Feelings Out of Control
Understanding involuntary emotional expression disorder

- The Power of Music
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- Stroke Finds a Mascot
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Staff and Consultants:
Dennis Milne, Vice President, American Stroke Association
Wendy Segrest, Director, American Stroke Association Operations
Debi McGill, Editor-in-Chief
Jon Caswell, Lead Editor
Jennifer Sellers, Writer
Pierce Goetz, Art Director
Michelle Neighbors, Advertising Sales

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PLAVIS® was developed in collaboration with other antiretroviral drugs, such as tenofovir disoproxil fumarate, emtricitabine, and raltegravir, to provide a more comprehensive treatment regimen for HIV-1 infection.
I am a speech-language pathologist and read each issue of your magazine and sometimes share items with patients. I was surprised and disappointed to see the article “Hunting with One Hand” in the September/October 2006 issue. Though some people apparently enjoy hunting, many are appalled at the senseless slaughter of innocent wildlife. Many people, including some who are disabled, enjoy spending time in the woods without killing the animals that live there. It would have been much more pleasant to read about one of those people.

Shirley Charney Feldman, MA, CCC/SLP
Gaithersburg, Maryland

I read Chuck Hofvander’s story “What Aphasia Has Taught Me” and had to tell myself to finish the story because I can’t read like I used to. I had to direct my thoughts back to the story.

My husband also read the story, and he said it was like me writing my story. He laughed saying I wanted to get my driver’s license so that I would have to think about being handicapped. Just like Chuck felt he had never had a stroke when he’s riding his tricycle.

Of all that I’ve overcome, aphasia was the most difficult. As Chuck wrote, “I can ‘think it’ but cannot ‘say it’ or ‘read it’ or ‘write it.’” That is the way I am. Sometimes I get mixed up when I order food at the drive-thru. This makes the young person angry until I get to the window to pay. Then they apologize or try to help me in some way.

It wasn’t my walk or limp or even falling down that bothered me, it was not being able to say what my mind was thinking. I was 54 when this happened. I didn’t have high blood pressure. I think it was 10 years of hormones.

Connie Wood, Survivor
White Hall, Arkansas

It will soon be six years since I had a stroke. My husband died about a year after that happened. I was alone! What to do? Well, I started to drive my car, took hold of myself and said, “I’m going to survive.” And so I did. My right arm is still not 100 percent, but I’m going to a therapist, and I’ll keep going until I can move my arm.

I live alone, and my friends tell me that they’re proud of me. Maybe God helped me recover, but I’m sure I had something to do with it.

Rochelle Saltz, Survivor
Brooklyn, New York

In response to your September/October 2006 article “Communication Advice from Experts: Individuals with Aphasia”: The MagnaDoodle® has helped me enormously. Using it, I don’t have to have paper and pencil to write messages. It costs about $15 at Toys-R-Us. Everywhere I go, MagnaDoodle goes.

Erik Nielsen, Survivor
Wilton, Connecticut

I had a hemorrhagic stroke a couple of years ago. My right leg is weak, I have drop foot and the toes are clawed. My foot size is 15, and there seems to be nothing available for feet that size. One catalog lists a “Gel Toe Crest” that might help the four small toes straighten some, but it is not large enough. I would like to find something that would help my small toes stay relatively straight when I am wearing shoes.

I’ve not seen anything at all to help a clawed large toe. If I could find such a product, I might be able to step off relatively normally with my right foot.

Also, my right arm is weak and I do not have full use of the fingers of that hand. I cannot really type, nor use tools. Are there computer keyboards available with extra large keys, preferably spaced more widely than normal? If I had such a thing, I could hit the proper keys with my right hand and really begin to type.

Right now I can hit the keys if I go very slowly — at a rate of less than five characters per minute, which is very laborious and exhausting. If I type a sentence, I have to rest. If I had a less exacting keyboard, I’m sure I could improve.

I have a voice program, which is better than nothing, but not nearly as good as really being able to type.

I would very much appreciate any information regarding products that might help my foot or my hand.

Peter Hartley, Survivor
Golden, Colorado

We Want To Hear From You

mail: c/o Editor-in-Chief
Stroke Connection Magazine
7272 Greenville Ave.
Dallas, TX 75231-4596
fax: 214-706-5231
e-mail: strokeconnection@heart.org

Letters may be edited for length and scientific integrity. The opinions presented are those of the individual and do not reflect those of the American Stroke Association.
A robotic therapy device may help people regain strength and normal use of affected hands long after a stroke. Robots may offer particular advantages in long-term therapy that requires intense, repetitive movement practice.

“Robot-assisted therapy may help rewire the brain and make weak limbs move better long afterwards,” said Steven C. Cramer, M.D., lead author of the study and associate professor in neurology, anatomy and neurobiology at the University of California, Irvine. “Robots can consistently and precisely perform the same task without getting tired, record and adjust to the patient’s responses, and provide feedback and virtual reality games that keep people interested and motivated. With the robot, a therapist could theoretically run 10 therapy sessions at once, or use a webcam to provide therapy from a distance at home.”

Researchers developed a hand-wrist assisting robotic device (HOW ARD) that monitors and aids patients as they grasp and release common objects. Seven women and six men, average age 63, participated in the pilot study using HOWARD.

Each patient received 15 two-hour therapy sessions, spread over three weeks, designed to improve their ability to grasp and release objects. All worked with HOWARD for the 15 sessions. For seven participants, HOWARD shaped and helped complete movements across all sessions, while six had complete support from HOWARD for only the second half of the sessions.

“The therapy isn’t passive; the brain has to jumpstart the program and initiate the motor command,” Cramer said. “But if the hand is weak and can only budge one-tenth of an inch, the robot helps to complete the task so the brain relearns what it’s like to make the full movement.”

At the end of three weeks, all patients had improved in their ability to grasp and release objects. Patients also developed a significantly greater range of motion in their hands and wrists and were rated as less disabled on a standard occupational therapy assessment tool.

“Assessing changes in before-and-after scores within each subject, these were highly significant gains after three weeks of therapy,” Cramer said. The average gain in function after therapy was more striking in patients who received robotic assistance during the whole session vs. only half.

“There were significant differences even though the groups got the same therapy, with the same content, for the same number of minutes. The only difference was that during the first half of the sessions, the robot did not move the hand and wrist for six of the subjects,” Cramer said.

“There is more ability to rebuild the brain than we realized in the past. Scientists are investigating the impact of using these things one at a time, but ultimately they will not be used in isolation,” he said. “I can imagine the power of using several of them together, with robots as one component, to make weak limbs move better in parallel with a restorative drug or growth factor.”

This year’s American Stroke Association International Stroke Conference in San Francisco brought together stroke experts from all over the world. The February conference showcased the findings of researchers in neurology, pharmacology and rehabilitation. Here are a few highlights.
Step Up to Your Potential

If foot drop from stroke is keeping you from stepping into your full potential, the NESS® L300™ may be able to help.

The NESS L300 reduces the inconveniences of foot drop by improving mobility. Using Functional Electrical Stimulation (FES) the NESS L300 activates the muscles that lift the toe while walking.

Utilizing wireless communication the NESS L300 may empower you to:
• Walk with a more natural gait, reducing the stress placed on your hip & knee
• Increase your walking speed and symmetry1
• Walk with greater confidence and ease over uneven surfaces

1. Ring H, Hausdorff JM. The immediate effects of a new FES Neuroprosthetic on gait stability and symmetry. 15th European Congress of Physical and Rehabilitation Medicine, Madrid Spain, May 2006 (conference proceedings)

B.P., a Wisconsin resident, has been living with foot drop since his stroke four years ago. The L300 has re-energized his recovery.

“It allows me to lift my foot higher—it was really neat because it allows my leg to be more flexible” he says.

For more NESS L300 information and an informative DVD or VHS, call: 800.211.9136 or 661.362.4850 • Visit our website at www.bioness.com

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Many stroke survivors have difficulty affording medication to help prevent another stroke, according to researchers who assessed medication access and associated barriers to care in a large national sample of U.S. stroke survivors. According to the investigators, an estimated 76,000 U.S. stroke survivors couldn’t afford medications during 2004. Affordability was lower among survivors who were under 65, black, female and had more co-existing conditions or poor health status. Factors limiting medication access included lack of transportation, lack of insurance and financial constraints. From 1997 to 2004, the percentage of survivors who couldn’t afford medications grew from 8.1 percent to 12.7 percent overall and increased in all regions but the Northeast. Investigators said health policies that improve access to medication are needed for this vulnerable and growing population of high-risk stroke survivors.

Many Survivors Can’t Afford Medication

A meta-analysis of 17 studies including 2,367 patients provides convincing evidence that the phenomenon of “aspirin resistance” is real. Researchers compared clinical outcomes of patients classified as “aspirin resistant” and “aspirin sensitive.” Resistance was defined as blood clotting despite aspirin therapy, while sensitivity was defined as the anti-clotting response to specific aspirin-therapy stimuli. Despite similar demographics in both groups, one-third of the aspirin-resistant patients suffered strokes, heart attacks, acute coronary syndrome or graft failures compared to only 15 percent of aspirin-sensitive patients. Risk of death was 5.7 percent in the aspirin-resistant group and 1.3 percent in the aspirin-sensitive group. Men were at a higher risk than women of being aspirin resistant. While aspirin therapy can be effective in treating heart and brain-related diseases, “not all patients benefit,” the researchers concluded. Since aspirin resistance can increase risk of an adverse clinical outcome, patients should be screened before being given aspirin as anti-clot therapy, the scientists said.

Aspirin Resistance a Factor in Adverse Patient Outcomes

Positive Insights into Successful Caregiving

Seventy-three stroke patient caregivers — spouses, adult children or friends — were questioned in bi-monthly telephone interviews about their caregiving experiences. Reported problems centered on frustration in day-to-day situations, feelings of inadequacy and struggling to find “normal” caring. However, reports of positive experiences outnumbered problems. Three themes in successful caregiving emerged: “making it through and striving for independence,” “doing things together and seeing accomplishments in others” and “reaching a new sense of normal and finding balance in life.” A representative comment was that the stroke caregiving situation “changed my outlook on life. I can let the small things go, because they can wait.” Researchers suggested their survey could help caregivers assume new behaviors and change to meet their responsibilities and could be used “to tailor interventions based on caregivers’ difficult, yet rewarding, experiences.”
Cholesterol Poorly Controlled in African Americans

Researchers in the area of the southeastern United States known as the Stroke Belt studied racial differences relating to cholesterol disorders. Forty percent of the 21,622 participants were black and 60 percent were white, average age 65; 54 percent of participants had cholesterol disorders, with no racial difference. However, after adjustments for demographic and conventional stroke risk factors, it was found that African Americans with cholesterol disorders were less likely to be aware, treated and controlled compared with whites. Researchers concluded that although cholesterol disorders do not appear to account for the higher rates of stroke in the Southeast, they may explain some of the excess stroke burden in African Americans.

Diabetes Risk Factors Not Well Controlled Despite Raising Stroke Risk

Despite recent guidelines urging rigorous control of risk factors for diabetes — a disease that increases the threat of stroke — researchers found that diabetes risk factors were not well controlled among acute stroke patients.

An analysis of data on almost 50,000 stroke patients with diabetes showed high rates of obesity, high blood pressure, cholesterol disorders and poor control of blood sugar when the stroke occurred. People who had undiagnosed diabetes at the time of their stroke had poorer control of diabetes risk factors than those in whom diabetes had already been established. Thus, these newly diagnosed diabetic stroke patients may be at higher risk for a recurrent stroke and cardiovascular complications.

Patients with better control of their diabetes are less likely to have microvascular complications such as renal failure, retinopathy and neuropathy. Diabetes has reached epidemic proportion in the United States; almost 21 million adults and children have it. The American Heart Association’s guidelines for stroke care recommend rigorous control of blood sugar in diabetic patients to reduce stroke risk.

To determine how well diabetes risk factors are managed in stroke patients, researchers analyzed data on 159,333 patients who presented to hospitals for treatment of stroke or transient ischemic attack (TIA). The researchers examined the status of various risk factors when the stroke occurred and whether patients’ diabetes had been diagnosed before the stroke.

More than 49,000 of the stroke patients had diabetes, including 46,436 with known diabetes when the stroke occurred and 2,630 whose diabetes was diagnosed at the hospital. Among patients with known diabetes, 31 percent were obese, 82.5 percent had high blood pressure and 41 percent had abnormal cholesterol. The level of LDL (bad cholesterol) averaged 106 mg/dL (less than 100 is recommended for diabetic patients). The glycohemoglobin (HbA1c) value (an indication of diabetes control) averaged 7.87 percent; less than 7 percent is the recommended level.

The patients with undiagnosed diabetes had a lower prevalence of obesity, high blood pressure and lipid disorders, but they had a higher LDL level and glycohemoglobin value. At hospital discharge, patients with undiagnosed diabetes at the time of their stroke had poorer control of diabetes and stroke risk factors.
STOP Stroke Act Passes U.S. House

The Stroke Treatment and Ongoing Prevention Act (STOP Stroke, H.R. 477) took a major step toward becoming law when it was passed by the full House of Representatives by voice vote on March 27. The STOP Stroke Act, which was introduced by Reps. Lois Capps (D-CA) and Chip Pickering (R-MS) in January, would help ensure that stroke is more widely recognized by the public and treated more effectively by healthcare providers.

“The House vote brings us closer to closing gaps in the awareness and treatment of a deadly disease that afflicts about 700,000 Americans each year and threatens quality of life,” said Larry Goldstein, M.D., chair of the American Stroke Association Stroke Council. “In recognizing the severity of this disease and the need to improve care, the House has taken a bold step in addressing this issue head-on. Now it’s up to the Senate to act quickly and pass the STOP Stroke Act during this session.”

In the Senate, the STOP Stroke Act was re-introduced by Senators Thad Cochran (R-MS) and Edward M. Kennedy (D-MA) on March 27. The STOP Stroke Act will provide states with the resources needed to implement coordinated stroke systems of care. It also authorizes a national public awareness campaign, a grant program to train medical professionals in newly developed tools and therapies, and a national clearinghouse to collect stroke data and share best practices.

To take action and urge your Senator to co-sponsor the STOP Stroke Act, join the You’re the Cure network today. Visit: www.strokeassociation.org/yourethecure.

Home Monitoring for A-fib Can Work

As many as 8 percent of strokes may be caused by undiagnosed atrial fibrillation (AF). According to New York researchers, identifying asymptomatic AF may identify at-risk patients. A modified blood pressure monitor designed to detect AF by assessing pulse irregularities may be able to identify patients at risk of stroke. Researchers placed the devices in homes to monitor pulse regularity of 19 outpatients with a previous history of AF. Electrocardiograms were used to further evaluate patients with an irregular pulse. Daily monitoring ranged from five days to five months. Seven patients had recurrent AF, nine had no irregular readings for an average of 82 days, and three had false positive irregular readings. The modified blood pressure monitors allowed for long-term home monitoring for AF in 16 of 19 patients. Researchers said the device should be useful for screening patients at high risk for developing AF and might help prevent strokes by identifying asymptomatic patients who are candidates for anti-coagulation therapy.

Know...

THE WARNING SIGNS OF STROKE:

- Sudden numbness or weakness of the face, arm or leg, especially on one side of the body
- Sudden confusion, trouble speaking or understanding
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, loss of balance or coordination
- Sudden, severe headache with no known cause

If you experience some or all of these warning signs, don’t wait. Call 9-1-1 right away.

Notes...
Is Your Current Stroke Treatment Costing You An Arm And A Leg?

Watching my patients go from initially learning grasp and release with the SaeboFlex® to functional tasks without the splint has been a life changing experience for me. I am brought to tears when I watch my patients with the SaeboFlex®.

~ Daryl Holt, OTR/L

To try on the SaeboFlex® was AMAZING! I was so excited to see my arm MOVE and that I could grasp and release ...was amazing.

~ Mary Graham, Stroke Survivor

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Pulled Over for Speeding:
A Proud Step in Recovery

I was coming home from a support group planning meeting at Presbyterian Hospital in Charlotte, N.C. I was excited because my new life purpose was now truly being fulfilled — helping stroke survivors and preventing stroke.

As I drove up Iredell Avenue I noticed a police car coming toward me. Suddenly its siren screamed and lights flashed as the policeman whipped the car around and raced up the hill. I pulled over, and the squad car pulled over behind me — of all things!

The officer motioned for me to pull around the corner, which I did, reluctantly. I rolled down my window as he approached. In a friendly voice he asked if I lived around this area. I said I did. He mentioned my Jersey plates and asked what brought me to the area. I blurted out, “I’ve had a stroke and a brain operation, and we wanted to start a new life.”

“May I see your driver’s license?” he said.
“Any particular reason?” I asked.
“You were doing 52 in a 35 zone.”

I had no idea an approaching police car could clock my speed while traveling in the opposite direction. Technology had once again passed me by. Suddenly I felt very old.

However, I did have to provide justification. I said, “Drivers have been getting very irritated with my driving. I have been way too slow, so I have been practicing speeding up.” I have to give him full credit — his facial expression didn’t change in the least!

I reached in my wallet and pulled out my debit card. I guess I wanted to deal with the financial side immediately — get it over Jersey-style.

“No, no, sir, your driver’s license.” I hadn’t been pulled over in decades, but I did know the protocol: Find your license, pull it out of your wallet, hand it over to the officer. Do not show the driver’s license while it is still in your wallet. I believe this is some sort of sobriety test. I didn’t need to worry, it was before 5 o’clock. However, my dexterity since my stroke is a little questionable. I’m glad he didn’t ask me to type!

It took forever to check my license. Even the officer found it necessary to explain the delay: “I guess it’s because it’s from New Jersey,” he said. I assume he meant it would take awhile to run off my lengthy criminal record.

After all this, the officer said, “Mr. Guns, you have been driving over the speed limit. I am going to give you a warning to slow down.” I thanked him for keeping me within the same limits as the other wannabe NASCAR drivers in the neighborhood.

I didn’t tell him that I was secretly thrilled to be pulled over for speeding. In fact, I could hardly wait to let my fellow survivors know that there’s still a little juice running through this old gasoline tank.

Bob Guns, Survivor
Mooresville, North Carolina
My name is Vickie, and my husband is Gordon. We have two sons, Gordie, who is 29, and Jesse, 24. We had a great family, and then everything changed in June 1997. I had been having seizures while asleep, and they got worse. I also felt very strange when I was awake, so my doctor had me get a scan X-ray, and that changed everything. The scan found a brain tumor above my left ear. The surgery was scheduled for July 30th, which happens to be my birthday.

When I went into the hospital for my surgery, I must have known something was going to happen because I looked at my husband and mom and started crying as I went into surgery. That’s all I remember. During surgery, the surgeon cut a blood vessel, and I had a bad stroke. I was paralyzed on the right side. At first I couldn’t talk, think or move my arm or leg. When I could talk, I called Gordon “Ralph,” the name of our dog.

I was a week in the hospital, but I don’t remember anything. My mom, Beverly Talbott, and Gordon tell me it’s just as well. From the hospital I went to rehab for a month. They helped me do everything I do around the house. Then I became an outpatient, and I really liked it because they would come home with me to see how I was doing. They were with me when I took my first shower. They took me to the store and were with me the first time I cooked. When I started as an outpatient, I was in a wheelchair; when I left I was wearing a brace for my leg and ankle and using a cane. I went to outpatient therapy for a long time, but as time passed I did more and more on my own.

I was 51 this past July. It’s been nine years since my surgery, and I’ve come a long way: I’m driving now. I cook all the time and bake a lot. I make quilts, from baby-size to king-size. I sew clothes, including pinning and cutting. I like to crochet using my right hand and a big hook. It’s all therapy. I plant vegetables and can the produce and make jam. I do as much or more than I did before the stroke. I even played pool!

My husband, sons and mother, who has passed away, stood by me through the whole thing. Our son Gordie got married, and I walked down the aisle with my husband and danced at the reception.

I still go to therapy twice a year to see how I’m doing. I am really happy, and I thank the Lord that I’m alive and getting better every day.

Vickie Stacy, Survivor
Amboy, Washington

“I am really happy, and I thank the Lord that I’m alive and getting better every day.”
Strategies for Survival

I am a 10-year stroke survivor. I was 60 years old at the time. One minute I was talking on the phone, and the next I was completely paralyzed on my left side. I was in the hospital in Birmingham, Ala. for a week, and then I spent six weeks in a rehab center.

I came home with a cane and wheelchair, and my home had to be made handicap accessible, so I could live there. My husband Jerry was my caregiver. He and I did my therapy every day. The majority of my therapy was created by my husband. He installed a pulley on the ceiling to work my arm. He attached a spring to the doorknob, and that device worked my arm. I exercised my hand and fingers for many hours.

At night, my hand would close tight, and I would be forced to use my right hand to pry my left hand open. We discovered that if we placed an empty toilet tissue tube in my hand with a strip of Velcro through it and fastened it on the back of my hand, it helped keep my hand relaxed. I slept with an empty toilet tissue tube in my hand for the next four years! Eventually I would squeeze one closed and would have to replace it — talk about cheap therapy! But it must have worked because I now have complete use of my hand and arm.

I found that walking was the best therapy for my leg and foot. I am a bit slower than I was, but I can walk without assistance.

I thought after my stroke that I would never drive again. In fact, I let my license expire. After six years, my best friend encouraged me to begin driving again. Of course, I had to take both the written and driving test, but I passed. Now I can drive myself anywhere I need to go.

I can do all the things I thought I would never do again — vacations, class reunions, spend-the-night parties. Yes, at age 71, I still enjoy spend-the-night parties. Each year eight of us from the class of 1953 spend a day and night together at one of our homes.

My friends, family and faith are what gave me the courage and will to get better. When I hear someone who has had a stroke, I call that person and try to encourage them to never give up. A stroke survivor should always keep a positive outlook, work hard and leave the rest to God. Always pray!

Nita Waid, Survivor
Parrish, Alabama

Don’t Cry at My Funeral If You’ve Forgotten I’m Alive Today

Yes, I know you are busy; I was once your age. I realize you have your family, and they come first, as they should. But how long does it take to make a phone call just to say, “I was thinking of you today, of the fun things we used to do together. I just wanted to say ‘I love you’ and thank you for being an important part of my life when I was a child.”

I know I am too old to run or play hide the thimble anymore, or take you to the cottage I no longer have, but still I need to hear your voice. I need to know you haven’t forgotten your aunt, and that I am still part of your heart. It would be nice to see you once in awhile, even if you only stopped to give me a hug. You see, I need hugs just like you needed hugs when your mom didn’t understand you or she was so busy she didn’t have time to listen.

The stroke stole my speech but not my heart. It still pumps inside me, and you live there. Yes, each one of you — you’re my family. Families are families no matter how busy we let our lives become. Love is a four-letter word, and it’s spelled T-I-M-E. I can’t converse as once I could, but I can listen. I’d love to hear about your children, what they are doing in school, what they are involved in.

Have you forgotten I took time off work to watch your ballgames, to take you fishing or buy you something you really wanted?

When we do have our times together at Thanksgiving and Christmas, you talk around me, not to me. I’m not an object. I’m still your aunt, part of the family. At least I’d like to feel I was by having a sandwich together once in awhile or getting a call just because you thought of me. I get very lonely shut up in my wordless world.

I really need you; I only wish you needed me, even a little. So please, don’t cry at my funeral if you’ve forgotten I’m alive today.

Name withheld by request
If You Make It a Determination…

My husband Joe and I were leaving the mall when Joe remembered he needed to buy something in one of the stores. I was tired and told him I’d sit on a bench and he could pick me up on his way back, so he took off.

I sat down on the bench next to a lady in a wheelchair. Next to her on another bench was a nurse, and they were talking about the people walking by. The nurse said, “You could be like that again if you only did your exercise.”

I turned to the woman in the wheelchair and asked, “Did you have a stroke?” She just looked at me and didn’t say a word, but the nurse said that she had.

I said, “So did I,” and I got that look from the woman. The nurse said, “You look great.”

I said, “I was in a chair just like she is.” Then to the woman I said, “Do you know what made me get out of the chair?” She gave me that look again. “It doesn’t fit in some doorways, and it doesn’t go up and down stairs, and I have a sunken living room,” I got that look again.

I stood up in front of her and pivoted and said, “Look at me. It took work. I went from a bed and looking at four walls and a ceiling to a wheelchair that couldn’t climb stairs to a walker that couldn’t go through narrow aisles. Getting really angry helped me. I went from ‘why me’ to ‘what can I do to get out of this?’ You may think it should be easy, but it’s not. If you make it a determination, you’ll get out of that chair. If not, you’ll be in that chair forever and welcome to it.”

I turned to the nurse and said, “Good luck,” and to the wheelchair lady I said, “You, too. Be happy whatever way you swing it.” I headed off to meet Joe who was coming out of the mall.

I never saw them again, but I hope I helped in some way. I guess I’ll never know.

Loretta Mikosz, Survivor
Spring Hill, Florida

Loretta Mikosz

Life Changes

One, pause, two, pause, three
Slowly, carefully
Forward motion

Once so smooth,
So sure, so swift
Now so glad to even move

Month by month
Long days ahead
Weeks of perseverance

Within the confines of my tower
Safe, secure and unafraid
Making effort every day

Left a time
I must roll out
Begin life again
Just we two

Unreal, confused
A life so changed
Role reversal, he and I

Some thoughts one never shares
Disciplines of self control
Body, mind, inner self

Years of struggle
Much love and care
Independence within a sphere

Life goes on
Adjust your pace
Smile, find all that’s good

Muriel Cowan, Survivor
Carmichael, California
STROKE TARGETS BY COLOR.

Know where you stand. The odds are African Americans are twice as likely to suffer a stroke as white Americans.

Beating the odds isn’t about winning, it’s about living.
You have the power to end stroke. 1-888-4-STROKE / StrokeAssociation.org
To honor Vandross’ irreplaceable legacy, several music-industry friends recently recorded “Forever, For Always, For Luther, Volume 2.” The CD, a follow-up to an initial 2004 collection of tribute songs, not only features some of today’s most talented recording artists, it also communicates life-saving information about stroke.

Produced by Rex Rideout and Bud Harner, “Forever, For Always, For Luther, Volume 2” includes interpretations of Vandross songs by Will Downing, Patti Austin, Gerald Albright, Jonathan Butler, Norman Brown, Everette Harp, Jeff Lorber, Maysa, Najee, Wayman Tisdale, Kevin Whalum and Kirk Whalum. The warning signs of stroke and other related information are printed on every CD, and a portion of sales will go to the American Stroke Association.

Downing, who performs “Superstar” on the CD, has made an extra effort to help fight the disease that claimed his close friend’s life. He is a National Ambassador with the American Stroke Association’s Power To End Stroke program, which raises awareness among African Americans, who have a disproportionately high risk of stroke. While on tour, Downing also sponsors bowling tournaments to raise awareness and funds.

“Trying to raise awareness can be difficult, but it is a labor of love for me,” Downing said. “At our events, people are staggered when they hear the statistics for African Americans and stroke. I know it sparks conversations, and suddenly people realize that they all know someone who has been affected. People leave with a sense that they must be conscious of their own diet and physical well-being. If each one of them will educate just one more individual, that can have a big impact.”

Dr. Bruce Ovbiagele, a volunteer with the American Stroke Association, is another strong believer in the need for increased awareness. “When you look at the African-American community, you see a greater disposition to virtually all the risk factors for stroke,” said Ovbiagele, assistant professor of neurology at the University of California, Los Angeles. “This is exacerbated by the fact that there’s such a shortage of good, accurate information out there on stroke, especially in the black community. That’s leading to a stroke epidemic in the black community, and it’s critical that we act now to stop it.”

(continued)
Vandross had an extensive family history of cardiovascular disease and diabetes, and battled to control his weight during much of his adult life. His mother, Mary Vandross, who has lost several family members to stroke and diabetes, is urging others who may be at risk to reach out for help. “Don’t keep your symptoms to yourself,” she said. “Let someone in your family know so they can help. Do not keep it a secret.”

One way to find help is to contact Power To End Stroke, which has resources to help people increase their awareness and lower their risk. “The idea behind ‘Power’ is that by simply being aware, people will begin to focus in a way they haven’t before,” said Yolanda King, national spokesperson for Power To End Stroke and daughter of the late Dr. Martin Luther King Jr. and Coretta Scott King.

For more information on Power To End Stroke, or to order “Forever, For Always, For Luther, Volume 2,” visit www.StrokeAssociation.org/Power. Power To End Stroke is nationally sponsored by the Bristol-Myers Squibb/Sanofi Pharmaceuticals Partnership.

NATIONAL AMBASSADORS HONORED

On May 5, the American Stroke Association will hold a special awards gala in Atlanta to honor outstanding local and national Power To End Stroke Ambassadors for their efforts to raise stroke awareness within the African-American community. The honorees include the following national Ambassadors:

Yolanda King
Speaker, actor, writer, teacher, producer, daughter of Dr. Martin Luther King Jr. and Coretta Scott King, and the first national ambassador of the Power To End Stroke campaign

Edgar J. Kenton III, M.D.
Neurologist and national spokesperson for the American Stroke Association and Power To End Stroke campaign

Will Downing
Jazz artist and recipient of many Grammy Awards and the NAACP Image Awards

Pastor Rudolph W. McKissick Jr.
Nationally famous senior pastor of Bethel Baptist Institutional Church in Florida and passionate advocate for African-American wellness

Mark McEwen
Former major network weatherman, anchor, entertainment reporter, news personality and stroke survivor

Mary Ida Vandross
Traveling evangelist and mother of the late singer Luther Vandross
All in favor of a better non-surgical treatment for correcting foot drop, raise your foot.

Introducing WalkAide — a new treatment option for people experiencing foot drop. Using sophisticated sensor technology and Functional Electrical Stimulation (FES), WalkAide stimulates the muscles that flex your foot at the appropriate time during the walking cycle, helping you walk much more naturally and efficiently. Most patients with upper motor neuron-related foot drop who try WalkAide experience immediate and substantial improvement in their walking ability. Non-invasive and easy to use every day, WalkAide increases your mobility, stability, confidence and independence. Now you have a better way to get a leg up on foot drop.
STROKE MESSES WITH YOUR MIND, JUST ASK ANY SURVIVOR. AND THERE’S NO PREDICTING JUST WHAT KIND OF MESS IT WILL LEAVE.
The catalog of deficits caused by stroke is as wide ranging as the functions of the brain — from movement to speech to memory to emotions. Recently researchers have renamed an emotional deficit experienced by many survivors. Previously it had several names, “emotional lability,” “reflex crying (or laughing),” “emotional incontinence” or “pseudobulbar affect”; the new term is “involuntary emotional expression disorder” (IEED).

“IEED refers to a loss of control of affect or emotional expression such that a person more frequently, easily and intensely expresses emotion,” said Dr. Robert Hartke, a psychologist in the stroke program at the Rehabilitation Institute of Chicago, and also an assistant professor in the department of psychiatry and behavioral sciences at Feinberg School of Medicine at Northwestern University in Chicago.

“Most definitions of IEED state that the emotional expression is uncontrolled and without an apparent trigger. However, in my clinical practice, most people with the disorder have limited control, and the triggers are logical and identifiable. That doesn’t mean that the triggers are obvious to an observer or something the survivor would have been emotional about before their stroke.”

UNDERSTANDING IEED

“To understand what the disorder is, one must first understand and be able to distinguish between ‘affect’ and ‘mood,’” said Dr. Mark Sandberg, director of psychology and community re-entry at St. Charles Hospital in Port Jefferson, N.Y. “Mood is an emotional state that lasts for prolonged periods of time; think of it as our emotional ‘climate.’ Affect is more of a moment-to-moment emotional expression — our emotional ‘weather.’ IEED is a disorder of affect. A person’s ability to regulate their outward emotional expression is damaged in IEED, and stroke is one of the common reasons why such damage occurs.”

IEED results from a malfunction in communication between the cortex, a more-evolved area of the brain that controls how we think about and label feelings, and the sub-cortical area, which is more primitive and controls how those feelings are actually expressed. “IEED is always associated with various neuropathologies,” said Dr. Sandberg. “It involves a loss of cerebral control involving emotional motor expression. It is not a neurological disorder like depression, although the person with IEED may also be depressed. It is a neurologically based disorder of affective expression.”

WHAT IT FEELS LIKE

Peter Arnold, 66, of Chicago, can attest to the loss of control that comes with IEED. Before his stroke in 1991, he was a high-dollar commercial real estate attorney not prone to emotional displays. “Now I cry at the drop of a hat, and people have told me that that’s the result of the stroke,” he said.

Peter had two hemorrhagic strokes as a result of arteriovenous malformation. “Recently I was at a dance recital with a fellow stroke survivor, and I got very emotional. It was a friend’s recital, and I cried when we went in and I cried when we left. It’s not like I walk around the streets crying, I’m just more emotional than before.

“I didn’t realize it at first because I was living in ‘therapy world,’” he continued. “We stroke survivors go through a lot of readjustment to the outside world. Simple things, like crossing the street, can be very intimidating, especially here in Chicago. Those drivers are anxious to get going when the light turns, and because I’m handicapped, it might take me a little longer to get across, and the drivers would start honking and inching forward. I would stop in the street and start yelling at them. Even today I get angry at stupid things, like the way people drive, but mostly I control it.”

“The majority of stroke survivors can identify a thought or event that causes their tearfulness,” said Dr. Hartke. “Most frequent stimuli are associated with sentiment, such as thoughts of family, loss and recovery associated with the stroke, kind gestures or expressions of sympathy, frustration over dependency, or even a sense of gratitude. Other people’s emotional expression can also precipitate it. I have seen this when working with survivors in group therapy. The idea of crying for no reason is perhaps fueled by the fact that the stimulus could be unusual or not obvious to the outside observer.”

There is not a consensus of opinion about how common IEED is after stroke. Research studies with larger samples estimate the prevalence at 11–34 percent. It appears...
to be more prevalent in older patients and those who have had prior strokes or who experience stroke in certain parts of the brain, like the basal ganglia.

The disorder often brings consequences on an emotional, social and occupational level. “If a person has been emotionally reserved all of their life, onset of IEED after stroke can feel self-alienating and anxiety-provoking,” said Dr. Hartke. “Stroke survivors I have worked with make comments about how it makes them feel unlike their usual selves, out of control and crazy. IEED can cause social embarrassment and disrupt or distort communication in ways that are puzzling and frustrating to a stroke survivor. It can also slow down therapy sessions while survivors regain their composure. In the more intense IEED sometimes seen in survivors of brainstem stroke who may have had a tracheotomy, it can be exhausting and put a person at risk for aspiration.”

“The consequences of IEED can be disabling to social and occupational functioning, and can surely undermine a survivor’s self-esteem and psychological well-being,” said Dr. Sandberg. “Most of the time it creates a pattern of uncontrollable crying; less common is uncontrollable laughter. You can imagine the social consequences of such behavior, particularly when it occurs within a social exchange.”

### IEED AND DEPRESSION

Although survivors with IEED may be depressed, IEED and depression are distinct disorders. IEED involves a disconnection between mood, which is the cognitive aspect of emotion, and affect, which is its physical expression. “Many patients with IEED also experience depressive symptoms,” said Dr. Sandberg. “And depression can make the affective displays more prominent. However, the bouts of uncontrollable expression are out of proportion to the underlying mood, and unlike depression, the features of which last over time, IEED symptoms come quickly and then leave. Most of the clinical features of depression are not features of IEED.”

### TREATMENT

Given that the disorder carries so many names, it is not surprising that there is no agreed-upon treatment. Proper diagnosis is step one.

“It is important to keep in mind that IEED has to be taken in context,” said Dr. Marilyn Kraus, a neuropsychiatrist and associate professor of psychiatry and neurology at the University of Illinois at Chicago’s Center for Cognitive Medicine. “IEED is rarely an isolated entity. For example, it can occur with other types of mood and behavior problems or cognitive problems.

“First, a full assessment of the patient’s neurobehavioral status is needed,” she said. “It is necessary to know if there are cognitive deficits, or other mood or behavioral problems, so any treatment targets as many symptoms or deficits as possible and doesn’t worsen other problems. For example, in a patient with IEED who also has attention problems, a goal would be to choose an agent that could help with the emotional dysregulation and either help improve attention or at least not worsen it. Conversely, a patient with insomnia or anxiety might benefit from an agent associated with sedation or that has a more calming effect.”

Although a new drug is currently being evaluated, at this time there are no FDA-approved medications specifically for IEED; however, off-label treatment with antidepressants has had some success. Tricyclics and

(continued on page 22)
Every thoughtful husband and wife knows the time eventually will come when one of them will have to carry on alone, and perhaps spend many years as a widow or widower. The American Heart Association has prepared a practical, supportive brochure to help spouses prepare for life without their marriage partner. It will help you be ready “when the time comes” not only to handle the details and decisions that follow a spouse’s death, but also to deal with financial and practical matters—indeed, to resume life as effectively as possible.

For more information, please visit us at americanheart.org/plannedgiving or e-mail us at plannedgiving@heart.org.
selective serotonin reuptake inhibitors such as Elavil, Zoloft and Prozac are the most frequently used, generally in doses lower than those prescribed for depression. Anti-epileptic drugs may also be useful for stabilizing survivors’ moods.

“There are side effects possible with all the medications that can be used,” said Dr. Kraus. “The thing to keep in mind is that an injured brain may be more sensitive to side effects, so practitioners should generally start with a low dose and go slowly with any increases.”

Peter Arnold does not take medication for IEED, though he does take anti-seizure medication to control seizures that resulted from his strokes 15 years ago. He’s learned how to overcome his bouts of uncontrolled emotion through self-observation. “The most distressing thing to me is being taken over by my emotions,” he said. “Most people don’t control themselves. Through Alcoholics Anonymous (AA) and training I’ve received to be a drug and alcohol counselor, I’ve gotten the tools I need to understand why I get so emotional.

“At first, I was more detached from the events; they just seemed to happen,” he continued. “But then I started to feel the feelings, and that opened up a whole world of feelings that I didn’t know I had. I was always an emotional person, but I didn’t realize it. It took a long time for me to figure out who I was. It produced a lot of revelations.”

HOW TO RESPOND

Family and friends often feel uneasy when they observe an episode of crying or an angry outburst. “The best thing for them to do is be supportive,” said Dr. Sandberg. “When the episode is over, help the survivor redirect their attention back to the previous conversation or activity and resume what had been their focus of attention. Family support is a critical factor in resuming a meaningful and satisfying life when faced with residual neurological features from a stroke.”

“From a more psychological and behavioral standpoint, education of the stroke survivor and their family as to what IEED is all about can be extremely helpful,” said Dr. Hartke. “There are simple behavioral strategies that can help, such as distracting the person from the stimulus, or having the stroke survivor use verbal clarification about how they are really feeling in order to regain control and clarify communication. In some instances, taking slow, deep breaths can help. None of these strategies has been systematically studied. I suggest them based on clinical anecdotal experience with patients.”

The intensity of the emotional response may decrease over time, especially if it is associated with a single stroke or other neurological event. Research suggests that frequency and intensity diminish during the first year post-stroke.

“It is important for family and friends to realize that IEED is an emotional reaction with a definite physical cause,” said Dr. Hartke. “I often describe it as a misfiring or disconnection in the brain that disables a filter or moderating mechanism so that emotional expression can just ‘pop out,’ like an emotional thunderstorm. Where in the past the survivor may have only experienced the cognitive portion of an emotion and ‘kept it inside,’ now he or she has much less control of the nonverbal expression of it.

“When family members realize this, it is easier for them not to focus on the expression — which can prolong it — but rather aid the survivor through distraction, which can help them move through the expression more quickly and with less embarrassment,” said Dr. Hartke. “It is important for family members not to get embarrassed along with the survivor. Instead, they could ask for verbal clarification of how the survivor is really feeling: For example, asking, ‘Are you really that sad right now, or is this just one of those moments because of your stroke?’ This way the survivor can gain control by more clearly stating how he feels.”

When survivor Peter Arnold starts to go off into an angry response in traffic, for instance, his wife Paulette steps in. “She tells me, ‘stop it,’ and I do. I just let people go around me now. I realize I can’t control other people.

“It took a lot of work, but I’ve learned to control my emotions much better,” Peter continued. “I feel that being more emotional has improved me in some ways. I feel more empathy for people now. I never really cared about other people before. I feel more compassion now.”
This past February (2007), Dr. Robert Hartke, a psychologist at the Rehabilitation Institute of Chicago, and two other investigators published the results of a pilot study of small writing groups made up of stroke survivors. Their aim was to evaluate whether such groups assist in long-term recovery and to assess whether expressive writing helps survivors deal with post-stroke trauma.

In the study, 26 survivors met four times in small groups and wrote short essays about their recovery. Essay themes included coping with recovery and personal growth and changes in self-concept. The study was funded by the National Institute of Disability and Rehabilitation Research.

According to published results, the group experience was well received by participants, and measurements showed a trend toward improvement in positive identity, although there was no significant change in depression or well-being.

“We often communicate with and disclose ourselves to others through personal stories,” said Dr. Hartke. “By telling of our accomplishments, trials, joys and sorrows, we show others who we are and give meaning to our lives. The survivors’ essays illustrate the range of issues, opinions and feelings that can be part of the inner lives of individuals coping with recovery. They convey how perseverance, self-reliance and conviction can lead to an ultimate triumph. The authors offer their reflections on their experiences in the spirit of hope and support to others recovering from stroke, their families and intimate others. I may be biased, but some of the essays are quite elegant.”

In his essay, survivor Bill Tyda wrote:

“I think I have finally come to the conclusion that there can be no comparison of one survivor to another. We are each unique unto ourselves. With the help of the rehab team we each come to that understanding; the sooner the better. For some that realization may come during the immediate period after stroke; for others it may take years. So avoid comparisons!”

Dr. Hartke’s study was published in the January/February 2007 issue of Topics in Stroke Rehabilitation. The 26 essays are available in PDF format for easy download at www.rrtc-stroke.org. In the search window, enter “expressive writing.”
ere’s a word all stroke families hate — “plateau.” Of course, plateau is commonly used to describe that point in time when a survivor stops making big improvements in function. But it is also often attached to another unfortunate circumstance: when medical insurance stops paying for therapy. Of course, without continued therapy, the likelihood of improvement decreases dramatically. Have you ever heard a stroke survivor say, “I just had too much therapy after my stroke. I wish I’d stopped after three months. That was plenty.”?

For many survivors, functional improvement is incremental and is likely to continue for a long time. Ongoing, long-term therapy is the key to this incremental improvement, and that is exactly what the label “plateau” jeopardizes.

“When I see how much long-term therapy means to survivors in terms of functional improvement, I am appalled that there is no funding for long-term therapy,” said Bev Greer, director of the Stroke Recovery Center in Palm Springs, Calif.

**A West Coast Original**

The Stroke Recovery Center (SRC) in Palm Springs, Calif., is one of the few places in the United States that has actually taken steps to remedy this situation. They offer stroke-specific therapeutic programs — individual and group exercise programs, individual and group speech therapy, and recreational therapy programs — to stroke survivors at no charge. You read that right, all their programs are free; there is, however, no free lunch — that chef-prepared experience will set you back $3.

The roots for the SRC concept were planted 30 years ago by Dr. Irving Hirshleifer, a Palm Springs cardiologist who began offering therapy as an adjunct to his everyday practice. “He believed it was totally unfair to abandon survivors after rehab,” said Greer. “He knew they could improve if they could get the help. He also felt very strongly that this rehab should be free.” Dr. Hirshleifer died four years ago, but his widow, Marilyn, still volunteers in the kitchen at SRC.

Today, this nonprofit operation occupies its own building and serves about 200 survivors each year. They have two full-time recreational therapists and a nurse, plus an exercise physiologist who comes in for four hours, three days a week. They depend on volunteers for speech therapy. Survivors must have a doctor’s release for exercise, and they must be able to take care of their personal needs. “Unfortunately, we are unable to provide one-on-one care, so clients must be somewhat self-sustaining or have a caregiver,” said Greer.

**An East Coast Edition**

In the early ’90s, Mary Jo Schreiber, a nurse at the Kessler Institute for Rehabilitation in New Jersey, visited the SRC to offer a presentation on stroke rehabilitation. Impressed with what she saw, she wondered if similar services could be offered to patients in her area.

“I returned to New Jersey with the goal of opening a second stroke activity center,” said Schreiber. “As a former caregiver of a stroke survivor and a registered nurse, I had been working exclusively with stroke families for several years. I have experienced first-hand the failure of the system to provide assistance for optimal recovery and improved quality of life.”
In 1997, Schreiber started the New Jersey Stroke Activity Center (NJSAC). At the time, the New Jersey Department of Health didn’t even track stroke as a separate category, lumping it in with cardiovascular disease. “If the health department didn’t have that information, they certainly didn’t know how many New Jersey survivors were living in isolation, trying to cope with the unique problems caused by stroke,” Schreiber added.

Unlike the SRC, the NJSAC offers its exercise classes and music and speech therapy programs at various hospitals, medical schools and therapy centers in northern New Jersey. They also sponsor survivor and caregiver support groups. All programs are free. In addition, the NJSAC has sponsored several cruises for stroke families. Although not free, the cruises are reasonably priced and very popular, with more than 1,200 survivors registered.

“We currently have 10 programs running,” said Schreiber. “All our programs offer some type of therapy, support and networking. The facility provides the therapist and room. Some hire therapists from the outside, some use therapists on their staff. Those interested call me, and I give them the information they need to attend the program they are interested in. My goal is to have three free-standing facilities like SRC, in northern, central and southern New Jersey, while continuing to open and coordinate satellite programs so all stroke survivors have access to continued therapy, activities, support and networking.”

Heartland Edition

The American Stroke Foundation (ASF) was started in 1997 in Kansas City, Mo., by stroke caregiver Shirley Rose and her daughter Robbie Small. After her husband’s strokes, Rose went through the wrenching experience of adapting to a life filled with unexpected challenges. Painfully aware of how few resources were available to stroke families once insurance stops paying for therapy, she took action.

“In 2000, ASF purchased a house in a residential neighborhood,” said Rita Griffith, ASF president and CEO. “It was a welcoming environment where survivors could participate in classes to assist them in recovering skills needed in everyday life. In 2004 we expanded into a new 6,000-square-foot location, then moved again in 2005 to our current home in Mission, Kansas. That same year we started a second facility in Kansas City, Missouri, that’s open Tuesday and Thursday to better serve the inner core. Last year, we provided 24,000 hours of service to survivors in this area.”

ASF programs include aphasia classes, handwriting basics, reading and vocabulary, computer classes, exercise and cooking classes, a class called “That Darn Arm” as well as support groups for survivors and caregivers. ASF partners with several local and regional therapist-training institutions to help staff their programs. There are two speech therapists plus additional speech-therapy students and their professor; two social work professionals; an occupational therapy professor and at least two OT students; two nursing professionals and up to six nursing students; a music therapist; and two personal trainers. ASF will also soon roll out the Stroke Academy, which will make their programs available to survivors outside the Kansas City area. Watch their Web site (www.americanstroke.org) for more information.

“We offer five hours of classes every day,” said Griffith. “At the two locations that totals 35 hours of therapeutic instruction per week. We ask that our clients pay a $125 annual membership fee, which (continued)
translates to 48 cents a day if clients come every day we’re open. There is no extra charge for classes. We serve about 100 clients each week. They must be able to care for their own personal needs or have a caregiver or aide with them. We don’t offer skilled-nursing services. We’re more like a community center for stroke families. Many of our independent clients use the facility as a day center where they spend the entire day so their spouses can work without worry. Caregivers use us as a source of respite care so they can have time alone.”

How the Clients Feel

For many stroke families, programs like these are nothing short of a godsend. In addition to the opportunity for continued therapy, the activity centers become extended families, where survivors find emotional support, social interaction in a comfortable setting and a pathway toward regaining independence. It not only gives them a place to go where they will be challenged to improve their physical condition, the experience will also enhance their independence. These three programs give their participants a purpose, and that is a vital step in anyone’s recovery.

“Before ASF I was depressed, sitting at home every day, but I go up there almost every day now,” said Kurt Braasch of Kansas City, who had a brain-stem stroke two years ago. “We’ve been members for 18 months, and I’d say I’ve progressed by 30 percent. I speak a ton better. I have inflection in my voice and I can sing. I can read and write again. They’ve really helped me develop my mind.”

Braasch helps raise funds for ASF sponsoring a twice-yearly Texas Hold ’Em poker tournament. “Last year we raised $1,800 in four hours,” he said. “And we had a ball. The people love it. We get a lot of support from the doctors and nurses.”

Norm and Rosella Brown are members of the SRC, which they discovered after moving to Cathedral City, Calif., from the Kansas City area where Norm had had a stroke in 1993. Norm has gone practically every day for the past four years.

“The stroke center became a new life for me,” said Norm. “They started me out with professionals immediately. I fell in love with all the other clients right away because we all have so much in common. Everybody makes you feel like you’re wanted and that you really are somebody.

“I’d say I spend five to six hours there every day,” he continued. “You don’t have to spend that kind of time there to benefit, but I enjoy being there. They really worked on my hand, and I can pick things up now. I can walk a lot farther than I did before. It has really helped me mentally. I’m a happier person because I feel that I belong to something and look forward to going every day.”

Rosella appreciates the improvements because it gives her some independence and that makes her a better caregiver. “You have to maintain a spirit of wanting to be a caregiver,” she said. “You can’t treat it as daily drudgery because that breaks you down. I highly recommend going to a caregiver support group because you meet people who have the same problems you do and you can discuss things openly.”

Caregiver (and nurse) Vicky Galofaro of Lincoln Park, N.J., agrees that support groups are key for both caregivers and survivors. After her husband Tony’s stroke in 1998 at age 54, he was almost forced to stay at home alone because Vicky had to work to maintain health insurance. Tony and Vicky both participate in support groups at Kessler Institute that are sponsored by NJSAC.
“The support group has really given Tony a sense of camaraderie. It not only gave him a place to go on Friday nights, but it’s also given him a purpose,” said Vicky. “We went on a cruise with NJSAC and also to Las Vegas. We do lots of things together and help each other out, especially for new stroke families. We help them get accustomed to this new way of living; it makes it easier for them to adjust.”

For John and Barbara Gilmore, adjusting to life after stroke has been eased by participating in programs at ASF. John, who formerly worked as a firefighter and farrier (someone who shoes horses), had a series of transient ischemic attacks (TIAs) as a result of vasculitis, and as a consequence he has had severe short-term memory loss and can no longer work. He began rehabilitation after his TIAs, but like so many, he faced limited insurance coverage. “We heard about ASF in rehab one day and we went right over there,” said Barbara. “John started doing therapy immediately.

“They have wonderful resources there because they have many students who come in,” she continued. “It’s great for socialization, and it really seems to benefit people with aphasia. It’s also a great resource for us caregivers. I was at such a loss because I had never anticipated this situation, and I found it so rewarding to be with other caregivers. You gain insights into this new life you’ve been thrown into overnight. It helps you deal with the grief of what you’ve lost and regain some balance. It gives me some social time and a feeling of camaraderie. You can’t handle this job by yourself 24/7.”

“I can honestly say the SRC saved my life,” said Patricia Donahue of Desert Hot Springs, Calif. She had a stroke five years ago at age 65. “I was in pain, angry and resentful. I knew I couldn’t just sit around all day feeling sorry for myself. I hesitated at first to go to the SRC, but now I go every day. I’ve made many friends. I was pretty shy, but they got me out of my shell. I work out every morning and also take Spanish lessons and do arts and crafts for the mind. Once a week I go horseback riding at the Pegasus Riding Center, which has a relationship with the SRC. The riding has really helped me strengthen my limbs.

“I think you are more likely to get to know someone that has walked in your shoes,” Patricia continued. “Everybody here takes care of each other. It gives you a family feeling. Most survivors have problems with depression, and the many activities keep our minds and hands busy.”

**CONTACT INFORMATION**

Stroke Recovery Center  
www.strokerecoverycenter.org  
2800 East Alejo Road • Palm Springs, CA 92262  
760-323-7676

New Jersey Stroke Activity Center  
www.njsac.org  
725 Joralemon St. • Suite 191 • Belleville, NJ 07109  
973-450-4114

American Stroke Foundation Stroke Activity Center  
www.americanstroke.org  
5960 Dearborn • Suite 100 • Mission, KS 66202  
913-649-1776 • 866-549-1776

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“I CAN HONESTLY SAY THE SRC SAVED MY LIFE. I WAS IN PAIN, ANGRY AND RESENTFUL. I KNEW I COULDN’T JUST SIT AROUND ALL DAY FEELING SORRY FOR MYSELF.”

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Patricia Donahue (center) rehabs with some SRC friends  
Patricia Donahue at the Pegasus Riding Center  
Vicky and Tony Galofaro
Ora-Light provides a balanced program of lip and tongue exercises using an innovative set of practical tools. Ora-Light helps to maximize rehabilitation outcomes of patients with oral motor deficits including dysarthria, dysphagia, apraxia, articulation disorders, oral cancer resections and laryngectomee rehabilitation. We recommend that for better response Speech Language Pathologists should initiate treatment within three months after stroke for effective rehabilitation.

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www.aphasia.com
A Coyote Is Born

Tim Derk didn’t have to grow into the role of The Coyote — he was born for it. At a very early age, he displayed aptitudes for both athletics and stage performance. In fact, Tim’s mother claimed that his first words were “Ta Da!” Tim himself always believed he was destined for something unusual in life.

As a teenager, he began playing tennis, a sport that eventually brought him to Trinity University in San Antonio as a student athlete. After college, Tim taught tennis to pay the bills, but he still needed something to keep his “inner ham” happy. So he began participating in community theater productions. In a 1983 production of a Cole Porter music review, Tim caught the attention of the San Antonio Spurs’ public relations agency director, Jack Pitluck, who would eventually recommend Tim as the new mascot for the team.

Life on and off the Court

Russ Bookbinder, the Spurs’ executive vice president for business operations, once told Tim, “Make an impact or get off!” These words weren’t lost on Tim. He animated The Coyote with gusto, filling his time on the court with improvisation, athletic showmanship and boundless enthusiasm. Off the court, he soon became San Antonio’s most recognizable citizen, averaging almost 200 community appearances a year.

The National Basketball Association (NBA) is known for its larger-than-life personalities, but one of its most colorful characters was never on a roster. As “The Coyote” mascot of the San Antonio Spurs, Tim Derk created a character that, for a time, was even more famous than the basketball franchise he represented. The characteristics that made The Coyote so famous — creativity, athleticism, commitment — are the very same attributes that would aid its creator in the most important physical event of his life: recovering from a stroke.
As The Coyote, Tim learned to suffer through occupational hazards, such as a broken nose, torn rotator cuffs and borderline heat exhaustion. In fact, he had one of the highest life insurance premiums in the entire NBA. One night in 2003, after a playoff game, Tim didn’t worry much about an event that would later be recognized as a transient ischemic attack (TIA) — he just chalked it up to overexertion or dehydration from the game.

Tim had about a dozen more “episodes” in the following months. But when he sought medical advice, no one seemed to recognize stroke risk in an athletic 47-year-old with an otherwise commendable health status.

**The Show Doesn’t Always Go On**

It was following a visit for medical tests that Tim’s stroke actually began. His physical and mental states went quickly downhill as his wife, Colleen, drove him home. Despite his protests, she took him straight to an emergency room. “It was on that evening,” Tim said, “that my career as a mascot ended.” Due to paralysis on the right side of his body, his life would change drastically in the next few months. Instead of jumping off trampolines and running up and down the basketball court, he would pass the time relearning how to grasp objects and walk to the bathroom.

As any survivor knows, rehabilitation is an uphill battle; but for Tim, who had led a very vigorous life, being bedridden was torture. “Imagine running or lifting weights every day for more than 20 years and suddenly being forced to sit still,” he said.

Tim wanted to start his rehabilitation right away — at times even trying to advise his doctors on what his prognosis would be. And even though it hadn’t yet become clear to him that he would no longer be The Coyote, Tim’s ultimate goal wasn’t to return to work, it was to dance again with his 7-year-old daughter Mairin.

He was able to use the “unusual” skills he’d developed as The Coyote in his recovery. He found that working all of those years in a coyote costume, which offered no peripheral vision, had been the perfect preparation for learning to improve his balance during physical therapy sessions. However, being The Coyote didn’t prepare Tim for everything. Loss of balance was a major problem, and he had to work hard to improve function in the right side of his body — particularly his right hand, where he experienced a great deal of clonus (shakiness and involuntary muscular contractions).

Tim found that writing his book, *Hi Mom, Send Sheep: My Life as The Coyote and After,* was a big help. While many behavioral therapists will agree that writing can be a helpful part of any recovery process, Tim found the actual process of writing to be just as helpful physically as psychologically. “In writing the book, I found that the dexterity in my once-paralyzed right hand drastically improved,” he said.

Tim’s recovery has been remarkable in many respects: He not only relearned walking, but is now able to run again. He also revived his theater career by appearing in a five-week run of *Damn Yankees* at the San Pedro Playhouse. He is very aware, however, that not all stroke cases end up like his: “I’m very cognizant of not wanting to seem at all flippant about stroke,” he said. “I do not want to imply that (based on my recovery) all stroke patients will end up dancing with their daughters, but I do want to emphasize that by doing your very best during rehab, you will at least end up the very best you can be.”

Despite the many strides he’s made, Tim is the first to admit that he’s never going to be the athlete he once was. According to his estimates, he’s only 20 percent of the tennis player he used to be, and his bowling game went from a pre-stroke 256 (and 172 in his Coyote... (continued)
costume) to 66. He has also recognized other changes, courtesy of his stroke. For instance, he finds that he is much more emotional than he once was. And for a while, his greatest post-stroke fear was that he had lost his sense of humor.

But Tim found that the encouragement he received from his family, physical therapists, and even his Labrador puppy, aided him in his journey through rehabilitation. He also received an outpouring of support from many other directions: members of the Spurs’ team and association; the San Antonio community; fellow NBA mascots; sportscasters and commentators; friends; and fans from all walks of life.

Life in the Second Half

One of the toughest parts of his recovery was accepting the fact that he would never again be The Coyote. The Coyote had become his alter ego; he had gone to great lengths guarding The Coyote’s true identity so that fans would just see the character, not the man behind the mask. But Tim said that only when he stopped focusing on his career did he really start thinking about the people in his life: his family and even his fans.

Now Tim thrives in his new role as manager of mascots for Spurs Sports and Entertainment, where he directs all aspects of mascot development for the Spurs as well as San Antonio’s Women’s National Basketball Association (WNBA) and American Hockey League (AHL) teams. While he is still more active than many people (stroke survivors or not), he has taken more time for his health, his family — Colleen, Mairin and his son Griffin — and his many supporters.
**Acalculia—**

Math Challenges after Stroke

By Patricia Phaneuf, B.S.; Juliana Baldo, Ph.D.; and Janet Patterson, Ph.D., CCC-SLP

Janet Patterson is a member of the American Speech-Language-Hearing Association

**Few of us** need to solve a differential equation or calculate the amortization rate on a loan. On the other hand, most of us take for granted that we’re able to figure the tip in a restaurant, balance the checkbook, or estimate the grocery bill before reaching the checkout counter. For someone with acalculia (a-kal-kuh-lye), however, common tasks like these can become exceedingly difficult.

Acalculia is a deficit in which a person is unable to add, subtract, multiply and divide, or to perform complex multiple-step mathematical operations. As a result, a person may be unable to tell time, follow a recipe or count change. Acalculia is distinguished from dyscalculia (a learning disability) in that it is acquired rather than developmental, and is usually a result of stroke or other brain trauma, particularly in the left hemisphere.

Research has shown that certain areas of the brain are connected to functions such as word processing and number processing. Although no one location has been identified for all math functions, most activity seems to be in the parietal (side) area of the brain. The prefrontal area (in the front of the brain) also plays a role in complex, multi-step operations.

For many people who have experienced a stroke and acalculia, everyday math is a challenge, but it is one that can be met with confidence by applying a commonsense outlook. For starters, be easy on yourself. After a stroke, the brain needs time to rewire itself. While that’s taking place, you can compensate by using some simple strategies. For example, don’t struggle to calculate exact number amounts when estimates will do. Even those diagnosed with acalculia can often estimate dependably. Or take the advice of Stanislaus Dehaene: *buy a calculator!* He’s a French neurologist who believes that doing rote math tasks in your head is cruel and unusual punishment (though he himself spent many years of his life mastering mathematics). Leave the exact calculations to a spouse, a companion or a calculator and realize that in many cases, close enough is good enough.
Next, realize that where there are language problems, there may also be difficulties in calculating and performing basic math operations. Even simple calculations may seem impossible at first, but try to reduce frustration or embarrassment and focus on the math problem. One key to recovering math abilities is to shore up other abilities; improving language may, surprisingly, improve calculation. If possible, continue speech therapy to strengthen reading, writing, speaking and comprehension skills — and keep at it every day. Here are a few examples of strategies:

- practice simple word problems;
- create a sheet of math facts and review it often;
- count and roll change;
- read and prepare easy recipes.

All of these activities will help strengthen different areas of the brain and will encourage new neural connections.

Another way to build math skills is to focus on memory. Mathematical skill requires memory, so working to strengthen memory will improve math abilities. “Chunking,” or segmenting information into manageable “chunks,” can help a person remember it. Phone numbers are an example of chunking — area code + first three digits + last four digits. Another way to practice chunking is to group items in a list. For example, when writing a grocery list, group similar items together, then practice memorizing and reciting them.

Sequencing also aids memory: Ask someone to write a list of familiar words out of sequence — such as October, April, February, or wash, sort, dry — and practice putting them in the correct order. Another sequencing task is to plan your day: Write down your activities and check your memory. Make a to-do list every day and try to organize it in the most efficient way. For example, if you need to do errands, organize them one way to minimize gas use, or another way to minimize time.

Memory and math skills can be aided in other ways. One strategy is to write information and then say it. If speaking the answer from memory is difficult, it might help to write the numbers or the math problems and then read them. When performing a mathematical operation, try whispering the problem, and the means for solving it, as practice. Create a cheat sheet for math chores such as dividing or subtracting numbers, performing basic multiplication, or calculating gratuities and sales tax. Laminate the card and carry it with you. Review it and read it out loud often.

Context helps language and math processing. Practice math word problems by putting them in real life terms such as: “If I want to buy batteries for 10 gadgets in my house, and I need two batteries for each gadget, how many will I need?” Or “If each two-pack of batteries is $3.99 how much will it cost me?” Conversely, take a real life situation and transfer it into a math problem such as: “When there is a roomful of people having dinner at my house, and out of 23 people 17 want coffee, two want nothing and the rest want tea, how many coffees and teas will I serve?”

While we don’t know exactly how the brain recovers, we do know it is more malleable than once thought. We know that uninjured brain areas can compensate for injured areas. The brain activates cells in the areas that are used most, so do things like play card games that require counting, such as bridge and cribbage. Roll those pennies, nickels and dimes, and role-play counting change for purchases.

These and other activities will strengthen math skills and build confidence. Remember to keep practicing and to use every opportunity to improve memory, sequencing and planning — all language skills to be sure — but skills that also underlie the ability to perform the math we use every day.

To locate an ASHA-certified speech-language pathologist near you, go to www.asha.org and click on “Find a Professional” or call (800) 638-8255. 

American Speech-Language-Hearing Association

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“Large, immense, enormous, humongous, mammoth, gigantic, super colossal, biggest in the city” … these were just a few of the words used to describe the grand opening of a new market in our neighborhood. Each one was emblazoned on a large, immense, enormous, humongous, mammoth, gigantic, Sunday Times advertising insert.

 Apparently the marketing campaign paid off, because this place dominated elevator conversation in our apartment building for a week. Freshness, quality and choice were key points, but the subject always came back to the roasted, organic free-range chickens. The consensus was that these chickens of true nobility and good breeding were a culinary treat. They not only ate better meals than I did, but unlike regular chickens that are kept in cramped coops (my New York apartment comes to mind), these lucky fowls are free to roam around, which apparently minimizes stress and a need for medication (this is where I come to mind).

 I don’t know anything about chickens, but I am an astute observer of the New York City pigeon, so this theory made some sense to me. Pigeons wander around the streets all day bothered by nothing and oblivious to everything. They ignore speeding cars, car alarms, honking horns, and even sirens. They must be the most relaxed, laid-back birds on the planet. They’re mellower than Johnny Mathis singing “Misty.”

 Although I understood the concept, I was still more than a little skeptical. It seemed to me that all this relaxation might be rendered irrelevant once your neck is stretched over a tree stump waiting for the axe to fall.

 I was intrigued enough, though, that one day it seemed like a good idea to venture out to this colossal market and try their noble bird. It meant a much longer walk, but I figured I could go grocery shopping and get in a little physical therapy at the same time. I felt awkward as I passed the now pint-sized grocer where I normally shop. It was like I was having an affair with the hot new market in town! A longer walk was an understatement. This place was in another time zone. I was becoming a free-range stroke survivor; only my stress level was increasing. I guess the chickens and pigeons are just happy to be out walking around. Kind of like the way I felt the day I finally got out of the hospital. But this was different — now I was on a mission.

 To endure the length of this excursion, I decided to turn it into an adventure, like Humphrey Bogart in the “Maltese Falcon.” Only instead of “Sam Spade, private detective, gets involved in murderous hunt for valuable statuette,” it was “John Kawie, free-range stroke survivor, gets involved in strenuous hunt for delectable roasted bird … the Maltese Chicken.”

 Soon enough, I entered the market slack-jawed. I had never seen such a mob. Did Elvis come back from the dead? Nope. It was all for organic chickens, pickles and kale.

 I found myself in the checkout line, and I had just walked through the front door! That’s how mobbed it was. I had a quick Google-Earth vision of myself and realized the distance between me and this bird was too vast. Way too vast for this stroke survivor.

 Chinese take-out anyone? $\text{\&}$

 Editor’s Note: Read John’s personal stroke story, “Life is at the Curb,” from the September/October 2003 issue of Stroke Connection at strokeassociation.org/strokeconnection, or book his one-man show about stroke recovery, “Brain Freeze,” by contacting him at jkawie@aol.com.
Impaired mobility is a common and frustrating consequence of stroke. It can also create a significant health risk, deep venous thrombosis (DVT).

“Deep venous thrombosis is a clot that forms in one of the veins of the extremities,” said David G. Sherman, M.D., Ross J. Sibert Research Fund Distinguished Chair and Professor, Division of Neurology in the Department of Medicine at the University of Texas Health Science Center in San Antonio. “Typically, we’re concerned about the ones in the legs, although they can happen in the pelvis as well. Lack of mobility or paralysis is the primary cause.

“Blood is moved by contraction of the muscles,” explained Dr. Sherman, “and it is the movement of the legs that pushes blood up toward the heart.” Therefore, impaired mobility of the legs results in “venous stasis” or the abnormal return of blood to the heart. This is the main cause of clots forming in the leg.

It is not always easy to tell when you have DVT. “The typical symptoms of DVT are pain and swelling in the leg,” explained Richard D. Zorowitz, M.D., Visiting Associate Professor and Chairman of the Department of Physical Medicine and Rehabilitation at Johns Hopkins Bayview Medical Center in Baltimore, Md. “However, sometimes DVT may present without symptoms.”

Even without symptoms, DVT can be extremely problematic. “If a piece of the clot breaks off and travels to the lung, known as a pulmonary embolus (PE), it can cause shortness of breath or even death. About 5 percent of hospitalized stroke survivors will have a clinically diagnosed DVT and about 2 percent will have a diagnosed PE. However, without preventative drugs, 50 percent of hospitalized patients develop acute DVT within five days following a stroke.”

“In addition to venous stasis,” Dr. Zorowitz said, “two of the major causes of DVT are hypercoagulability, a medical condition that causes blood to clot more easily, and vessel injury, as clots can form more easily when tissues are damaged.”

“People who have a paralyzed limb may unknowingly cause some trauma to that limb, because they can’t feel when they hit or bump it against something,” said Dr. Sherman. “Any trauma to that leg increases the risk.” Thus strokes resulting in partial paralysis put survivors at significant risk of DVT, even aside from the problem of decreased circulation.

The timeline for DVT is fairly consistent. According to Dr. Sherman, “DVT usually occurs in the hospital between days two and seven. However, the risk can extend on for...
weeks or months, as long as the limb is paralyzed. Patients with chronic pulmonary disease, congestive heart failure, obesity, dehydration and any kind of trauma to the limb are at greater risk.”

“Stroke survivors at greatest risk of developing DVT are those with a history of previous DVT,” added Dr. Zorowitz. “Other factors that add to the risk include cancer, heart disease, and diseases of the immune system. DVT can occur during pregnancy or even after delivery, too. Also, there is a higher risk of DVT in patients using oral estrogen contraceptives.”

Using blood thinners is the most common treatment for DVT. “However,” Dr. Zorowitz explained, “because of the risk of bleeding, survivors of hemorrhagic stroke should be treated initially with compression boots or compression stockings, but in most cases can start anti-coagulation therapy within 48 hours. Compression boots alternately provide pressure to each leg and help blood to flow out of the leg.” Most stroke survivors are given blood thinners as preventative DVT treatments upon hospitalization, and compression boots and stockings are common preventative measures, as well.

“DVT usually carries a short-term risk after stroke,” said Dr. Zorowitz. “For whatever reason, the body adapts to disability or lack of mobility after several weeks or months, and the risk of DVT decreases over time. This is not to say that patients do not get DVTs in the long term — they do. However, the numbers are much smaller as time passes.”

Despite the relatively low percentages of stroke survivors diagnosed with DVT or subsequent PE, the corresponding risks of developing one or both of these conditions are significant enough to warrant some education on their prevention.

“The potential risk for DVT in stroke survivors emphasizes the need of preventive anticoagulative therapy and proper training in the use of other treatments such as elastic stockings and compression boots. Most importantly, the risk emphasizes the need for exercise, early ambulation and the need to engage as much and as quickly as possible in rehabilitation,” Dr. Sherman said. More than anything else, working early to get up and get moving can lessen the possibility that deep venous thrombosis will affect a stroke survivor’s recovery.
Books About Stroke

By Maria Meyer and Paula Derr, RN, with Jon Caswell
CareTrust Publications LLC
ISBN 0-9664767-8-6

This is a practical, hands-on guide for caregivers of stroke survivors. It takes you through all the steps of home care, from making the home safe and comfortable to handling activities of daily living such as toileting, bathing and wheelchair transfers. It also examines proper nutrition; personality change after stroke; effective communication with professionals to acquire needed services and care; and easy self-care techniques to help caregivers avoid burnout. Written with the same clarity, practicality and sensitivity as Stroke Connection Magazine.

How to Prevent Your Stroke
By J. David Spence, MD
Vanderbilt University Press
ISBN 0-8265-1537-1

Dr. David Spence is a leading expert on stroke prevention. He wrote this book in the hope of preventing strokes based on advice he has given to more than 16,000 at-risk patients. Divided into two sections: “What Your Doctor Can Do” and “What You Can Do,” this guide provides clear and easily understood information on a complex subject. Dr. Spence focuses on practical knowledge; there are even gourmet “anti-stroke” recipes.

By Madonna Siles
Hampton Roads Publishing
ISBN 1-57174-476-2

This book chronicles the experience of the author (Siles) and her friend Eve, who had a near-fatal aneurysm. Eve was discharged from therapy in a zombie-like condition. Using motivational techniques borrowed from her experience in advertising, Siles appealed to Eve’s subconscious to bypass the brain damage and restore normal functioning. Part memoir, part recovery manual, Brain, Heal Thyself is a guidebook for those who find themselves having to make life-and-death decisions for those they love.

I Will Survive: Techniques for Coping with a Health Challenge
By Corinne Laboon
Seaboard Press
ISBN 1-59663-521-5

People who face severe health challenges — and those who care for them — often experience feelings of helplessness. This book makes the point that you can choose to break under the stress or you can bounce back like one of those inflatable clown punching bags. It includes personal stories and emotion-provoking exercises to help you find the fortitude needed to face such circumstances. Includes a special section addressing the needs of children and adolescents.

These book summaries are provided as a resource to our readers. These books have not been reviewed or endorsed by the American Stroke Association.
Physical inactivity is a major risk factor for heart disease and stroke, yet in our highly stressed culture, it seems many people just don’t have the time to do anything about it. For instance, surveys show that Americans work 164 more hours per year than just 20 years ago. And today, more and more jobs involve sitting for hours at a time — whether it’s behind a desk, in front of a computer or beside a telephone.

In response to this sedentary trend, the American Heart Association has launched Start! to help Americans improve their health by walking. Start! focuses on walking because it’s easy and free and has the lowest dropout rate of any type of exercise. Even better, it can be done in the workplace during work hours. Although exercise walking may not be possible for some stroke survivors, they should encourage their caregivers and relatives to enroll in the program.

Walking has many proven health benefits. Every hour of vigorous exercise produces a two-hour gain in life expectancy. Brisk walking for 30 minutes a day can lower bad cholesterol (LDL) levels and blood pressure, and helps you lose weight and keep it off.

To register, go to www.AmericanHeart.org/start. Registration gives you immediate access to MyStart! Online, an easy-to-use fitness and nutrition tracking tool. You can also receive monthly e-newsletters, weekly summaries of your fitness and nutrition activity, healthy recipes and advice from experts on diet and exercise.

Beat Your Risk

Hypertension is a leading risk factor for stroke and other cardiovascular diseases, and yet many people do not know their blood pressure numbers or what they mean. This interactive Web site (www.beatyourrisk.com) explains how your blood pressure affects your cardiovascular health and what you can do about it.

After entering your height, weight and blood pressure (you need to know your blood pressure numbers; the site does not measure your blood pressure), you receive feedback that explains how your blood pressure levels affect your risk of stroke and heart disease risk. The site includes an extensive library of easy-to-understand information about hypertension — what it is, how it damages the cardiovascular system and how to combat it. A short follow-up assessment examines the effect of positive lifestyle changes, such as weight loss and increased physical activity, on blood pressure.

For anyone at risk of stroke, high blood pressure is critically important because it can be modified by treatment and lifestyle changes. This new Web site can help you and your family members beat the risk!

Healthy Podcasts Now Available

Now it’s easier than ever to get reliable health information. The American Heart Association/American Stroke Association now has a library of podcasts available for download. To check out the offerings, visit www.AmericanHeart.org and type “podcasts” in the search window.
The International Foundation for Research and Education on Depression (iFred) is a nonprofit organization dedicated to researching causes of depression to support those affected by it and to combat the stigma associated with depression. The World Health Organization predicts that by 2020 depression will be the second leading cause of health impairment worldwide.

Many people do not get help with depression because they don’t feel comfortable asking for it. “People would rather tell their bosses they committed a crime than say they have a mental illness,” said Kathryn Goetzke White, iFred founder. “We need to foster an environment where people feel comfortable getting help, they feel good about openly celebrating an individual’s ability to recover from a depressive episode, and support and applaud them in moving forward in a battle similar to that of any other illness.”

International Foundation for Research and Education on Depression
2017-D Renard Ct.
Annapolis, MD 21401
(410) 268-0044
www.ifred.org
e-mail: info@ifred.org

The National Organization on Disability is a good resource for disabled people looking for employment. Their motto is “It’s ability, not disability, that counts.” In addition to news and advocacy, they have many resources for people with disabilities who are reentering the job market. They also have information on assistive technology and access to housing, healthcare, transportation and education. There’s also helpful information on Social Security’s Ticket to Work Program.

National Organization on Disability
910 16th St. NW, Suite 600
Washington, DC 20006
(202) 293-5960 (phone)
(202) 293-7999 (fax)
(202) 293-5968 (TTY)
www.nod.org
e-mail: ability@nod.org

Resources

iFred

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Annapolis, MD 21401
(410) 268-0044
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National Organization on Disability
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Indications and Usage

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- Recent MI, Recent Stroke or Established Peripheral Arterial Disease
- Patients who have undergone percutaneous coronary intervention (PCI) with or without stenting, or established peripheral arterial disease, PLAVIX® has been shown to reduce the rate of the combined end point of cardiovascular death, non-fatal MI, or refractory ischemia in patients treated for at least 1 year. The clinical important adverse events observed in CAPSURE, CLARITY, and CLARETT are discussed below.
- Acute Coronary Syndrome

For patients with non-ST-elevation acute coronary syndrome (unstable angina or non-ST-elevation MI) including patients who are to be managed medically and those who are to be managed with PCI or CABG, PLAVIX has been shown to decrease the rate of a combined endpoint of cardiovascular death, non-fatal MI, or refractory ischemia in patients treated for at least 1 year. The clinical important adverse events observed in CAPSURE, CLARITY, and CLARETT are discussed below.

Contraindications

Lack of adequate data is not an indication for the use of clopidogrel in patients with acute ischemic stroke or transient ischemic attack who are treated with intravenous thrombolysis. PLAVIX has been shown to reduce the risk of death from any cause and the rate of the combined endpoint of death or non-fatal MI, or refractory ischemia in patients treated for at least 1 year. The benefit is not known to persist when patients receive primary angioplasty.

Intracranial hemorrhage.

Use in Hepatically Impaired Patients:

In the CAPSURE trial, patients receiving PLAVIX in a similar setting of patients age 70 and older with a history of MI, refractory ischemia, and diabetes mellitus, and who had been treated with aspirin and other antiplatelet therapies, were randomized to receive PLAVIX plus aspirin versus placebo. The primary end point was the occurrence of ischemic stroke or death from any cause. In the group receiving PLAVIX plus aspirin compared with placebo, primarily aspirin, gastrointestinal bleeding and asymptomatic intracranial hemorrhage (grade 3/4) were lower (2.1% vs. 2.9%) and were the same in both groups. The overall incidence of ischemic stroke was 1.8% in patients receiving PLAVIX plus placebo and 0.7% in patients receiving PLAVIX plus aspirin.

Table 5: Occurrence of bleeding complications (% patients)

<table>
<thead>
<tr>
<th>Type of Bleeding</th>
<th>PLAVIX (n = 10,402)</th>
<th>Placebo (n = 10,387)</th>
<th>Placebo minus PLAVIX</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major bleeding</td>
<td>1.8 (0.8%)</td>
<td>3.1 (1.1%)</td>
<td>1.3 (0.3%)</td>
</tr>
<tr>
<td>Intracranial bleeding</td>
<td>0.6 (0.3%)</td>
<td>0.7 (0.4%)</td>
<td>0.1 (0.1%)</td>
</tr>
<tr>
<td>Gastrointestinal bleeding (all grades)</td>
<td>4.3 (2.8%)</td>
<td>4.7 (2.6%)</td>
<td>0.4 (0.1%)</td>
</tr>
<tr>
<td>Gastrointestinal bleeding (grade 3)</td>
<td>0.6 (0.3%)</td>
<td>0.7 (0.4%)</td>
<td>0.1 (0.1%)</td>
</tr>
<tr>
<td>Gastrointestinal bleeding (grade 2)</td>
<td>3.7 (2.4%)</td>
<td>3.9 (2.2%)</td>
<td>0.2 (0.1%)</td>
</tr>
</tbody>
</table>

| Other bleeding complications (all grades)             | 3.8 (2.2%)          | 4.1 (2.1%)          | 0.3 (0.1%)          |
| Other bleeding complications (grade 2)                | 3.2 (2.0%)          | 3.4 (1.9%)          | 0.2 (0.1%)          |
| Major bleeding due to aspirin                        | 1.0 (0.5%)          | 2.2 (0.6%)          | 1.2 (0.7%)          |
| Incomplete response to aspirin                       | 1.4 (0.8%)          | 1.8 (0.7%)          | 0.4 (0.1%)          |

Other adverse experiences of potential importance occurring in ≥2% to 5% of patients receiving PLAVIX (clopidogrel bisulfate) in the controlled clinical trials are listed below. These changes in laboratory parameters occurred in ≥2% of patients treated with PLAVIX compared to placebo. The clinical importance of these changes in laboratory parameters is not known. In patients treated with PLAVIX, PLAVIX plus aspirin versus placebo plus aspirin by age category is provided in Tables 6 and 7 for the CLARETT and CAPSURE trials, respectively (ADVERSE REACTIONS).

Table 6: Number (%) of Patients with Bleeding Events in COMMIT

<table>
<thead>
<tr>
<th>Type of Bleeding</th>
<th>PLAVIX (n = 4,231)</th>
<th>Placebo (n = 4,231)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major bleeding</td>
<td>2.1 (1.0%)</td>
<td>3.5 (1.7%)</td>
</tr>
<tr>
<td>Intracranial bleeding</td>
<td>0.4 (0.2%)</td>
<td>0.6 (0.3%)</td>
</tr>
<tr>
<td>Gastrointestinal bleeding (all grades)</td>
<td>4.4 (2.3%)</td>
<td>4.8 (2.4%)</td>
</tr>
<tr>
<td>Gastrointestinal bleeding (grade 3)</td>
<td>0.4 (0.2%)</td>
<td>0.5 (0.2%)</td>
</tr>
<tr>
<td>Gastrointestinal bleeding (grade 2)</td>
<td>3.0 (1.6%)</td>
<td>3.3 (1.6%)</td>
</tr>
</tbody>
</table>

Table 7: Adverse Events Occurring in ≥2.5% of Patients in CAPSURE

<table>
<thead>
<tr>
<th>Body System</th>
<th>Event</th>
<th>Incidence % (Placebo - PLAVIX)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body as a whole</td>
<td>General adverse events</td>
<td>3.9 (1.9%)</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>Ischemic stroke</td>
<td>0.7 (0.1%)</td>
</tr>
<tr>
<td>Central nervous system</td>
<td>Ischemic stroke</td>
<td>0.7 (0.1%)</td>
</tr>
<tr>
<td>Cutaneous</td>
<td>Ischemic stroke</td>
<td>0.7 (0.1%)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>Ischemic stroke</td>
<td>0.7 (0.1%)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>Sepsis</td>
<td>0.4 (0.2%)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>Necrotizing enterocolitis</td>
<td>0.2 (0.1%)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>Perforated ulcer</td>
<td>0.2 (0.1%)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>Perforated ulcer</td>
<td>0.2 (0.1%)</td>
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<td>Perforated ulcer</td>
<td>0.2 (0.1%)</td>
</tr>
</tbody>
</table>

In addition, clinically relevant events to those observed in CAPSURE in a frequency ≥2.5% have been reported during the CAPSURE and CLARITY controlled trials. COMMIT collected only limited safety data.

Other adverse experiences of potential importance occurring in ≥2% to 5% of patients receiving PLAVIX (clopidogrel bisulfate) in the controlled clinical trials are listed below. These changes in laboratory parameters occurred in ≥2% of patients treated with PLAVIX compared to placebo. The clinical importance of these changes in laboratory parameters is not known. In patients treated with PLAVIX, PLAVIX plus aspirin versus placebo plus aspirin by age category is provided in Tables 6 and 7 for the CLARETT and CAPSURE trials, respectively (ADVERSE REACTIONS).
If you’ve had a stroke, your chance of having another is 9 times greater.

Help raise your protection against another stroke with PLAVIX. If you’ve had a heart attack or stroke, the last thing you want is another one sneaking up on you. PLAVIX may help. PLAVIX is a prescription medication for people who have had a recent heart attack or recent stroke, or who have poor circulation in the legs (peripheral artery disease) causing pain.

IMPORTANT INFORMATION: If you have a stomach ulcer or other condition that causes bleeding, you shouldn’t use PLAVIX. When taking PLAVIX alone or with some medicines including aspirin, the risk of bleeding may increase. To minimize this risk, talk to your doctor before taking aspirin or other medicines with PLAVIX. Additional rare but serious side effects could occur.

Please see important product information for PLAVIX on the previous page(s).

PLAVIX offers protection. PLAVIX is proven to help keep blood platelets from sticking together and forming clots, which helps keep your blood flowing. This can help protect you from another heart attack or stroke.

Talk to your doctor about PLAVIX. For more information, visit www.plavix.com or call 1-888-682-7815.

Blood platelets can stick together and form clots. PLAVIX helps keep blood platelets from sticking together.

American Stroke Association®
A Division of American Heart Association
National Center
7272 Greenville Avenue
Dallas, TX 75231-4596

If you need help paying for prescription medicines, you may be eligible for assistance. Call 1-888-4PPA-NOW (1-888-477-2669), or go to www.ppa.org

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