The official newsletter of the World Federation of Neurology

Plan Addresses Epilepsy in Latin America

BY JEFF EVANS
Elsevier Global Medical News

Last year, member nations of the Pan American Health Organization endorsed a strategy and action plan on epilepsy that seeks to improve the identification, treatment, and human rights of people with epilepsy.

The strategy and action plan is sorely needed. In the Americas, about 5 million people have epilepsy, but it is estimated that more than half of those with epilepsy in Latin America and the Caribbean have no access to services, according to the WHO.

The International League Against Epilepsy (ILAE) appointed Dr. Medina; Dr. Jorge Rodriguez, chief of PAHO Mental Health; and

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Knowledge of New Mutation in ALS, Dementia Grows

BY BECKY McCALL
Elsevier Global Medical News

In recent months, the discovery of the C9ORF72 mutation has added fresh insight into the causes of frontotemporal dementia and amyotrophic lateral sclerosis, and no w a series of new studies describes the frequency of the mutation and how the mutation reveals itself clinically in a spectrum of phenotypes in patients with either disease.

The series of studies found that the mutation most often is associated with behavioral variant frontotemporal dementia (FTD), and occurred in 2%-5% of patients with sporadic FTD and 15%-48% of patients with familial FTD. For amyotrophic lateral sclerosis (ALS) patients, the mutation occurred in 4%-7% of sporadic cases and 22%-43% of familial cases. Another 20%-40% of patients who show symptoms of both diseases had the mutation; the rate reached almost 50% among these patients with a family history of ALS or FTD. Some studies reported finding the mutation in 0%-28% of patients who have pr e-sent with the progressive non-fluent aphasia variant of FTD.

The eventual clinical impact of identifying the C9ORF72 mutation is the availability of a population of at-risk carriers of the mutation to aid research into the preclinical phase of disease, according to Dr. Kevin Talbot, professor of motor neuron biology at the University of Oxford, England.

Rather than work in the phase of established disease, which may be intractable to disease-modifying therapy, this provides a ne w departure to a phase in the natural history of ALS w hic h has hitherto not been amenable to study. Dr. Talbot was a coauthor on a study that screened 4,448 patients with ALS and 1,425 patients with FTD for the mutation (Lancet Neurol. 2012 March)

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In This Issue of World Neurology

The WFN Nominating Committee is now accepting nominations for an elected trustee post. See Page 2

The Latin American Federation of Neurological Societies was recently formed. See Page 3
New Leadership to Continue WFN Mission

Anyone can make additional nominations by obtaining the supporting signatures of five or more authorized delegates and submitting the name(s) of the individual(s) in question to the Secretary-Treasurer General, in care of the London Secretariat office.

The nominations need to arrive at least 30 days prior to the date of the Council of Delegates meeting.
The Formation of the Latin American Federation Of Neurological Societies

The development of a Latin American Federation of Neurological Societies was launched during the 13th Pan American Congress of Neurology in La Paz, Bolivia, held March 4-8. This follows the Marakesh Proclamation for the formation of such a Federation during the World Congress of Neurology in Marrakesh, Morocco, Nov. 12-17, 2011. This was initiated by Gustavo Roman and Ana Robles, the outgoing Regional Director for Latin America, and representatives from the Latin American countries: Juan Carlos Duran (Bolivia), Francisco Cardoso (Brazil), Sergio Castillo (Chile), Jesus Rodriguez (Colombia), Dennis Chinchilla (Costa Rica), Ana M. Robles (Dominican Republic), Oscar Del Brutto (Ecuador), M. Tuilo Medina (Honduras), Ricardo Rangel Guerra (Mexico), Fernando Gracia (Panama), Alejandro Scar amelli (Uruguay), and Santiago Fontiveros (Venezuela).

The World Federation of Neurology (WFN) ofered to consider providing, through its grants program resources to create an infrastructure for the new Federation until such a time as a more permanent source of income can be obtained. In part to support the WFN Federation, and in part because having more frequent Congresses of Neurology will foster neurology in more regions, the delegates decided to move the Pan American Congress of Neurology from a 4-year cycle to a 2-year cycle in partnership with the WFN, the host society and the newly formed Pan American Federation of Neurological Societies. These delegates included Brazil, Mexico, Panama, Paraguay, Puerto Rico, and Venezuela. As such, a meeting was held in La Paz, Bolivia to host the Pan American Congress of Neurology in 2016.

In line with a new democratic spirit and development of a theme that thrived in the area of Bolivia and Peru, Puerta del Sol (The Sun’s Gate) is symbolic of the highly sophisticated culture that thrived in the area of Bolivia and surrounding countries between 700 and 1200 AD.

Puerta del Sol (The Sun’s Gate) is symbolic of the highly sophisticated culture that thrived in the area of Bolivia and surrounding countries between 700 and 1200 AD.

May the sun shine upon the newly formed Latin American Federation of Neurological Societies!
Over the Seas: Three 19th-Century Australia Neurologists

BY MERVYN J. EADIE, AO, MD, PHD

During the final two decades of the 19th century three Australian men, born within a decade of one another, undertook the long sea voyage from Sydney to Britain to further their medical and neurological experience. Their subsequent careers followed rather different courses that manifest different patterns of interchange between the neurologies of Europe and the antipodes. They were pioneers of a career pattern that many Australian neurologists and neuroscientists followed during the 20th century while Australian neurology matured and increasingly became educationally self-sufficient.

The first-generation Australians George Edward Rennie (1861-1923), Alfred Walter Campbell (1868-1937), and Gr afont Elliot Smith (1871-1937) were all educated in New South Wales at the stage of university entry. Rennie, who was born in Sydney, took a B.A degree from the University of Sydney because no Australian university medical course was available at the time and then sailed to London in 1883. He graduated with an MB in 1887 and with an MD a year later. After returning to Sydney, he worked as a physician and pathologist. In 1889, he again sailed to London, acquiring further neurological knowledge at Queen Square and qualifying as a member of the Royal College of Physicians. Returning to Sydney, he achieved a considerable local reputation as a physician with major neurological inter ests, publishing some neurological case reports and review-type articles. However, his career had little international neurological impact.

Campbell was born on a pastoral property near present-day Canberra. Although he was young enough to enter the new Sydney University medical course, he sailed to Britain in 1886 and graduated MB ChM (Edinburgh) in 1889. He spent 2 years gaining experience at Queen Square, in various British mental asylums, in Paris, and in Vienna with Baron Richard von Krafft-Ebing. His thesis, “The pathology of alcoholic insanity,” brought him an Edinburgh MD.

For 13 years, Campbell was medical officer and pathologist to the Rainhill Asylum in Liverpool, England. In that time, he published a substantial number of major neuropathological studies. These included his collaboration with Henry Head on the famous investigation of the pathology of herpes zoster that defined the distribution of the der meratoses and his g reat monograph of 1905, “Histological Studies of the Localisation of Cerebral Function,” which provided the first detailed account of the cytoarchitectonics of the primate and human cerebral cortex.

Campbell later returned to Australia after an absence of nearly 20 years. He spent the remainder of his life in Sydney practicing clinical neurology. Others had pre-empted him for appointments in neuropathology and psychological medicine. Campbell published further neuropathological and neurohistological studies of originality and merit, but his career in Australia was distinguished enough though it was, did not fulfill his earlier outstanding promise. He had been a way from his homeland for too long before returning.

Smith was born in the provincial town of Graf ton. He undertook the Sydney medical course and then spent several years carrying out neuroanatomical studies in that University’s anatomy department, gaining an MD with a scholarship, he sailed from Sydney to Britain, subsequently doing further research in the Cambridge anatomy department before occupying, successively, chairs of anatomy at Cairo, Egypt; Manchester, England; and University College, London. During his career, he was responsible for a great deal of anthropological, neuroanatomical, and paleopathological research, and collaborated with Dr. William H.R. Rivers in work on psychological trauma.

Smith also was involved in the Piltdown man affair. He was one of several authorities who accepted that a skull and jawbone found in 1912 in a gravel pit in East Sussex, England, were fossil remains of a hitherto unrecognized human ancestor; 40 years later they were proved to be part of a deliberate hoax. Nonetheless, Smith proved to be a very considerable figure in the Egyptology, anthropology, and neuroanatomy of his time, a fellow of the Royal Society, and a knight. On two occasions, in 1914 and 1924, he returned to Australia for visits, but never again lived in his homeland.

Most Australian neurologists in at least the first two-thirds of the 20th century tended to follow training and career patterns resembling that of Rennie. A few resembled Smith’s, and even fewer, Campbell’s. Few attained such great international scientific distinction as Campbell or Smith.

George Edward Rennie

Sir Grafton Elliot Smith

REQUEST FOR RESEARCH GRANT PROPOSALS

- Funds up to US $150,000 are available annually for support of research into new treatments, pathophysiology, and the genetics of benign essential blepharospasm and Meige syndrome (cranial and oromandibular dystonia). Research into photophobia, dry eye, and apraxia of eyelid opening as they relate to benign essential blepharospasm and Meige syndrome and their treatment will also be considered for funding.

- M.D. or Ph.D. required for principal investigator.

- Non-U.S. citizens working at institutions abroad are also eligible to apply for a research grant.

- Deadline to apply is Aug. 31.
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Working Group Is Interconnecting Young Neurologists Worldwide

By Walter Struhal, MD

Representatives from many regions within the World Federation of Neurology have become members of the International Working Group of Young Neurologists and Trainees since its formation in 2009 and its inaugural meeting at the World Congress of Neurology in Bangkok, Thailand.

The IWGYNT’s vision is to advocate for the interests of young neurologists on a worldwide basis within the World Federation of Neurology (WFN). We are proud that we have one member elected to represent our group within the WFN’s Education Committee.

Our mission is to:

- Represent the interests and initiatives of residents and young neurologists with a single voice.
- Establish networking among young neurologists.
- Support international training exchange.

The group is organized as a panel consisting of two delegate pairs from each continent. Delegates may be sent only by a national or international neurological body representing young neurologists in that area. Currently, Africa, Asia, Europe, and Australia/New Zealand have sent delegates to the IWGYNT. In the first 2 years of our existence, we have focused on establishing a network among young neurologists in the continents we are representing.

Africa

Our two delegate pairs from the Pan African Association of Neurological Sciences, Dr. Rufus Akinyemi and Dr. Jason Burton, already have a working network of young neurologists via ANZAN. They are currently trying to foster training exchange with other continents.

Asia

Our delegate from the Association of East Asian Nations Neurological Association, Dr. Surat T anprawate, was extremely active in promoting the IWGYNT at Asian meetings and administ ating the Facebook page of the IWGYNT. He has established a working network of young Asian neurologists.

We are very proud to support the establishment of a young neurologists and trainees group in New Delhi, conceptualized by Prof. Man Mohan Mehndiratta. We owe Prof. Mehndiratta many thanks for his dedication to young neurologists’ issues.

In 2011, Dr. Tissa Wijeratne, originating from Sri Lanka and working in Australia, has joined as second Asian delegate. His advocacy of efforts for young neurologists has resulted in the initiation of the Asia Pacific Federation of Young Neurologists and Trainees (www.epaynet.org). These efforts were led by Prof. Mehndiratta, and we are confident that this will be a strong representation of young neurologists from the Asia and Pacific region.

Australia/New Zealand

The IWGYNT’s delegates from the Australian and New Zealand Association of Neurologists (ANZAN), Dr. Kate Ahmad and Dr. Jason Burton, already have a working network of young neurologists via ANZAN. They are currently trying to foster training exchange with other continents.

Europe

The delegates of the European Association of Young Neurologists and Trainees (EA YNT, www.eaynt.org), Dr. Cristian Falup-Pecurariu and myself, are enjoying a well-working young neurologists network in Europe.

We promoted the IWGYNT at many European meetings and several online and print articles and tried to actively interconnect all groups involved.

North America

There are currently no representatives from North America, but we are in close cooperation with the American Academy of Neurology’s Consortium of Neurology Residents and Fellows (CNRF). Members of the IWGYNT are for the second time invited to contribute to the CNRF’s meetings at the AAN congress.

Central America

Dr. Cumara O’Carroll, a committed young neurologist at the Mayo Clinic in Scottsdale, Ariz., USA, is a liaison to the IWGYNT. She is interested in supporting young neurologists in Central America, and to gether with Dr. Marco T. Medina, she recently initiated an exchange program with Honduras.

South America

Unfortunately, the IWGYNT has currently cooperations with only individual South American young neurologists.

WCN 2011

At the 2011 World Congress of Neurology in Marrakesh, Morocco, Prof. Wolfgang Grisold and Prof. Mostafa El Alaaoui Farti generously offered a free workshop and a free booth at the congress. The IWGYNT, together with the European Association of Young Neurologists and Trainees (EAYNT), organized a free workshop and a booth. Both initiatives were successful and well visited.

Dr. Struhal is chair of the International Working Group of Young Neurologists and Trainees and a past president of the European Association of Young Neurologists and Trainees. He works in the Department of Neurology and Psychiatry at the General Hospital of the City of Linz (Austria).

The Young Neurologist Workshop in Marrakesh, chaired by Dr. Stephen M. Sergay and Dr. Wolfgang Grisold, featured lively discussion.

Calendar of International Events

2012

7th World Congress for NeuroRehabilitation
May 16-19, 2012
Melbourne, Australia

SSIF Annual Meeting in Multiple Sclerosis
May 21-23, 2012
Valencia, Spain
www.seromysprofosia.org

12th International Conference on Myasthenia Gravis and Related Disorders
May 21-23, 2012
New York, USA
www.nyas.org/ MG12

Third International Conference “Advances in Clinical Neuroimmunology” ACN 2012
May 31-June 1, 2012
Vienna, Austria
www.acn2012.eu

13th Asian Oceanian Congress of Neurology
June 4-8, 2012
Melbourne, Australia
www.aocn2012.com

47th Annual Congress Canadian Neurological Sciences Federation
June 6-8, 2012
Ottawa, Ontario
www.cnfederation.org/congress.html

22nd Meeting of the European Neurological Society
June 9-12, 2012
Prague, Czech Republic
www.congres.ch/ens2012

1st African Epilepsy Congress
June 21-23, 2012
Nairobi, Kenya
www.epilepsyfromafrica2012.org

16th Congress of the European Federation of Neurological Societies
Sept. 8-11, 2012
Stockholm, Sweden
www.efns.org/efns2012

10th European Congress on Epileptology (ECE)
London, United Kingdom
www.epilepsylondon2012.org

8th World Stroke Congress (WSC 2012)
Oct. 10-13, 2012
Brasilia, Brazil
www2.kenes.com/wcnr2012/Home

2013

XXI World Congress of Neurology
Sept. 21-26, 2013
Vienna, Austria
www2.kenes.com/wcn/Pages/Home.aspx
REGIONAL FOCUS: LATIN AMERICA
Addressing the Need for Reliable Data in Emerging Countries

The World Health Organization has stated that it is crucial that countries all over the world improve their data collection systems to assess health indicators and measure the impact of public health policies and resource utilization at the population level. This is particularly important for noncommunicable diseases (NCDs) such as cerebrovascular disease in Latin American countries where relevant epidemiological data are scarce and available.

During a United Nations meeting Sept. 19-20, 2011, participants from 113 member states, including 34 heads of state and 2 representatives from the American Heart Association and the World Stroke Organization, analyzed the problem of NCDs, particularly in emerging countries. The main goal was to generate strategies for improvement through coordinated research initiatives and a global monitoring framework, mainly in low- and middle-income countries, where 80% of deaths from stroke and coronary disease occur each year. There was general agreement as to the World Health Organization’s (WHO’s) coordinating role.

As part of the initiative on improving data collection systems and improving the measurement of public health policies, the WHO has identified three major challenges regarding NCDs:

- The capacity of countries to respond (for example, by improving inadequate or nonoperational health infrastructure in many countries, expanding health system capacity and giving a higher priority to NCDs, and developing national NCD programs and policies on stroke).
- Advancing toward multisector action (for example, by systematically engaging the health sector with other sectors across government).
- Monitoring and measuring results (for example, through high-quality and adequately supported NCD surveillance of risk factors, outcomes, and health system responses, with a common set of indicators).

In regard to the third challenge, consistent information of the actual and precise picture of NCDs in most Latin American countries is desperately needed.

Latin American health systems could certainly benefit by improving the volume and quality of research on NCDs. Population-based studies from Latin America are necessary to provide local reliable data and should be specifically designed to represent most populations with low-middle and upper-middle income economies. The inadequate extrapolation of facts from European or Northern American sources, that surely do not represent the Latin American reality, should be avoided. It is pointless to attempt secondary stroke prevention policies solely on the basis of those sources, without knowing the cause of the initial strokes in the first place. The development of entirely Latin American studies would be the much needed stepping stone to generate proper public health policies in the region.

MEETING ROUND-UP
Movement Disorders Course in Tanzania a Success

The World Federation of Neurology Association for Parkinsonism and Related Disorders collaborated with the Medical Association of Tanzania to hold a Parkinson’s and Movement Disorders conference at the Protea Hotel Courtyard, Dar es Salaam, on Feb. 11.

The meeting was well attended with approximately 30 physicians from all over the country. The meeting happened to follow the end of a physician’s strike in Tanzania. Dr. Namala Mkopi, the current president of the Tanzanian Medical Society, helped to organize this meeting along with Dr. Tanya Simuni and Dr. Daniel Truong from the United States.

Dr. Simuni of Northwestern University, Chicago, spoke on the differential diagnosis of Parkinson’s disease and on the nonmotor symptoms of Parkinson’s. I gave a talk about Parkinson’s disease and the tr eatment of Parkinson’s disease. In between talks, Dr. Ryan Uitti of the Mayo Clinic, Jacksonville, Fla., USA, demonstrated the proper neurological exam. He also presented information on parkinsonism, dementia, and tremors. Dr. Hubert Fernandez of the Cleveland Clinic in Cleveland, Ohio, USA, presented on the topics of multiple system atrophy, progressive supranuclear palsy, and chorea. Dr. Truong of the Parkinson’s and Movement Disorders Institute, Orange County, Calif., USA, spoke on dystonia and other movement disorders, including restless legs syndrome and myoclonus. Some presentations also focused on nonmotor education-based treatments such as cueing therapy – walking in time to a metronome beat or improving gait in Parkinson’s disease.

Infectious diseases such as HIV/AIDS comprise the majority of health issues in Tanzania, but with advances in available treatments for infectious disease, and as the population ages, there will be greater numbers of people with chronic conditions such as Parkinson’s disease. But resources in Tanzania are limited. The entire country has only three neurologists and one MRI scanner. Many patients continue to use traditional healers or home remedies to help with their symptoms.

Currently, the prevalence of Parkinson’s disease in sub-Saharan Africa is controversial. Data on this subject are limited, but a few studies that have been conducted reported prevalences lower than in other parts of the world.

A recent study estimated the prevalence of Parkinson’s disease in Tanzania to be 20 per 100,000 population, which is still lower than the prevalence reported in the United Kingdom. Patients with Parkinson’s disease in Tanzania are usually not diagnosed or treated for the disease, which has been regarded to be a part of the normal aging process by many in the country.

In Tanzania, standard medications used to treat Parkinson’s disease are difficult to obtain and expensive. Most patients are unable to afford medication to treat their diseases and they will ration the medications provided by the government. For example, in part of one sociological study in rural Tanzania, 28 patients with Parkinson’s disease were identified; the majority of whom were not previously diagnosed. Only two were taking medication to treat the symptoms of the disease.

Dr. Frei is director of clinical research at the Parkinson’s and Movement Disorders Institute, Orange County, Calif., USA.
Chagas-Mazza Disease and Stroke: A Call for Attention

Emigration of infected patients to developed countries has changed the epidemiology of the disease.

A fter malaria and schistosomiasis, Chagas disease is the thir d most common par asitic infec tion worldwide, af fecting most y South American populations w ho ve lo w incomes and restricted access to medical care. It is caused by the flagellate protozoan Trypanosoma cruzi. The Brazilian physician Carlos Chag as described the disorder in 1909. In Ar gentina, it is known as Cha gas-Mazza disease, in honor of Salvador Mazza, the Ar gentine ph ysician w ho in 1926 investig ated and described its epidemiologic life cy cle and over the years became one of its leading researchers worldwide.

About 14 million people ha ve emi grated to Europe, Nor th America, Japan, and Australia in the past 20 y ears, many of them asymptomatic infected patients coming from endemic regions. This resettlement, together with that of Salvador Mazza, has changed the epidemiology of the disease. This resettlement, together with that of Salvador Mazza, has changed the epidemiology of the disease.

To reduce the high infection risk in South America, Currently, around 100 million people live in the endemic regions where Tryp anosoma infantum (the household insect responsible for T. cruzi transmission) is detected. Appro ximately 25% ha ve the chronic form of the condition and are at risk of heart failure and subsequent is chemic stroke. Early diagnosis and secondar y pre vention measures should be encouraged in chag asic stroke. Around 20%-25% of infected stroke patients are e classified as cryptogenic. Consequently, patients with ischemic car dioembolic or cr y ptogenic stroke should be immuno logically screened for T. cruzi infec tion, especially if they come from endemic regions.

Clinical trials are needed to assess the efficacy of anticoagulant therapy for primary and secondar y stroke pr even tion in this condition. Although some studies have reported an association be tween chronic T. cruzi infection and cog nitive impair ment with or without is chemic stroke, the r elation between ischemic stroke and dementia has not been properly investigated. The World Health Organization control measures initia ted against T. infantum have had a dramatic ef fect in lowering the prevalence of the disorder. However, the chronic latency period before the chronic clinical stage arises will maintain this illness as an impo rtant public health problem for decades. Therefore, prior to the indication of any therapy or pr evention strategy, the in clusion of Chagas-Mazza disease in the differential diagnosis of stroke is essential.

References

New Projects Are Underway in Countries

Dr. Carlos Acevedo, secretary general of the Interna tional Bureau for Epilepsy, proposed the strategy and action plan. They worked with a team of more than 30 experts from Latin America to draft the document, which received final approval at a PAHO meeting in Washington D.C., USA, on Sept. 29, 2011. P AHO member states agreed to:

- Make epilepsy a national health policy priority in each country.
- Strengthen legislation to protect the human rights of people with epilepsy and eff ectively enforce laws.
- Strengthen primary care systems and integrated services networks to promote universal and equitable access to medical care e for people with epilepsy.
- Ensure the availability of the four antiepileptic drugs that are considered essential for treatment: phenobarbital, phenytoin, carbamazepine, and valproic acid.
- Improve neurological services to detect and manage cases at the primary care level.
- Support effective participation by the community, pa tient associations, and family members in activities designed to improve the care of people with epilepsy.
- Promote educational initiatives within and between countries to combat stigma and discrimination against people with epilepsy.
- Provide the means to improve the production, assessment, and use of information in the field of epilepsy.

The document is meant to outline a framework for 'each country to develop its own agenda specific to its needs.'

Dr. Medina

The Honduran Treatment Gap Project is one example of a na tional pro gram that Dr. Medina hopes can be applied in other countries to improve community involvement in the care of people with epilepsy and to increa se the number of people w ho re ceive treatment or prevention services.

The first phase of the demon stration project sought to deter mine the treatment gap and prevalence of epilepsy in Honduras. In a study of community interven tions on the incidence of epilepsy and the preva lence of active epilepsy in rural Salam uncertainty, inci dence declined from 93/100,000 individuals in 1997 to 36/100,000 in 2005 and pre vidence declined from 15/1,000 in 1997 to 12/1,000 in 2005. However, it is not significant differences. However, the rate of symp tomat ic epilepsy caused by neocysticerco sensitization significantly from 17% in 1997 to 14% in 2005. Com munity interventions included an education and media campaign, animal husbandry training for pig farmers, construction of water projects and proper sewage dis posal, constr uction of a mater nal and child health clinic, deworming of Salamá county school students, and ongoing taeniases sur veillance (Epilepsia 2011:52:1177-85).

In 1997, the tr eatment gap for epilepsy in Salamá County was 58%, based on the prevalence of active epilepsy. More recently, a cross-sectional study involving house-to-house s creen ing of 2,000 randomly sel ected households in the nearby city of Juticapa found a prevalence of active epilepsy of 6.5/1,000 individu als and a treatment gap of 48% for active epilepsy, acc ording to Dr. Medina and his associates.

Several other efforts are already underway in other Latin American countries that address the PAHO strategy and ac tion plan. Dr. Medina said in northern Peru, the Bill and Melin da Gates Foundation has provide d funding to develop programs to reduce the incidence of pre ventable epilepsy in Colombia, new le gislation is being intro duced that is designed to protect people with epilepsy. Brazil has a demonstrative program supported by the WHO that aims to improve education and reduce the treatment gap for people with epilepsy. Programs in Chile have been successful in improv ing access to anti-epileptic drugs for people with epilepsy.

PATIENTS WITH ISCHEMIC CARDEOVASCULAR OR CRYPTOGENIC STROKE SHOULD BE IMMUNOLOGICALLY SCREENED FOR T. CRUZI INFECTION.

THE HONDURAS TREATMENT GAP PROJECT IS AN EXAMPLE OF A NATIONAL PROGRAM THAT COULD BE APPLIED IN OTHER COUNTRIES.
You are cordially invited to participate in the 5th Congress of the Pan-Asian Committee for Treatment and Research in Multiple Sclerosis in Beijing, China. Healthcare professionals from 18 countries are expected to congregate at this meeting to learn, discuss and share opinions, ideas and best practices on Multiple Sclerosis.

As a participant, you will:

- Be better equipped to treat your patients, based on new and practical knowledge to improve your patient care. A fully customizable scientific program to meet your individual educational needs.
- Keep abreast on the latest therapeutic, technological and practice management tools.
- Connect and network with the MS community to share experiences, best practices, and get advice that will benefit you in your practice throughout the year

For more information on PACTRIMS 2012 please visit:

www.pactrims.org or write to secretariat@pactrims.org
Program Highlights Dancing as Therapy for Parkinson’s

Dancing is receiving new attention for its therapeutic value in Parkinson’s disease in a network of new dance classes that have spread internationally. One of the most well-known and successful modern dance companies in the United States, the Mark Morris Dance Group (MMDG) is promoting a program called Dance for PD that it developed with the Brooklyn (N.Y., USA) Parkinson Group.

The Dance for PD project at MMDG began in 2001 when Olie Westheimer, the director of the Brooklyn Parkinson Group, conceived the idea based on her experience with her husband, Dr. Ivan Bodis-Wollner, a neurologist and Parkinson’s disease specialist.

Dr. Olie Westheimer was the wife of neurologist and Parkinson’s disease specialist, Dr. Ivan Bodis-Wollner. She approached MMDG, and the program was initiated with support of the dance group itself and some foundation grants.

Dance combines physical exercise, mental function, rhythm, and social interaction, and a good time. Because it is usually done in a group setting, it also encourages social interaction and friendships. It is likely that patients would more likely continue to participate in it than in a simple exercise such as treadmill running (unless perhaps they can simultaneously listen to music or watch television). The caregiver also benefits from dance.

There is already published evidence that tango offers a variety of benefits to patients. In one study, there was a head-to-head comparison between a group of patients with Parkinson’s disease and healthy controls. Patients in the Parkinson’s group received a tango instruction, while healthy controls received a dance instruction. The results showed that patients in the Parkinson’s group had improved balance, gait, and quality of life compared to the controls.

In his 2010 inauguration speech, World Federation of Neurology President Vladimir Hachinski conveyed a clear message: “Asia has more than 60% of the global population, yet in some areas, the education of neurology in young neurologists does not keep up with the patients’ needs for neurological care.” For this reason, it is essential for WFN to help vitalize the educational activity in this region among others.

Since I was appointed as the head of the Asia Initiative, I have been trying to promote the educational activities in neurology with the aid of many friends inside and outside Asia. It is for this reason that I invite you to attend the Asian-Oceanian Congress of Neurology (AOCN) 2012 meeting in Melbourne, Australia, June 4-8.

The Dance for PD program has spread internationally, and now has more than 1,500 students in 60 locations in the USA, Europe, and India who participate in classes based on the original Brooklyn model.

The program also trains teachers in the methods and approaches that seem most successful. The Dance for PD network is rapidly expanding, and the program will shortly have a series of videos available to introduce the fundamental method to patients who can’t attend a class or for patients who want to practice between classes.

Parkinson’s disease, like most diseases, should not be treated with medications alone. Lifestyle and activity are also important. Dopaminergic medications and maybe also deep brain stimulation are helpful, but so too is dance. Why not get better and have fun at the same time?

More information about Dance for PD is available at danceforparkinsons.org.
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Surgical Removal Boosts Brain Thrombus Recovery

BY MITCHEL L. ZOLER
Elsevier Global Medical News

NEW ORLEANS – An investigative, minimally invasive surgery for reducing intracranial clot volume following an intracerebral hemorrhage showed promise in results from a randomized trial. In the controlled study, 54 patients who underwent clot removal by minimally invasive surgery (MIS) had a 10% increase rate of achieving a modified Rankin Scale (mRS) score of 0-2 at 180 days, compared with 39 patients managed by conventional, medical therapy, Dr. Daniel F. Hanley said at the International Stroke Conference.

The next step will be a pivotal, controlled study planned to enroll 500 patients at 35-50 centers, with an expected study duration of 5 years. Dr. Hanley and his associates at Johns Hopkins University in Baltimore, Md., USA, the site of their study, presented their findings from the study’s primary outcome, which was the size of the clot; if you can do anything meaningful to reduce the size of a clot, it should benefit patients. But agg. resuscitiveness in removing clot must be balanced against minimizing manipulation of brain tissue. The goal is to remove as much clot as possible without doing damage. The results did not include information on brain edema following surgery, but it looks like the trauma of intervention on patients had balance better outcomes.

Among the subgroup with a clot burden of at least 50 mL, MIS led to a 17% increase rate of patients achieving an mRS of 1-3, compared with the controls, and 13% of the MIS patients and none of the controls. An mRS of 1-3 occurred in about 35% of the MIS patients and about 25% of the controls.

The prespecified goal of MIS was removal of at least 15 mL of clot, and surgeons achieved this in about a third of the MIS patients. When patients attained that level of clot reduction, they had a statistically significant, 3.7-fold increased rate of having an mRS of 1-3 at 180 days, compared with patients who did not reach this goal.

Among the subgroup with a clot burden of at least 50 mL, MIS led to a 17% increase rate of patients achieving an mRS of 1-3, compared with the controls, and 13% of the MIS patients and none of the controls. An mRS of 1-3 occurred in about 35% of the MIS patients and about 25% of the controls.

Need for CT Perfusion Imaging in Acute Stroke questioned

BY MITCHEL L. ZOLER
Elsevier Global Medical News

NEW ORLEANS – The extra time needed for CT perfusion imaging in patients with an acute ischemic stroke may not be warranted, based on a retrospective analysis of 418 patients treated at nine U.S. tertiary stroke centers.

The analysis showed that the outcomes in patients assessed using CT perfusion (CTP), were similar to those in patients w orked up with noncontrast CT (NCCT), and that CTP added an average of 48 minutes to the time elapsed between the start of imaging and the completion of the perfusion procedure, Dr. Rishi Gupta said at the International Stroke Conference.

Additional imaging did not translate into better clinical outcomes or reduced hemorrhagic or vasogenic edema. The analysis of these between-group differences were statistically significant. In a multivariate analysis, the use of CTP was not a significant determinant of a good clinical outcome.

Average time from the start of CT imaging to reperfusion was 175 minutes in the NCCT patients and 221 minutes in the CTP group.

Dr. Gupta presented two additional analyses designed to compare outcomes using the two imaging methods in closely matched subgroups. In one analysis, he focused exclusively on the 291 patients in the database who had occlusions at the M1 site of the middle cerebral artery. In these patients, NCCT saved an average of 40 minutes, compared with CTP, and outcomes were not significantly different.

The analysis showed successful reperfusion in 65% of the NCCT patients, compared with 71% of the CTP patients. The rates of symptomatic and asymptomatic hemorrhage were also similar in the two subgroups. None of these differences was statistically significant. In a multivariate analysis, the use of CTP was not a significant determinant of a good clinical outcome.

Average time from the start of CT imaging to reperfusion was 175 minutes in the NCCT patients and 221 minutes in the CTP group.
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OBITUARY

Richard Koch Olney (1947-2012)

BY MICHAEL J. AMINOFF, MD, DSC

Richard Koch Olney died peacefully on Jan. 27 from amyotrophic lateral sclerosis, a disorder on which he had focused his energy as a physician, educator, and clinical investigator for many years before he himself was diagnosed with it.

He was born in Munich, Germany, in 1947, where his father was an engineer in the U.S. Army. After a year in Germany, several years in West Virginia and other parts of the United States, and a year in Japan, the family finally settled in Oklahoma. He did his undergraduate studies at the University of Pennsylvania, Philadelphia, USA, and the University of Oklahoma, Norman, USA, following which he went to Baylor University, Houston, Texas, USA, where he received his MD degree in 1973. He then began residency training in psychiatry at the University of California, Los Angeles, USA, but soon transferred to the neurology program at the Oregon Health Sciences University (OHSU) in Portland, USA, becoming a board-certified neurologist in 1980. After a brief stint in practice, he joined the faculty of OHSU and the Oregon Institute of Neurological Diseases in 1983, where he founded the Center for Human Genetics and Genomics.

He was appointed Associate Editor of Muscle & Nerve in 1990, and to the editor-in-chief of several other journals shortly thereafter. He held a number of offices in the various professional organizations to which he belonged. He was the author of numerous original papers, review articles, and book chapters relating to his research interests, which initially focused on the use of electrophysiological techniques to investigate the operation of the neuromuscular system in health and disease and, more recently, on amyotrophic lateral sclerosis (ALS). Indeed, he personally conceived and directed the Comprehensive ALS Center at U.C.S.F., and it is a cause for sadness that he himself eventually became a patient there, being cared for with devotion by the very staff whom he had trained. His unit became one of the most respected units in the country. He had never been a leader in the way he used to be, a self-appointed spiritual leader, but a leader of ideas.

He was a great clinical teacher who could let others know what they did not know without upsetting or hurting them. He befriended many of his students and never sought their thanks for the quiet help that he gave them. He had a first-class mind and the temperament of a gentleman.

He also deliberately and courageously publicized his illness with the hope of increasing a awareness of the disease, becoming a national spokesperson on ALS. His efforts were rewarded by the Lifetime Achievement Award of the American Association of Neuromuscular & Electrodiagnostic Medicine, and by an award for public education from the American Academy of Neurology Foundation. The sad irony of his personal plight captured the attention of the media and, in the numerous articles that appeared about him in the national press and on radio and television programs, he discussed the nature of the disease, the impotence of basic and clinical studies, and the need for controlled clinical trials of potential therapies. He thereby gave us a human face and dimension, coming to personify the disease to the general public and national agencies, both in the United States and overseas. This may yet prove to have been his greatest achievement, for it will undoubtedly help both individuals trying to cope with the disease and those concerned with advancing its treatment.

Clinical Presentation Varieties

Mutation • from page 1

The discovery and the subsequent characterization among patients who have FTD, ALS, both FTD and ALS, or primary progressive aphasia are just the first steps of many before treatments can be based on the new knowledge, said Dr. Paul Schulz of the department of neurology at the University of Texas, Houston, USA, where his lab examines the mechanisms underlying the disease and, more recently, on amyotrophic lateral sclerosis (ALS).

Initially, no mutation had been found even after repeated sequencing of the investigational region on chromosome 16p21, but eventually, the two research groups independently identified the precise nature of the long-sought-after mutation (Neuron 2011;72:245-56; 257-68). It proved to be a GGGGCC hexanucleotide repeat in the noncoding region of the C9ORF72 gene.

The discovery of the mutation and the recognition of its association with both diseases, the first step along the road toward a therapy, was the culmination of many years of research. "After various experiments, it was realized that the abnormal gene was invisible to gene sequencing because the hexanucleotide bound to itself," explained Dr. Schulz. "As a result, it was not penetrable by normal PCR (polymerase chain reaction) amplification. Now that this mechanism of mutation is known, I’m sure gene hunter s are looking for others that are also ‘silent.’" 

Screening in FTD and ALS

In the Lancet Neurology study of 4,448 ALS patients and 1,425 FTD patients from the United States, Europe, and Australia, researchers found the C9ORF72 mutation in 7% of sporadic ALS in white patients and 4.1% of black patients. It was present in 6% of white patients with sporadic FTD. The results of those with familial FTD or ALS were more surprising, with the expansion present in 38% of all patients with familial ALS and 25% in white patients with familial FTD.

The discovery and characterization of the mutation are the first steps of many before treatments can follow.

DR. SCHULZ

A series of four papers published in Brain by groups from the Netherlands, Manchester, England, London, England, and the Mayo Clinic in Rochester, Minnesota, and Jacksonville, Florida, USA, reported the results of screening large cohorts of patients with FTD totaling nearly 1,200 cases. Overall, 7%-12% of the cohort tested were found to have the mutation (Brain 2012;135:693-708; 723-35; 736-50; 765-83). Another two papers and the same Mayo Clinic paper reported on the frequency of the mutation in patients with ALS. In 563 ALS patients from northern England, including 63 with a family history of ALS, the C9ORF72 expansion was found in 11%, but it occurred more often among patients with familial ALS (43%) than with sporadic disease (7%) (Brain 2012;135:751-64).

Among patients with familial ALS, the mutation occurred in 38% of 141 Italian cases (including 57% in 21 Sardinian cases) and in 22% of 41 German cases (Brain 2012;135:784-93). Mayo Clinic researchers detected the mutation in 7% of 229 ALS patients and in 24% of 34 patients with familial ALS, parkinsonism, or dementia. Only 4% of sporadic ALS cases had the mutation. Among patients with a clinical phenotype of FTD and ALS, the prevalence of the mutation was 22%, but it approached 60% among those with a positive familial history (Brain 2012;135:765-83).

"All of these statistics mean that this hexanucleotide repeat is fairly common amongst those with familial FTD or ALS, or especially FTD with ALS," according to Dr. Schulz. But familial FTD was present in only 40% of those with familial ALS, and familial ALS was present in only 5% of ALS patients, he noted. "This means that most sporadic FTD..."
**Eminent Neuroscientists: Their Lives and Works**

By K. B. Bhattacharyya


**BOOK REVIEW**

**History of Neurology Text is a Welcome Addition**

By FRANÇOIS BOLLER, MD, PHD

Dr. Boller is a neurologist in Bethesda, Md., USA.

Continued from previous page

ALS, or FTD-ALS patients are not accounted for. In sporadic FTD, which is more common than familial FTD, then the rate of C9ORF72 mutations appears to be between 2% and 5%,” Dr. Schulz said.

**Effect of Other FTD/ALS Mutations**

The new C9ORF72 expansion joins two other mutations found in patients with FTD and/or ALS, namely, those affecting the genes for microtubulin-associated protein tau (MAPT) and progranulin (GRN). In a commentary on the studies featured in Br ain, Dr. John Hodges of Neuroscience Research Australia and the University of New South Wales in Sydney, Australia, noted that the effects of the London-based group (Br. Brain 2012;135:736-50) provide some insight into how likely it is that a patient would have a C9ORF72 mutation and whether this likelihood could be predicted based upon family history and clinical features.

The researchers found that the prevalences of the three mutations were roughly equal in their sample. They also found that using their Goldman scoring method for quantifying family history—which is 88% of patients with a score of 1 (representing an autosomal dominant family history of FTD or ALS) had a mutation in one of those three genes. However, the Mayo Clinic samples suggest that the C9ORF72 mutation is the most common FTD mutation, present in one-third of patients with a family history.

**Links Between FTD and ALS**

The C9ORF72 mutation may also provide some insight on the link between FTD and ALS. In all cohorts, the prevalence of C9ORF72 was highest in those with FTD/ALS at 20%-40%, and a more common 30%-40% of the FTD/ALS cases had a positive family history (Dr. Br. ed Dicker-
son, director of the frontotemporal dementia unit and laboratory of neuroimaging at Massachusetts General Hospital in Boston, Mass... USA, said that linking FTD and ALS through this gene was especially important because it would likely lead to research that sheds light on the causes and effects of the two diseases.

This “once again underscores the value that studying one neurodegenerative disease can have for other neurodegenerative diseases,” he said. “In the case of this gene, advances in understanding its role in FTD will have direct implications for understanding its role in ALS, and vice versa.”

Dr. Mar pel Mesulam, director of the cognitive neurology and Alzheimer’s disease center at Northwestern University in Chicago, USA, said that “essentially how the hope raised by the C9ORF72 finding will be realized is currently unclear, since we do not yet fully understand the function of the C9ORF72.” He added that the discovery also generates new hypotheses. “Why does the same type of mutation cause ALS in some patients, behavioral FTD in others, and PP A?”

**Who Should Undergo Screening?**

Given that some patients had the C9ORF72 mutation without a strong family history, “the most important immediate clinical implication is that we will be getting screening patients for this mutation once a standard laboratory test for the gene becomes available,” Dr. Dickerson said.

In a commentary, Rosa Rademakers, Ph.D., of the Mayo Clinic in Jacksonville, Fla., USA, argued that the use of a clinical screening algorithm may not work because detailed information about family history is often not available. At the moment, caution is advised on testing because “our pre-existing understanding of the disease penetrance and range of clinical phenotypes associated with this mutation is poor and the smallest repeat size needed for pathogenicity is unknown.” Dr. Rademakers wrote.

The sources interviewed for this article did not have enough financial disclosures. Dr. R. edemakers disclosed that she has a patent pending on the discovery of the hexanucleotide repeat expansion in the C9ORF72 gene.
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