# **EWAITING ROOM**

## Calling Caregivers of Color



frican-American and Hispanic caregivers of people with Alzheimer's disease are more likely than caregivers of other races to dismiss the symptoms of Alzheimer's as an inevitable part of getting older, according to a survey by the Alzheimer's Foundation of America. This lack of understanding

leads to a delay in getting help.

"Not enough education is being provided to these communities," says Eric J. Hall, chief executive officer of the Alzheimer's Foundation. "We need to take a hard look at that."

"Alzheimer's disease is a devastating illness that is by no means a normal part of aging," explains Warachal E. Faison, M.D. assistant director of the Institute for Research Minority Training on Mental Health and Aging and clinical director of the Alzheimer's research and clinical programs at the Medical University of North Carolina. "It's crucial for caregivers to be able to identify symptoms early and bring their loved one to a doctor without delay for proper diagnosis and treatment."

Among surveyed caregivers who reported not knowing enough about the disease to recognize symptoms, roughly 7 in 10 attributed a delay in diagnosis to either fear that something could be wrong, fear of the responsibility of caring for someone with Alzheimer's, having never been offered a memory screening, or having little access to a health care professional.

As part of their effort to educate people of color about Alzheimer's, the Foundation will offer free memory screenings all over the country—including

in many houses of worship—on November 13, 2007. "Many African American and Hispanic caregivers look to religious leaders for this kind of information and support," Hall says.

For more information about National Memory Screening Day or Alzheimer's disease, go to alzfdn.org or call toll-free 866-232-8484.

### **NEUROBICS** Can you figure out the common expression represented by each picture?











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SEE ANSWERS ON P. 13

## **WAITING ROOM**

#### **NEUROLOGY NEWS**

## Genetic Discrimination

ongress is on the verge of breaking a 12-year impasse over legislation that would ban the use of genetic information by employers and health insurers. On April 25, 2007, the Genetic Information Nondiscrimination Act (GINA) of 2007 was passed in the U.S. House of Representatives by a vote of 420-3. The Senate has yet to vote, but President Bush has endorsed the bill.

The specter of genetic discrimination has haunted Americans since the beginnings of genetic testing more than 30 years ago, but the launch of the Human Genome Project in 1990 and the subsequent advances in testing have given those fears a human face.

Take Rebecca Fisher, a former medical librarian living in Oakton, Va., who was diagnosed with aggressive breast cancer at 31. Because the disease runs in her family, Fisher pressed her daughter Katie to get tested before leaving for college. The test showed that Katie has the breast cancer gene. "After the doctors explained everything health-wise," Fisher says, "they summed up by saying, 'Don't ever be without a group insurance plan.' And that was a stunning realization."

Proponents of GINA say that without legal protections, patients are less likely to get tests that could benefit their health and to participate in research that can lead to better treatments. Fear of genetic discrimination could impact research on many neurological disorders, such as Alzheimer's disease, Parkinson's

> disease, stroke, and Huntington's disease.

"We can't look [potential study participants in the eye and tell them their fears are unwarranted until we have effective federal legislation to prevent that," says Francis Collins, M.D., Ph.D. who directs the National Human Genome Research Institute.

For more information on the Genetic Information Nondiscrimination Act of 2007, go to genome. gov/24519851 or visit the Web site of the Library of Congress at thomas.loc.gov.



#### SCREENING ROOM

## Away from Her

Capri Films, 2007

n the one hand, Away from Her is about the relentless love Grant (Gordon Pinsent) has for his wife of more than four decades, Fiona (the luminous Julie Christie), who has early onset Alzheimer's disease. On the other, it's about the ravages the illness levels on those left behind. Fiona understands the imminence and certainty of her downward trajectory better than her husband, who remains willfully ignorant. "I think all we can aspire to in this situation is a little bit of grace," Fiona says wisely. But it's easier said than done.

To its credit, Away from Her, which is based on the Alice Munro story "The Bear Came Over the Mountain," doesn't shy away from practical matters. Early in the film, after Fiona stores a skillet in the refrigerator, the couple is seen poring over care-giving literature, including the classic The 36-Hour Day: A Family Guide to Caring for People with Alzheimer Disease, Other Dementias and Memory Loss in Later Life (Hyperion, 1989), now in its fourth edition. After Grant places Fiona in a facility—and is shut off from contact with her for a month, until she gets settled—he comes to visit only to learn she no longer recognizes him. What's worse, Fiona has forged a deep connection with Aubrey, a severely incapacitated man who lives in the facility.

The film also bravely addresses the financial cost of care. When Fiona becomes despondent after Aubrey's wife Marian (Olympia Dukakis) removes her husband from the facility, Grant visits Marian with a request. He wants her to take Aubrey back to revitalize Fiona. Marian's uncomplicated response: "If I pay, I'll lose the house. The house is the only thing we own outright."

Early on, Fiona quietly comments that she is beginning to disappear. Away from Her elegantly and fearlessly describes the story of that vanishing—and the love that sustains the fragile presence of the people we care about. —Coeli Carr

#### **OUR KIND OF WOMAN:**

## **Building Herself a Better Brain**

arbara Arrowsmith Young was labeled "retarded" when she was was a student. So she built herself a better brain. "In elementary school I could see everyone else learning how to read and write, but I couldn't," she recalls.

The teacher thought that Barbara was stupid and stubborn. "I got the strap a number of times. So I learned to do things like put my thermometer on the radiator just long enough to stay home but not

enough to be sent to the hospital."

Young also had a phenomenal memory and an iron will, and she got through by memorizing during lunch and after school. "I hung in there with extra energy and brute force," Young says.

Still, thinking skills

that most of us take for granted were alien to her. "I had difficulty recognizing symbols and symbol patterns—what is now called dyslexia," Young remembers.

On a deeper level, Young's inability to understand the relationships between symbols meant that she had trouble understanding grammar, logic, cause and effect, and basic math concepts.

"I had trouble attaching meaning and order to things, which made it difficult to interpret language," Young says. "I would play conversations over and over in my mind to understand them, but you can't come back three hours later and contribute to a discussion. It was like functioning in lag time, and the world felt flat."

After struggling through the first few years of a graduate program in education, Young came across the work of neuroscientist Mark Rosenzweig, Ph.D. "Rosenzweig had shown evidence of neuroplasticity in rats, and he said, 'Why can't we apply this to humans?' I was desperate to create exercises to stimulate my own brain function." Neuroplasticity is the theory that the nerve cells in our brains and nervous systems are malleable. Dr. Rosen-

zweig showed that the brain changes its structure with each different activity it performed.

Instead of practicing compensation, as many children with learning disabilities and victims of stroke are taught to do, Young created exercises to strengthen her weak areas. She read

hundred of cards with clock faces showing different times on the front and the correct times on the backs. She shuffled the cards so she couldn't memorize them and attempted to tell the time as quickly as possible. At the end of several weeks, not only could she read clocks faster than the average person, she started to understand what people were saying as they said it.

Young eventually opened the Arrowsmith School (arrowsmith.org) based on the principles she learned. Her success gives hope to people with learning disabilities as well as to victims of stroke and other brain injuries. And for that, Barbara Arrowsmith Young is our kind of woman.

#### **OUICK TIPS**

## **How to Catch Summer Zzzzs**

n the dead heat of summer, getting a good night's sleep can be difficult. People with multiple sclerosis and other neurological disorders can be extra sensitive to heat, as it often exacerbates symptoms. Meir Kryger, M.D., director of research and education at the Gaylord Hospital of Sleep Medicine in Connecticut and Chairman of the Board at the National Sleep Foundation, offers these tips for cooling off at bedtime:

- ☑ DON'T BE AFRAID OF THE DARK. In the morning, close windows and pull down shades to reduce heat from direct sunlight. This will keep the house cool for when you return in the evening.
- ✓ HITTHE SHOWERS. A cold shower before bed might do the trick. Spraying yourself with a plant mister can also be helpful. Some people find the transition from a warm shower to room temperature an effective way to get rid of stickiness.
- ☑ CHECK YOUR AC. Make sure your air conditioning works properly and clean the filter regularly. If you don't have an AC, ask a friend or relative with one if you can sleep over.
- ✓ HYDRATE. Drink water continuously throughout the day. If you sweat profusely, you might need a drink with electrolytes. However, if you have a heart condition, check with you doctor before increasing your salt intake.
- ✓ REFRESH YOUR BED. Sleep with just a sheet and switch to bed clothes made with moisture-wicking fabric.
- ✓ Visit the National Sleep Foundation's Web site at sleepfoundation.org

### **EXPRESS YOURSELF THROUGH ART**

Do you have a secret talent for drawing, painting, or graphic design? Send us your artwork about living with a neurological condition. One submission will be published in the Nov/Dec issue of *Neurology Now* and the artist will receive \$100. People with epilepsy can also submit art to the Expressions of Courage contest, co-sponsored by the Epilepsy Foundation and Ortho-McNeil (**expressionsofcourage.com**).

**NEUROBIC ANSWERS FROM P. 10:** BURN THE MIDNIGHT OIL; POUR YOUR HEART OUT; SPIN DOCTOR; DRAW THE CURTAINS; HIT PARADE.

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