing absolute gamma power can extract the hidden, high-frequency physiological footprint of these hyper-excitable cells.

Discussing these findings with leading global experts provided profound insights that will directly impact my ongoing work as a professional master candidate in artificial intelligence in health care.

The congress was not only a platform for presenting research but also an incredible environment for professional growth. Meeting with my mentor, Prof. Taras Voloshyn, in person was a major highlight. Our ongoing discussions regarding my role as a mentee in the EAN Mentorship Program have been instrumental in shaping my clinical and academic trajectory.

I also had a passionate discussion and got many photos with Prof. Julia Mayer, head of the EAN education department. I met new friends and neurologists from different countries, shared information about neurology in each of our countries, and promised to keep in touch for future neurology events.

Together, we had an informative and helpful tour of the neurology department at Geneva University Hospital.

Engaging with neurologists from around the globe reinforced my motivation to advance pediatric neurology networking across Africa, an initiative I am deeply passionate about in my capacity as the country team representative for Egypt for the African Academy of Neurology (AFAN).

Dr. Mohamed Mahmoud Mohamed Abdelhamid Abdelkarem presents a research paper at the European Academy of Neurology Congress.

Attending the 12th EAN Congress has been a milestone in my early career. The knowledge acquired, the connections made, and the exposure to cutting-edge neurological research are assets I brought back to my daily practice in Egypt.

I am profoundly thankful to the WFN, including Jade Levy, project manager, for facilitating this transformative experience. •

Mohamed Mahmoud Mohamed Abdelhamid Abdelkarem is a junior neurology resident at the Suez Medical Complex, Egypt Health Care Authority in Egypt.

WORLD FEDERATION
OF NEUROLOGY

WORLD FEDERATION OF NEUROLOGY DIGITAL NEUROLOGY UPDATES (WNU 2026)

28-29 OCTOBER 2026

EARN UP TO
13 CME CREDITS

Empowering Minds,
Advancing Neurology:
Education and Advocacy for
a Healthier Tomorrow

REGISTER TODAY

wnu-neurology.com

HISTORY

The Framing of Neurasthenia

The diagnosis of neurasthenia evolved from its medical origin before disappearing in the early 20th century.

BY PETER J. KOEHLER

"The history of psychiatry, more than any other branch of the medical sciences, is marked by the phenomenon of 'rising' and 'falling' diseases." – Marc S. Micale.[1]

In Part 1 of this series, **"The Framing of Diseases Throughout History,"** I discussed the concept of "hysteria" through the ages. The condition was already known in classical antiquity, albeit under a different name. Throughout history, it has been framed in different ways and in different contexts, eventually loosening its medical meaning and disappearing over the course of the 20th century. The term itself remained reserved for behavior that exhibits overwhelming or uncontrollable fear or emotional outbursts; in other words, it took on a nonmedical meaning as for instance in "mass hysteria" or "political hysteria."

In this second part, I will discuss neurasthenia or weak nerves. Although the remarkable statement above pertains to psychiatry, this article focuses on a condition that was initially regarded as an organic disorder. Moreover, it takes place in an era when neurology and psychiatry were practiced by a single specialist: a nerve-doctor or neuropsychiatrist. Let us first discuss a case study.

A Famous Case

A nine-year-old French boy began experiencing episodes of "a choking sensation." More episodes followed, especially in the spring. His parents consulted a doctor, Professor C., who, after conducting a differential diagnosis, ultimately concluded that the boy had asthma. In the 19th century, this had been considered a neurosis.

As an adult, the person was believed to suffer not only from asthma, but also from sleep disorders. He appeared to be sensitive and had a heightened awareness. For some time, he was admitted to a sanatorium for neurotic persons as advised by Dr. S. At the age of 51, he thought he was having a stroke, from which his mother had suffered, and consulted Dr. B. It turned out, however, to be barbiturate intoxication. Not long after, he died of bronchitis. As it happened, his father had written a book in collaboration with a neuropsychiatrist on neurasthenia several decades earlier. After all, this was also the diagnosis that was applied to the patient.

Many of you may have recognized the patient as the famous author of the seven-volume novel "A la Recherche de Temps Perdu (Remembrance of Things Past)"(1913-1926), one of the two novels considered to be the best of the 20th century (the other being James Joyce's "Ulysses," 1922). We are talking about Marcel Proust (1871-1922) and his physician-neuropsychiatrist professor Jules Cottard (1840-1889; his name is associated with the Cottard delusion, in which the patient believes he is dead or does not exist), Paul Sollier (1861-1933), and last but not least, Joseph Babinski (1857-1932).

Weakening of Nerve Function

Adrien Proust (1834-1903), Marcel's father, a professor in the department of hygiene at the Paris Faculty of Medicine, and Charcot's pupil, neuropsychiatrist Gilbert Ballet (1853-1916), had published "L'hygiène du Neurasthénique" in 1897 (See Figure 1), during a period in which the diagnosis neurasthenia had become fashionable.

Although the term had been mentioned earlier in the 19th century, neurasthenia or nervous exhaustion was described by New York neurologist George M. Beard (1839-1883; see Figure 2) in an article in 1869 and more extensively in his monographs of 1880 (see Figure 3) and 1881.[2,3,4] The symptoms included:

- chronic fatigue and lack of energy
- headaches, often described as a throbbing sensation
- sleep problems or nonrestorative sleep
- difficulty concentrating and mental fatigue
- sensitivity to noise, light, or stimuli
- digestive problems
- heart palpitations or a feeling of weakness in the body
- irritability and emotional instability
- feelings of anxiety or a depressed mood

In general, it can be said that the diagnosis was based on vague symptoms that were difficult to assess objectively. It became a flexible diagnosis and a catchall term for a wide range of symptoms that were not easily explained from a medical standpoint.[5]

The new disease, however, had already been described in 1867 by Edwin Holmes Van Deusen (1828-1909), asylum physician of Michigan Asylum for the Insane in Kalamazoo, Michigan.[6] He wrote: "As to the term neurasthenia, it is an old term, taken from the medical vocabulary, and used simply because it seemed more nearly than any other to express the character of the disorder and more definite, perhaps, than the usual term 'nervous prostration.'"

Indeed, the term "neurasthenia" can already be found in the fifth edition of Robley Dunglison's "Dictionary of Medical Science" (1845). In the 13th edition of 1856, we find the following description: "Debility or impaired activity of the nerves." Thanks to Beard's post in New York and his in-depth research into what he initially called the "American disease," he was hailed as the discoverer of the new disease, soon to become fashionable. He visited various institutions and gave lectures in Europe, after which he wrote an article on the subject.[7]

Marcel Proust (photograph by Otto Wegener, c. 1895); public domain.

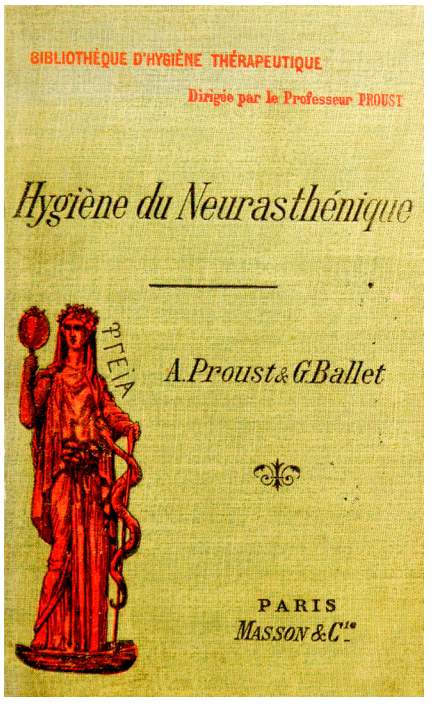


Figure 1. Title page of Hygiène du Neurasthénique (1897); Wellcome Collection, public domain.

Neurasthenia spread to Europe where it found fertile ground, particularly in France and Germany, and to a much lesser extent in England and the Netherlands. In Paris, Charcot believed Beard's 1880 book was a remarkable monograph. Neurasthenic patients accounted for most of the neurological cases he saw in his private practice, and he found them unbearable, writing "Poor Beard."[8]

In his book on neurasthenia, German psychiatrist Rudolf Arndt (1835-1900) was critical, calling it "Yankeekrankheit." He wrote: "Die Krankheit ist immer dagewesen; sie hat nur den Namen gewechselt (The disease has always been around; it has simply changed its name)."[9] Franz Carl Müller (1860-1913), director of a water spa, even published a "Handbuch der Neurasthenie" (1893).[10]

In England, reactions were mixed; there were both supporters and opponents. Thomas Stretch Dowse (1832-1912) published "On Brain and Nerve Exhaustion (Neurasthenia) and on the Nervous Sequelae of Influenza" (1894).[11] Others were critical, arguing that it was simply old wine in new bottles and that it was not limited to a particular social class.

Beard's most important sources for the new disease concept were English physiologist Marshall Hall's (1790-1856)

see **HISTORY** *page 20*

Figure 2. George Miller Beard; National Library of Medicine, digital collections, public domain (NLM Image ID: B02556).

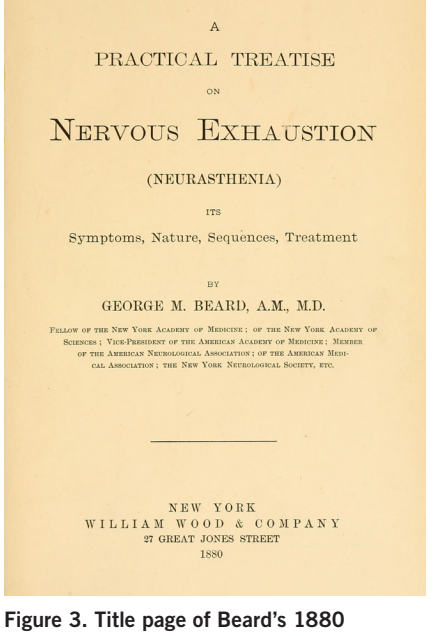


Figure 3. Title page of Beard's 1880 monograph; Wellcome Collection, public domain.

HISTORY

continued from page 19

spinal reflex activity (1833), German physiologist Emile Dubois Reymond's (1818-1896) discovery of the action potential (1848), and American inventor Thomas Edison's (1847-1931) work on electricity. Medical electricity had been the subject of Beard's monograph about a decade earlier: "A Practical Treatise on the Medical and Surgical Uses of Electricity: Including Localized and General Electrization" (1871).[12]

The concept of neurasthenia was linked to new insights in the field of thermodynamics, including the law of conservation of energy. It was believed that overwork, along with toxic, metabolic, and infectious diseases, could cause the condition. Modern civilization — including the telegraph, science, the steam engine, newspapers, and education for women — played an important role.

The diagnosis was primarily made among highly educated individuals and city dwellers, particularly successful men. Beard believed that if it was not treated, it could lead to prolonged depressive mood, chronic physical symptoms, social withdrawal, reduced work productivity, and increased susceptibility to other illnesses. Treatment, he believed, should include rest and recovery, change of scenery, proper nutrition, physical activity, electrical therapy, and psychological support.

From Social to Psychological Etiology

Initially, it was believed that neurasthenia was an organic disorder of the central nervous system and, as mentioned, occurred primarily in highly educated individuals. Businesspeople, doctors, and writers alike could fall victim to it. Several other writers besides Marcel Proust are known to have suffered from neurasthenia and to have written about such characters in their novels (including Henry James (1843-1916), Edith Wharton (1862-1937), and Virginia Woolf (1882-1941)).

However, as fatigue was difficult to measure and the disease lacked neuropathological findings, the organic origin became problematic around 1910. During that period, the disease was gradually diagnosed in people from lower socioeconomic backgrounds, in women, and in immigrants as well. It was no longer "the American disease."

These factors gradually paved the way for a psychological explanation of the condition. Psychological symptoms were no longer considered the result but became a cause. In the meantime, several clinical syndromes branched off from neurasthenia, including anxiety neurosis (Sigmund Freud (1856-1939)) and obsessive-compulsive disorder (psychasthenia, Pierre Janet (1859-1947)).[13] Whereas rest cures, drug treatments, and electrostimulation had previously been used — when the illness was still considered an organic condition — these treatments were now replaced by psychotherapy, and rest cures were regarded as harmful. The role of suggestion was recognized, and the relationship between patient and doctor took on greater significance.

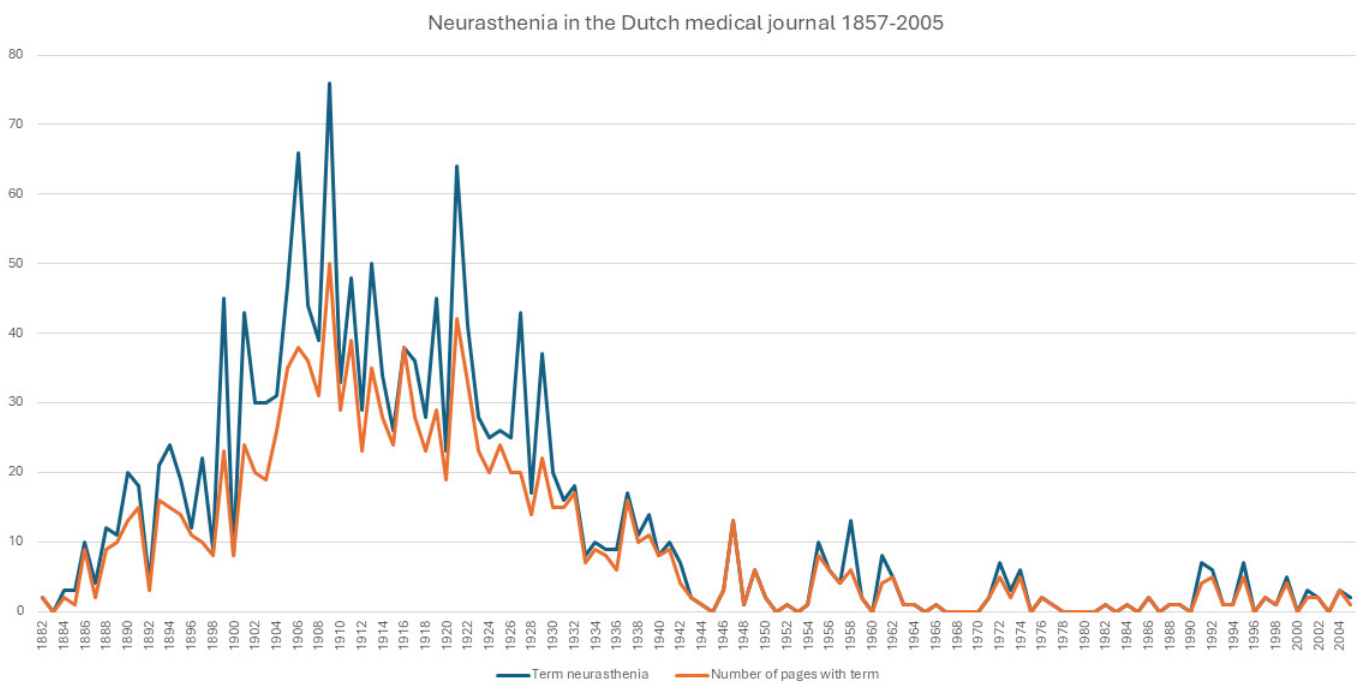


Figure 4. Neurasthenia frequency and number of pages in Ned Tijdschr Geneeskd (1857-2005).

Neuropsychiatrists in City Practices

During this period, a significant sociocultural phenomenon emerged in many countries. The idea arose that patients with mental disorders who required institutionalization — mostly patients who would be considered psychotic today — should be distinguished from "nervous" patients who posed no danger to society or to themselves. This phenomenon was not only in the interest of patients because of the stigma of insanity, but also of the physicians who treated them.

These patients suffered from "nerves" or were "nervous" and needed rest or a course of cold-water therapy. They could be admitted to new types of institutions, sanatoria, rather than lunatic asylums. (The name of the latter gradually changed to "psychiatric hospitals" or "psychiatric institutions.") This division meant that alienists, psychiatrists, and neurologists had the opportunity to establish their own successful practices in the city. For many doctors, this also meant an improvement in their social status.

When it gradually became clear that the disease had a psychological, rather than organic origin, there were still neurologists who claimed that techniques to identify changes in the nervous system were still lacking but would become available in the future. In 1927, one-third of American neurologists were still treating patients with neurasthenia or psychasthenia. That same year, the renowned Swiss-American psychiatrist Adolf Meyer (1866-1950) lamented the fact that American doctors, and neurologists in particular, were still treating patients with neurasthenia. They were reluctant to abandon the diagnosis and clung to the idea of an organic cause.

Disappearance of Neurasthenia

After the first decades of the 20th century, the diagnosis neurasthenia gradually disappeared. The rest cure seemed to offer no relief, and the illness became increasingly common among the lower social classes rather than the upper ones. Neurologists no longer treated these patients, and the condition was considered rare, particularly in England.

When the illness was still regarded as physical in nature, doctors showed more understanding toward their affluent patients who were overworked, but now they were no longer "interesting." It is likely that most patients who were previously diagnosed with neurasthenia were subsequently diagnosed with depression. The gradual disappearance can be followed in various editions of "Cecil Textbook of Medicine," in which the text on the subject changed from one chapter (first edition of 1927) to one sentence (seventh edition of 1947). Another problem was that when the illness was considered psychological in nature, it was often viewed as "not real" in contrast to physical ailments.[13]

It is interesting to observe that the rise and fall of neurasthenia coincided with first-wave feminism (1870-1920). As mentioned above, several aspects of modernity were believed to play a role in the almost epidemic increase in the prevalence of neurasthenia. One of these was the role of women who demanded the right to vote in elections (woman's suffrage), education, and divorce.

Several medical historians, however, have argued that it may have been just the name of the diagnosis that disappeared. They refer to subsequent diagnoses including chronic brucellosis (1950s), chronic Epstein-Barr infection, post-viral fatigue syndrome, and myalgic encephalitis.[13]

If we look at nosographical systems of the 19th century, we see that the diagnosis was still present in Diagnostic and Statistical Manual: Mental Disorders (DSM) I to III (1952-1980), but had disappeared from the DSM-III-R (1987). As for the International Classification of Disease (ICD), it was found from ICD-2 (1909) up to ICD-10 (1992). In ICD-3-5 (1920-1938), it was called "hysterical neurasthenia." It was considered outdated in ICD-11 (2020). We must bear in mind that the World Health Organization (WHO) adopted ICD-6 in 1948.

Neurasthenia in Historic Medical Journals and Newspapers

The rise and fall of neurasthenia can also be followed in medical journals as well as in newspapers. As for medical journals, it was possible to do a bibliometric search of the Dutch general medicine journal *Nederlands Tijschrift voor Geneeskunde* (*Dutch Journal of Medicine*) that was founded in 1857. (See Figure 4.) Between 1857 and 2005, the term appeared 1,654 times, first appearing in 1882.

The New England Journal of Medicine (Boston Medical and Surgical Journal before

see **HISTORY** *page 21*

HISTORY

continued from page 20

1928) has 1,420 entries between 1869 and 2024. This search yields 71 pages, with 20 references per page. The last three pages cover the period between 1941 and 2024, which means that most of the articles were published between 1870 and 1940. I expect the graph to be like that of the Dutch journal.

As for newspapers, I searched the database of Dutch newspapers (Delpher,[14] a website with a collection of over 2 million newspapers from the Netherlands, the Dutch East Indies, the Antilles, the U.S., and Suriname from the period of 1618 through 1995) and the collection Chronicling America: Historic American Newspapers at the Library of Congress. (See Figures 5 and 6.)[15] The American database yielded 41,551 results (20,971 pages) from the period 1870-1949. The Dutch database contained 28,779 articles and advertisements (1870-1995). Some of the advertisements we find in these historical newspapers are interesting. (See Figures 7 and 8.)

Weak Nerves in the 18th century — the English Malady

It is interesting to note that if you search for the terms "weak nerves" or "nervous weakness" in American historical newspapers, you get many more results (1.4 million). Furthermore, the first result for "weak nerves" dates to 1767. It is a "letter to the printer" in *The New-Hampshire Gazette and Historical Chronicle* from December 1767, written by a certain doctor named Trahlur:

"I was present yesterday at the complaints of a patient, whose physician attributed them all to tea; and added, that few persons ought to drink tea after the age of 40; few at any age. A weak stomach, trembling limbs, giddy head, relaxed nerves, miserable low spirits, want of appetite, and universal langour, What a train of evils do arise from so paltry an indulgence. Is it not strange, Sir, that we cannot imitate our rational neighbourhood of the North? At Upsal, they drink a tea of select-herbs of their own growth; and there is scarce a weak man, or a man of weak nerves among them. I am, Sir, Your humble fervent, Trahlur." (See Figure 9.)[16]

Apparently, the doctor criticized by the letter's author believed that tea had a relaxing effect in the sense that it weakened the nerves.

In the 18th century, the word "nervous" had positive connotations, implying, among other things, strength, decisiveness, and the absence of weakness.[17] Conditions such as melancholia, vapeurs, "hysteria," and hypochondria were believed to have a neurological cause. An important book from this period was "The English Malady" by physician George Cheyne (1672-1743). Diseases resulting from overconsumption and a sedentary lifestyle were attributed to the central nervous system.

In **"Diseases of Civilization and Nervous Disorders in the Age of Enlightenment,"** (*World Neurology*, June/July 2020), I wrote that, at the time, the term "nervousness" was fashionable for physicians as well as patients. The well-known medical historian Roy Porter (1946-2002) noted "'Nervous' maladies became privileged in polite society, as tokens of their victims' cultivation, and 'nervousness' turned into a badge of honor, a mark of superior sensibility."[18] It was thought to be observed in particular in intelligent and rich people.

Although Beard, when writing about neurasthenia or "American nervousness," did not refer to the "English malady" of the previous century. The two conditions have much in common. The comparison cannot be better worded than in this conclusion of Porter's chapter:

"Sufferers from the English malady were said to have succumbed to profound

see **HISTORY** *page 22*

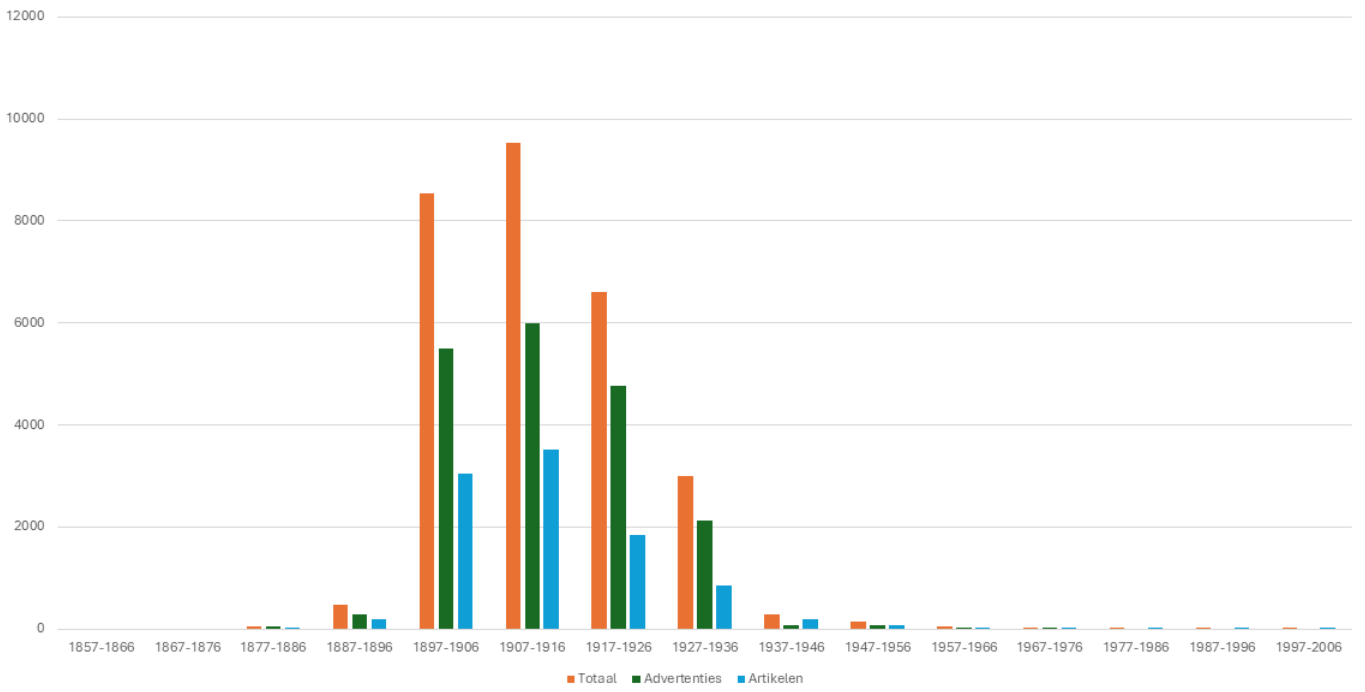


Figure 5. Neurasthenia frequency in Dutch newspapers.

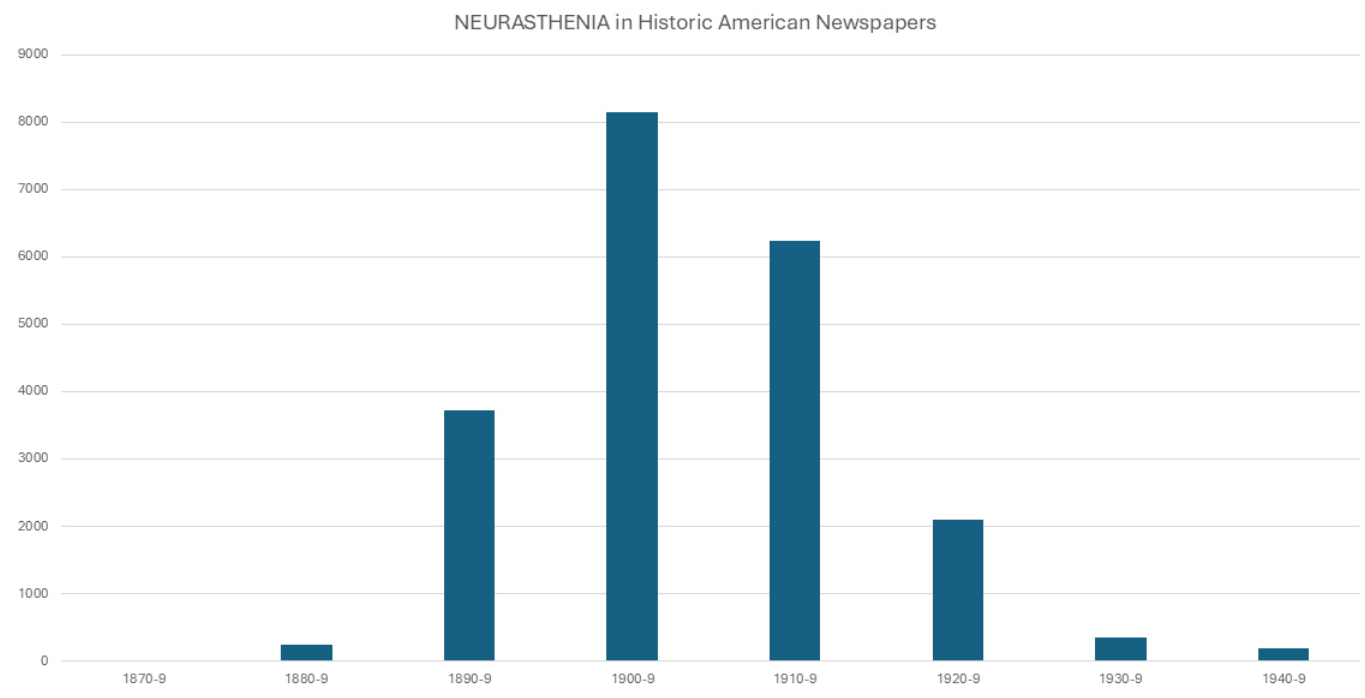
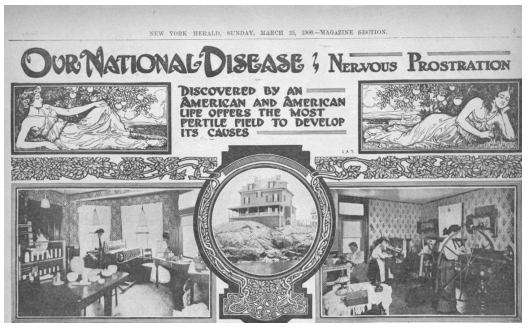


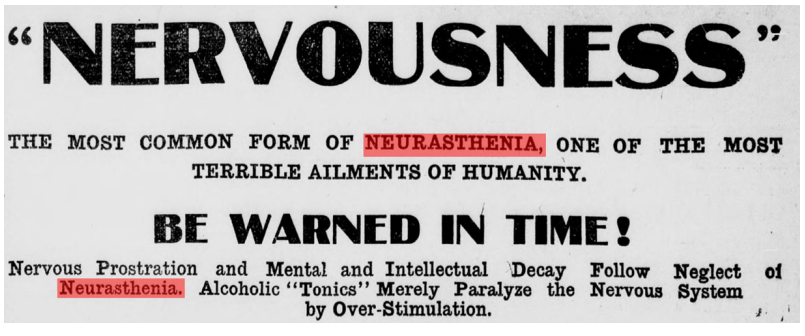
Figure 6. Number of hits with the term "neurasthenia" in Collection Chronicling America of Historic American Newspapers between 1870 and 1949.[23]


NEW YORK HERALD, SUNDAY, MARCH 25, 1906.—MAGAZINE SECTION.

OUR NATIONAL DISEASE ; NERVOUS PROSTRATION

DISCOVERED BY AN AMERICAN AND AMERICAN LIFE OFFERS THE MOST FERTILE FIELD TO DEVELOP ITS CAUSES

Figure 7. Illustration above an article in the *New York Herald* of March 25, 1906.[24]

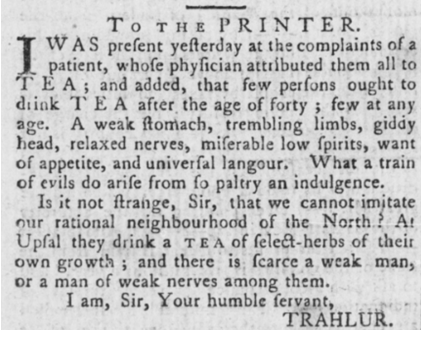

"NERVOUSNESS"

THE MOST COMMON FORM OF NEURASTHENIA, ONE OF THE MOST TERRIBLE AILMENTS OF HUMANITY.

BE WARNED IN TIME!

Nervous Prostration and Mental and Intellectual Decay Follow Neglect of Neurasthenia. Alcoholic "Tonics" Merely Paralyze the Nervous System by Over-Stimulation.

Figure 8. Advertisement for a tonic to prevent neurasthenia in *The New Haven Union* of March 1, 1906.[25]


TO THE PRINTER.

I WAS preſent yeſterday at the complaints of a patient, whoſe phyſician attributed them all to TEA; and added, that few perſons ought to drink TEA after the age of forty; few at any age. A weak ſtomach, trembling limbs, giddy head, relaxed nerves, miſerable low ſpirits, want of appetite, and univerſal langour. What a train of evils do ariſe from ſo paltry an indulgence.

Is it not ſtrange, Sir, that we cannot imitate our rational neighbourhood of the North? At Upſal they drink a TEA of ſelect-herbs of their own growth; and there is ſcarce a weak man, or a man of weak nerves among them.

I am, Sir, Your humble ſervant,

TRAHLUR.

Figure 9. "Letter to the Printer" in *The New-Hampshire Gazette and Historical Chronicle* of Dec. 11, 1767.[26]

HISTORY

continued from page 21

anxiety because they were engaged in the performance of glamorous, if taxing, parts on the Spectatorial stage of fashionable society; the disorder was thus the product of affluence, politeness and excess. A century later, neurasthenics were said to develop exhaustion and depression because they constituted an ambitious elite living in the fast lane in an economic system whose law was [a] struggle. The English malady was a refinement of the old pathology of luxury; American nervousness was a disease of labor. The malaise of the *bon ton* had given way to the disorder of the businessman."[18]

Summary and Conclusions

In the 18th century, when figures such as Robert Whytt (1714-1766) demonstrated that the nervous system plays a significant role in many diseases, and when the term "neurosis" was coined by his student William Cullen (1710-1790), a common clinical condition known as "nervousness" emerged.

The notion of "weak nerves" persisted throughout the 19th century; it was described by Beard as a new condition in the late 1860s and became widely accepted by the 1880s. Initially, it was believed to be an organic disorder that primarily affected men in the upper social classes. The concept had advantages for both patients (avoiding the stigma of being considered insane) and for the various practitioners (private practices in the city; the term "neurasthenia business" has been used).[19]

Gradually, in the early 20th century, it became clear that the disorder also occurred in other social classes and that the cause was psychological rather than organic. The diagnostic concept disappeared after it was subdivided into anxiety neurosis, psychasthenia, and depression. One might wonder to what extent there is a connection with various conditions exhibiting similar symptoms that emerged in the following century and for which no cause is known.[20,21,22]

For both "hysteria," as discussed in the first article of this series, and neurasthenia, it is true that not only biological factors, but also social and cultural factors played an important role in the emergence and disappearance of these conditions. Language, culture, and perhaps also power played a role in this.

As mentioned in Part 1, both "hysteria" and neurasthenia can be cited as examples of the fact that diseases are not immutable natural phenomena, but socially and culturally constructed concepts. They reflect contemporary medical knowledge, moral values, and social norms. Diagnoses may eventually become obsolete due to new insights, or they may no longer align with certain societal views regarding health and illness.

References:

1. Micale MS. On the "Disappearance" of Hysteria: A Study in the Clinical Deconstruction of a Diagnosis. *ISIS* 1993;84:496-526.
2. Beard GM. Neurasthenia, or nervous exhaustion. *Boston Med Surg J* 1869; 80:217-221.
3. Beard GM. *A practical treatise on nervous exhaustion (neurasthenia): its symptoms, nature, sequences, treatment.* New York, Wood, 1880.
4. Beard GM. *American nervousness: its causes and consequences, a supplement to Nervous exhaustion (neurasthenia).* New York, Putnam, 1881.
5. Rosenberg CE. The place of George M. Beard in 19th-century psychiatry. *Bull Hist Med.* 1962;36:245-59.
6. Van Deusen EH. Observations on a form of nervous prostration (neurasthenia) culminating in insanity. *Supplement to the Report of the Board of Trustees of the Michigan Asylum for the Insane* (1867-8). Lansing, George, 1869.
7. Beard GM. The asylums of Europe. *Boston Medical and Surgical Journal* 1880; 103:605-608.
8. Goetz CG. Poor Beard!! Charcot's internationalization of neurasthenia, the "American disease." *Neurology.* 2001;57(3):510-4.
9. Arndt R. *Die Neurasthenie (Nervenschwäche). Ihr Wesen, Ihre Bedeutung und Behandlung.* Wien & Leipzig, Urban & Schwarzenberg, 1885.
10. Müller FC. *Handbuch der Neurasthenie.* Leipzig, Vogel, 1893.
11. Dowse TS. *On brain and nerve exhaustion (neurasthenia) and on the nervous sequelae of influenza.* London, Baillière, Tindall and Cox, 1894.
12. Beard GM. *A practical treatise on the medical and surgical uses of electricity: including localized and general electrization.* New York, Wood, 1871.
13. Wessely S. Neurasthenia and fatigue syndromes. Clinical section. In: Berrios GE, Porter R. *A history of clinical psychiatry. The origin and history of psychiatric disorders.* London, Athlone, 1995, pp. 509-32.
14. Kranten » Ruim 18.000.000 Nederlandstalige pagina's | Delpher (last accessed 19 July 2026).
15. All Digitized Titles | Chronicling America | Digital Collections | Library of Congress (last accessed 19 July 2026).
16. *The New-Hampshire Gazette and Historical Chronicle* (Portsmouth, N.H.), December 11, 1767.
17. Lutz L. Neurasthenia and fatigue syndromes. Social section. In Berrios GE, Porter R. *A history of clinical psychiatry. The origin and history of psychiatric disorders*. London, Athlone, 1995, pp. 533-44.
18. Porter R. Nervousness, 18th and 19th-Century Style: From Luxury to Labour. In: Gijswijt-Hofstra M, Porter R (eds.). *Cultures of Neurasthenia. From Beard to the First World War.* Amsterdam, Rodopi, 2001, pp.31-49.
19. Vijselaar J. Neurasthenia in the Netherlands. In: Gijswijt-Hofstra M, Porter R (eds.). *Cultures of Neurasthenia. From Beard to the First World War.* Amsterdam, Rodopi, 2001, pp. 239-255.
20. Wessely S. Old wine in new bottles: neurasthenia and 'ME'. *Psychol Med.* 1990;20(1):35-53.
21. Wessely S. History of post viral fatigue syndrome. *Br Med Bull.* 1991;47(4):919-41.
22. Shorter E. *From paralysis to fatigue: A history of psychosomatic illness in the modern era.* New York, The Free Press, 1992.
23. Chronicling America | The Library of Congress (last accessed 15 March 2026).
24. Image 93 of The New York herald (New York [N.Y.]), March 25, 1906, (MAGAZINE SECTION) | Library of Congress (last accessed 15 March 2026).
25. Image 2 of The New Haven union (New Haven, Conn.), March 1, 1906, (POSTSCRIPT EDITION.) | Library of Congress (last accessed 19 July 2026).
26. Image 2 of The New-Hampshire gazette and historical chronicle (Portsmouth, N.H.), December 11, 1767 | Library of Congress (last accessed 15 March 2026).

WORLD FEDERATION
OF NEUROLOGY

NASA
Neurological Association of South Africa

XXVIII WORLD CONGRESS OF NEUROLOGY (WCN 2027)

23-25 OCTOBER 2027
CAPE TOWN, SOUTH AFRICA

ABSTRACT SUBMISSION IS OPEN

Visit: wcn-neurology.com