

# PATIENT EDUCATION RESOURCES TO HELP NEUROLOGISTS

By Orly Avitzur, MD, MBA

In last month's *Neurology Today*, US Surgeon General Richard Carmona, MD, and others spoke about poor health literacy and its limiting effects on patient comprehension and patient education. Although we acknowledge the importance of instructing and informing our patients properly, we are faced with the realities of busy neurology practices and an increasing time crunch. Under these circumstances, how can we afford to spend this extra time with each patient?

"You simply cannot afford *not* to," cautions Steven R. Rush, AAN Practice and Patient Safety Manager. "If you don't take the time to educate your patients appropriately, when problems arise, you either have to call the patient back or see them in the office again – taking up the slot for a new patient. Poor patient comprehension translates into future de-



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mands on your time and possibly increased liability. Also, it is ultimately a violation of the prime ethics directive *first, do no harm.*"

"Five years ago, following an AAN needs assessment survey, it became clear that neurologists were looking for better ways to help educate their patients," said Robin L. Brey, MD, Section Editor of the "Patient Page" in *Neurology*, and Professor of Neurology at the University of Texas Health Sciences Center in San Antonio.

"The AAN has been working to provide resources to address this request since that time," she added. "We need to provide good information to educate our patients. It is a challenge that takes time, but in the long run, it is a time-saver, reducing call-backs and improving compliance. It's also just good medicine and decreases the chance for errors and lawsuits," she advised.

## MEDICO-LEGAL RISKS

Just how does poor communication factor into the issue of medico-legal risk? Last summer, the Physician Insurers Association of America (PIAA) Data Sharing Project conducted a survey of neurology claims dating back to 1990 and resolved between 1998 and 2003. The study focused on 300 paid cases that specifically involved neurology patients, as reported by 24 PIAA member companies.

In the physician's office, communication issues either between providers or provider and patient were the second most frequent issue reported. About one-third of the alleged injuries that arose in the physician's office resulted from medication errors – either wrong prescription, over-prescription, medication that was contraindicated with other medications the patient was already taking, or medication abruptly discontinued.

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## THERAPY PIPELINE: VACCINES

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fensive capacity, Dr. Schwartz said.

"Controlling the action of regulatory T cells by neurotransmitters can open new horizons for therapeutic intervention ... of neurodegenerative mental conditions," she said.

She and other researchers are working toward developing autoimmune vaccine mechanisms that will encourage immune system intervention to enhance and facilitate neuronal survival by boosting peripheral immunity. They would accomplish this by vaccinating with universal weak anti-T cell antigen or its agonist, or by weakening suppression of autoimmunity by eliminating CD4(+)CD25(+) regulatory T cells.

"Such therapies could be developed to counter multiple neurodegenerative risk factors," she said.

"T cells that home in on the damaged CNS might then help restore homeostasis thereby regulating glial behavior and producing neurotrophic factors, while avoiding cytotoxic inflammatory activity," said Dr. McLaurin. "Since neurodegenerative diseases possess some common features deriving from the local chaos, the same vaccine might protect against several disorders associated with impairment of motor, cognitive, or mental brain function."

## GLATIRAMER ACETATE TRIALS

Glatiramer acetate (GA) is one of the breakthrough successes in neuroimmunology, researchers agreed. It is used today as

a drug or vaccine against multiple sclerosis (MS) and is the first example of successful treatment of the disease based on its relatedness to the myelin basic protein.

GA, made by Teva Pharmaceutical Industries, Ltd., is a polymeric therapy approved in the US and 38 other countries for treatment of the exacerbating-relapsing type of MS. Under a collaboration agreement, a joint project is in progress to use GA for Huntington disease, and for the attenuation of the progressive optic nerve and retinal degeneration that causes visual field loss and eventually blindness in glaucoma patients. GA is expected to enter phase 2 clinical trials in the near future for both these indications. There will also be a trial for amyotrophic lateral sclerosis (ALS).

"Using GA or similar compounds as vaccines, we can safely boost the protective autoimmune response in laboratory animals of acute and chronic [CNS] insults of mechanical or biochemical origin," said Dr. McLaurin.

Since vaccination appears to be effective even when given after a lesion has established insult, and because it protects against the toxicity of glutamate (the most common mediator of secondary degeneration), it might be used to treat chronic neurodegenerative disorders such as glaucoma, Alzheimer disease, Parkinson disease, and ALS.

"We're not talking about a magic bullet here, but GA appears to narrow the search considerably," she said.

## UNDERSTANDING NEUROINVASION

Adriano Aguzzi, MD, PhD, Associate

Dean of Research at the Institute of Neuropathology of the University Hospital of Zurich Medical School in Switzerland, suggested using prion disease to model other types of neurodegenerative diseases that are caused by "neuroinvasion" and are more prevalent than Creutzfeldt-Jakob disease (CJD). He noted that his research suggests they might respond to intracerebral inoculation and neurografts, tissue from mice bred with anti-prion protein.

Surveillance of prion-related disease in Switzerland has yielded some mysterious findings, Dr. Aguzzi said. Although prion disease is recognized as being hyperinvasive and hyperenervative – meaning the disease rapidly infects the tissue and quickly destroys nerves – of the liver and spleen, one-third of all cases in his country also have some muscle involvement, something he said he cannot understand.

"The good news is that muscle biopsy might offer a minimally invasive means of diagnosing CJD. The bad news is that there may be more problems for therapeutic intervention if the disease is present in muscles." It was first reported in skeletal muscles in 2002 (*Proc Natl Acad Sci* 2002;99(6):3812-3817).

Nonetheless, he said the findings should be somewhat reassuring in terms of public health: "It means you can eat a great steak, but stay away from organ meats like liver and especially the spleen."

## PRIONS AND IMMUNITY

Dr. Aguzzi also reported that his team has detected evidence of prions in the urine of infected laboratory mice, a

symptom they call "prionuria." He noted that two out of eight experimental mice had prions in their urine, a finding that could help explain the spread of chronic wasting disease among wild animals such as deer (*J Biol Chem* 2001;276(34):31479-31482).

"Prion neuroinvasion consists of an ordered sequence of events resulting in infection of the CNS," he said, explaining that requires the transepithelial migration of prions. After gaining access to the body from peripheral sites, prions colonize lymphoid organs in mice, humans, and sheep, he said.

"The failure of peripherally administered prions to elicit disease in immune deficient mice indicates that this is crucial for pathogenesis. B-lymphocytes are required for neuroinvasion upon intraperitoneal administration ... Genetic or pharmacological interference with lymphotoxic signaling effectively impairs pathogenesis," he explained.

"We have recently generated mice expressing lymphotoxins in lymphoid organs despite the absence of B lymphocytes, and this should help us determine the precise contribution of B lymphocytes to pathogenesis. The sympathetic nervous system appears to be involved in prion transfer to the brain, since sympathectomy delays or prevents pathogenesis, whereas sympathetic hyperinnervation accelerates it."

The researchers have also identified several components of the complement system that are modifiers of neuroinvasion efficiency. Pharmacological or genetic ablation interferes with neuroinvasion, presenting other opportunities for potential vaccine development, Dr. Aguzzi said. ★

## IN PRACTICE

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"Patients will often come to the office with a stack of Internet print-outs that contain erroneous information," Dr. Brey said. "It takes time to deal with *bad* information that causes people to think they have a disease they do not, or to ask for a treatment that is not appropriate. The AAN has been working on several resources, print and Web-based, to see that patients receive *correct* information."

## PATIENT EDUCATION RESOURCES

The following materials have been developed to help fulfill this mission:

**The Patient Page**, [www.neurology.org](http://www.neurology.org), was introduced in *Neurology* in July 2002, and it comes out online on a monthly basis. Page 1 consists of an editorial condensation of an article from the same month's issue of *Neurology* and is written in lay language. Page 2 consists of a fact sheet on the condition described including diagnosis, causes, and treatments, and pro-

vides links to relevant organizations for more information.

**The Brain Matters** Web site, [www.the-brainmatters.org](http://www.the-brainmatters.org), was introduced in November 2003 and developed in collaboration with patient advocacy groups. Each neurological disorder is discussed in terms of symptoms, causes, diagnosis, treatments, current research, and prevention. Each section also includes a patient story that is presented from a positive viewpoint.

**Patient Education Brochures** about a variety of disease states and Patient

Guidelines (migraine and dementia) are available print resources and are being updated for release at [www.aan.com/professionals/patient/patient\\_edu.cfm](http://www.aan.com/professionals/patient/patient_edu.cfm).

**Quality of Life Guides**, a new patient education book series, are being developed by the AAN Press in partnership with Demos Medical Publishing, covering an array of diseases and ailments that affect the brain and central nervous system. Written by neurologists and other experts in these fields, the books will provide a detailed discussion of each disorder, its causes, and the course it may follow, as well as answer a number of questions faced by patients and their families.

The first, a headache guide, *Migraine and Other Headaches* by William B. Young, MD, Assistant Professor of Neurology and Director of the Inpatient Program at the Jefferson Headache Center at Thomas Jefferson University in Philadelphia, PA, and Stephen D. Silberstein, MD, Director of the Jefferson Headache Center, is now available (See Sidebar, "New AAN Migraine Book for Patients").

## OTHER INITIATIVES

Alan M. Rapoport, MD, Director of the New England Center for Headache in Stamford, CT, said his group began writing their own pamphlets to hand out to patients and consolidated them into a book, *Conquering Headache*, which is currently in its 5th edition.

"Patients are given the book to read prior to their departure from the office and they are directed to specific topics," he said. "This allows for a more well-informed discussion with the patient at the subsequent encounter.

"We tell each patient what we believe to be their correct diagnosis and we discuss treatment options," Dr. Rapoport added. "We then inform them that a comprehensive discussion is included in the book and ask them to consider if our conclusions appear to be valid.

"We also give the patients calendars in which our nurses write instructions for scheduling medication and ask patients to document their usage accordingly. This way we can see if they have understood and if they are taking medication the right way," he noted.

## WEB SITES

Abraham N. Lieberman, MD, a practicing neurologist for 30 years and Medical Director of the National Parkinson Foundation, has written several books, including *Shaking Up Parkinson Disease* and *100 Questions and Answers About Parkinson Disease*. "An informed patient is better able to ask good questions and to recognize problems," he said. Dr. Lieberman also receives 20 to 40 questions every day from readers and estimates that he devotes three hours per day answering questions for the "Ask the Doctor" section of the Web site, [www.parkinson.org](http://www.parkinson.org).

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