

POLICY & PRACTICE

Alzheimer's Treatment Initiative

New efforts by the Alzheimer's Association aim to speed the development of drugs to treat the disease. The Alzheimer's Association Effective Treatments Initiative will bring together scientists, early-stage Alzheimer's patients and their families, and experts on the Food and Drug Administration drug approval process; the association also will seek input from government agencies and the pharmaceutical industry. The initiative has four goals: educate the public about value of clinical studies including clinical trials and increased enrollment in such studies; raise the profile and priority of Alzheimer's at all levels of drug development; involve patients in the drug development and review processes; and increase private and public funding for Alzheimer's research. "This is a devastating disease and the need for treatments is more urgent than ever, with 77 million baby boomers turning 60 this year," said Stephen McConnell, the association's vice president of advocacy and public policy.

Views on Stem Cells

Support for human embryonic stem cell research appears to be growing, with more than three-quarters of Americans who participated in a recent survey saying that they favor some form of the research. The survey, commissioned by the Coalition for the Advancement of Medical Research, found that 72% of Americans favor embryonic stem cell research, up from 68% in 2005. Most Americans also would favor an up or down vote in the Senate on H.R. 810, a bill that would ease restrictions on the use of federal funding for embryonic stem cell research. The legislation was passed in the U.S. House last year and advocates for stem cell research have been calling on Senate Majority Leader Bill Frist (R-Tenn.) to bring the legislation to the Senate floor. About 70% of survey respondents said the Senate should allow a vote on the bill or probably should allow a vote on the bill. In comparison, 18% of respondents said the Senate should not allow a vote on the bill or probably should not allow a vote. About 6% of respondents said they did not know. The poll was conducted by the Opinion Research Corp. and included a sample of 1,000 individuals taken last month.

Too Many Screening Tests?

Physicians are needlessly ordering certain diagnostic tests during routine preventive health exams, which is inflating the cost of medical care, according to a study from Johns Hopkins University. The U.S. Preventive Services Task Force has rated such diagnostics according to level of evidence; the Hopkins researchers looked at five tests. Two tests (complete blood count and hematocrit) had "C" ratings from USPSTF, meaning there was no recommendation for or against their use; three (urinalysis, x-ray, and electrocardiogram) had "D" ratings with a recommendation against routine use. The study, which used National Ambulatory Medical Care Survey data for 1997-2002 for outpatient visits for non-pregnant adults age 21 years or over, was in the May/June issue of the American Journal of Preventive Medicine, and was led by Dr. Dan Merenstein, who is now at Georgetown University. Cost data were

obtained from the Medicare fee schedule. Thirty-seven million visits were identified as preventive by physicians and 190 million as such by patients. Most visits were to family physicians, ob.gyns., or internists. Urinalysis was performed most frequently, about 25%-33% of the time, but urine cultures were ordered only 3%-6% of the time. Annual direct costs for hematocrit and urinalysis run about \$13-\$61 million, depending on if it was a physician- or patient-identified visit, the authors estimated. For the D-rated tests, costs ranged from \$47-\$194 million.

Electronic Health Record Review

The National Governors Association is helping member states form a group to examine the privacy and security issues raised by electronic health records. RTI International, a company that is working with the NGA, has offered subcontracts to 34 state and territory governments for the purpose of forming the Health Information Security and Privacy Collaboration. "The current fragmented health care system is broken and unsustainable, and governors recognize that health information technology offers the promise for improving the system," NGA Chairman Mike Huckabee (R), governor of

Arkansas, said in a statement. Awards for the subcontracts range from \$250,000 to \$350,000 and will require each state to bring together interested parties who will work together to breach existing barriers to health information exchange. "We are working with states to examine the barriers and opportunities for sharing health information on an interoperable basis," John Thomasian, director of the association's Center for Best Practices, said in an interview. "What are the things that haven't been encountered yet that will need to be addressed?" Mr. Thomasian asked.

—Joyce Frieden

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Juvenile Myoclonic Epilepsy (JME): Often underdiagnosed or misdiagnosed

More prevalent than one might think

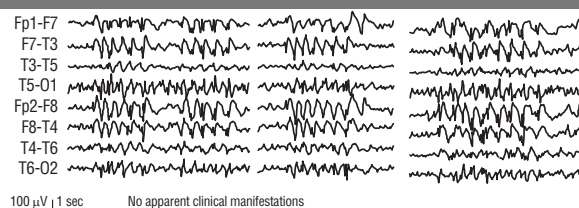
JME affects approximately 7% of all people with epilepsy worldwide.¹ The true prevalence remains unclear since many cases are underdiagnosed or misdiagnosed.^{2,3} Typically, JME presents between the ages of 12 and 18 years and is characterized by myoclonic jerks that usually occur upon awakening. The jerks rarely cause the patient to fall; however, the patient is likely to drop an object that he/she may be holding.¹ The syndrome, which patients have throughout their lives,¹ is inherited, although the mechanism for inheritance is still unclear.⁴

An idiopathic generalized epilepsy syndrome that is often treated as a focal epilepsy

JME is classified as a seizure syndrome within the group of idiopathic generalized epilepsies (IGEs). Some of the other syndromes included in the IGE group are: epilepsy with myoclonic absences, epilepsy with myoclonic atonic seizures, childhood absence epilepsy, juvenile absence epilepsy, and epilepsy with generalized tonic-clonic seizures.¹

Oftentimes, IGE seizure syndromes, such as JME, can be difficult to identify because features from one syndrome overlap with another.¹ For instance, generalized tonic-clonic seizures (GTCS) occur in over 90% of patients with JME; up to one third of these patients also experience absence seizures.^{1,4} And not all seizure types associated with the JME syndrome manifest at the same time.¹

Video-EEG of JME patient during hyperventilation⁵



Adapted with permission from Panayiotopoulos, 2005.

This can lead to a misdiagnosis and the selection of antiepileptic drug (AED) therapy that does not cover the spectrum of seizure types that the patient with JME may experience.^{2,6}

JME can present a diagnostic challenge for the clinician

JME is frequently underdiagnosed because myoclonic jerks can be missed for years. Often, it is not until after the patient has had the first generalized tonic-clonic seizure and the clinician then reviews the patient's history of earlier

myoclonic jerks, that a diagnosis of JME is made.³ It is for these reasons that the patient's medical history plays such an important role in the accurate diagnosis of JME.⁷

Correct diagnosis and appropriate treatment are key

The goal of AED therapy is to provide seizure freedom while minimizing side effects of the medication.⁷ Patients with JME require life-long treatment.¹ Establishing the correct diagnosis and prescribing appropriate AED therapy right from the start are critical to reducing patient morbidity.⁷

Recognize the characteristics of JME¹⁻³

- Symptoms begin during adolescence and require lifelong treatment
- Myoclonic jerks are the primary symptom
- Seizures usually occur upon awakening
- No loss of consciousness with myoclonic seizures
- Photosensitivity (about 30% of patients)
- Precipitating factors
 - Sleep deprivation
 - Fatigue
 - Stress
 - Alcohol
 - Menstruation
- Patients are of normal intelligence

Current treatment in JME

The selection of appropriate therapy for JME is difficult due to the scarcity of class I clinical trial evidence.⁶ Phenytoin, carbamazepine, and oxcarbazepine are sodium channel blockers and gabapentin enhances GABA-mediated transmission. These drugs have a narrow spectrum and are not considered optimal therapeutic choices for IGE syndromes such as JME.^{6,8-11} Lamotrigine, a sodium channel blocker, has been reported to worsen myoclonic seizures.^{6,9,12} Valproic acid, while shown to be effective in the treatment of JME, is associated with side effects such as hepatotoxicity, polycystic ovarian syndrome, and weight gain.¹⁰ It has been reported that it may bear a risk associated with developmental delays in children whose mothers were taking this drug while pregnant.^{10,13}

At UCB, Inc. we are keenly aware of the diagnostic and therapeutic challenges of JME and are dedicated to finding new ways to help clinicians manage their patients with this condition.

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