Fibromuscular dysplasia

Trying to get the right treatment, when nobody knows what’s wrong

• Meeting Big Goals
• Have You Heard the One About...
• Actions Speak as Loud as Words

Nurse and Stroke Survivor
Pam Mace
Feature Story
The String of Beads No One Wants 16
Fibromuscular dysplasia (FMD) is a little-known vascular disease that can have disastrous consequences, including stroke.

Meeting Big Goals 12
After David Layton’s stroke at age 55, he decided to reach 1,000,000 people with a stroke-prevention message.

Have You Heard the One About… 22
DeYip Loo was a world-famous magician, dedicated to his art. Today his wife and daughter, also a performer, are his dedicated caregivers.

Actions Speak as Loud as Words 26
Intentional gestures can help people with aphasia not only communicate better but also access spoken language more effectively.

Departments
Letters to the Editor 3
Stroke Notes 4
Readers Room 8
Life at the Curb 28
Everyday Survival 30

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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 following page.
PLAVIX®
Rx only: clopidogrel bisulfate tablets

INDICATIONS AND USAGE
PLAVIX® (clopidogrel) is indicated for the reduction of atherothrombotic events as follows:

- Recent MI, Recent Stroke or Established Peripheral Arterial Disease
For reduction of atherothrombotic events in patients who have had a recent MI, Recent Stroke or Established Peripheral Arterial Disease, PLAVIX® has been shown to reduce the rate of a composite end point of death, MI, stroke, or vascular death
- Acute Coronary Syndrome
For patients with an urgent or elective coronary artery stent placement procedure, PLAVIX® has been shown to reduce the rate of the composite end point of death, MI, stroke, or refractory ischemia
- Patients with >1 clinical events of ischemic atherothrombotic disease, PLAVIX® has been shown to reduce the rate of death from any cause and the rate of a composite end point of death, MI, stroke, or refractory ischemia. This benefit is not known to pertain to patients who receive primary angioplasty

CONTRAINDICATIONS
The use of PLAVIX® is contraindicated in the following conditions:

- Hypersensitivity to the drug, its substance or any component of the product.
- Active peptic ulcer disease or current bleeding

WARNINGS
Thrombotic, thrombolytic, or fibrinolytic therapy (See WARNINGS: Other Concomitant Therapy)

Other Concomitant Therapy

PLAVIX® is no longer to be used in combination with aspirin. PLAVIX is no longer to be used in combination with aspirin for the reduction of atherothrombotic events in patients who have had a recent MI, Recent Stroke or Established Peripheral Arterial Disease.

PLAVIX® was associated with a rate of intracranial hemorrhage of 185 cases per 100,000 patients; in comparison, aspirin plus clopidogrel was associated with a rate of intracranial hemorrhage of 2.2 cases per 100,000 patients.

OTHER IMPORTANT SAFETY INFORMATION (SeeWARNINGS)

- Body as a whole: dizziness, headache, back pain, myalgia, rash, flu-like symptoms
- Cardiovascular: angina, tachycardia, chest pain
- Gastrointestinal: nausea, vomiting, diarrhea, decreased appetite, abdominal pain
- Hematologic: bleeding, melaena, hematuria, hemoptysis, hematemesis, hematochezia, hemolytic anemia, aplastic anemia, pancytopenia
- Hypersensitivity: rash, urticaria, angioedema, anaphylaxis
- Metabolic: hyperglycemia, hypoglycemia
- Neurologic: confusion, somnolence, dizziness, syncope, peripheral neuropathy
- Pregnancy: fetal harm
- Blacks: more frequent bleeding

ADVERSE REACTIONS
PLAVIX® has been evaluated for safety in more than 42,000 patients, including over 6,000 patients treated for one year. The clinically important adverse events observed in CAPRIE, CLARITY, and CAPRIE are discussed below.

The overall incidence of bleeding in patients receiving PLAVIX® was 8.7% and was similar to that of patients receiving aspirin in CAPRIE and CLARITY and to patients receiving clopidogrel plus aspirin in CAPRIE and Clopidogrel Plus Aspirin in Diabetics (CAPID). In CAPPIE, the rate of bleeding in patients receiving clopidogrel plus aspirin was 11.0%, which was significantly higher than the rate in patients receiving aspirin alone (8.9%). The most common types of bleeding events observed in CAPRIE, CLARITY, and CAPRIE were gastrointestinal, umbilical, and peritoneal, each occurring in 1.5% to 2.0% of patients receiving PLAVIX® and aspirin. In patients receiving PLAVIX® plus aspirin compared to patients plus aspirin, gastrointestinal events were more common, whereas intracranial hemorrhage (0.8%) and fatal bleeding (2.0%) were seen in both groups.

Other clinically relevant adverse events which may be of clinical interest but were not frequently reported (<1%) in patients receiving PLAVIX® in the controlled clinical trials were listed below regardless of relationship to PLAVIX®. In general, the incidence of these events was similar to that in patients receiving aspirin (or in the other clinical trials):

- Nausea, Vomiting, Diarrhea
- Urinary tract infection
- Hematuria
- Angina
- Congestive heart failure
- Clotting disorder
- Dizziness, headache
- Flu-like symptoms
- Rash
- Upper respiratory tract infection
- Upper abdominal pain
- Urinary tract infection
- Vasodilation

Other potentially serious adverse events which may be of clinical interest but were not commonly reported (<1%) in patients receiving PLAVIX® in the controlled clinical trials were similar to that in patients receiving aspirin (or in the other clinical trials):

- Blunt as a whole: headache, myocardial infarction, cerebrovascular events
- Cardiac generalized: gastrointestinal disorders, herpes zoster, diarrhea, ejaculation disorders, back pain, arthralgia, myalgia
- Central and peripheral nervous system: disorders, confusion, hallucinations, taste disorders
- Dermatologic: alopecia, urticaria, angioedema
- Endocrine: hyperglycemia
- Hematologic: anemia, aplastic anemia, pancytopenia
- Hypersensitivity: angioedema, anaphylaxis
- Hypertensive: orthostatic hypotension
- Musculoskeletal: back pain
- Neurologic: dizziness, headache, somnolence, peripheral neuropathy
- Ophthalmic: visual disorder
- Pain: abdominal pain
- Skin: skin and appendage disorders, Eczema, Skin atrophy, systemic disorder
- Urinary: renal functional, acute renal failure
- Gastrointestinal and enterocolitis system disorders: karyogamy, neopterin, leukemia, idiopathic, nephropathy

Postmarketing Experiences

Other adverse experiences have been reported spontaneously from worldwide postmarketing experience:

- Tachyphylaxis
- Hypersensitivity reactions, anaphylactic reactions, urticaria
- Central and Peripheral Nervous System disorders: confusion, hallucinations, taste disorders
- Dermatologic: alopecia, urticaria, angioedema
- Gastrointestinal: orthostatic hypotension
- Hematologic: anemia, aplastic anemia
- Endocrine: hyperglycemia
- Hypersensitivity: angioedema, anaphylaxis
- Hypertensive: orthostatic hypotension
- Musculoskeletal: back pain
- Neurologic: dizziness, headache, somnolence, peripheral neuropathy
- Ophthalmic: visual disorder
- Pain: abdominal pain
- Skin: skin and appendage disorders, Eczema, Skin atrophy, systemic disorder
- Urinary: renal functional, acute renal failure
- Gastrointestinal and enterocolitis system disorders: karyogamy, neopterin, leukemia, idiopathic, nephropathy

OVERDOSAGE

Due to the low oral bioavailability of PLAVIX® (<5%), the likelihood of an overdose is unlikely. In the event of an overdose, PLAVIX® should be stopped and supportive measures initiated.

The immediate management of a patient who has ingested an overdose of PLAVIX® is symptomatic and supportive care. Gastric lavage is not recommended.
I was happy to read stories of how stroke survivors have coped. I had a stroke 9½ years ago; my husband cares for me. My biggest adjustment was to deal with memory loss. I am 79 years old, and we have an RV and have been to every state, including Hawaii and Alaska. Now I can’t remember much of any place. In August I fell and broke my arm in three places. Since my bones are brittle, the surgeon told my husband, “It was like putting together a jigsaw puzzle.” I am still in therapy and pray I’ll get back full use of my arm.

Violet Hofnagle, Survivor
Bloomsburg, Pennsylvania

I read all the letters to the editor very carefully, and I have never seen one that addresses my problem.

I am a survivor since 2001. I am grateful and lucky to be alive. I was away from home for six months after my stroke. I had brain surgery, a tracheotomy, feeding tube, etc. I can now walk with the aid of a semi-walker, my speech is fairly good and I guess I’m one of those miracles we keep hearing about.

My problem is that I cannot rise or sit by myself. I must have assistance in and out of my wheelchair, lift chair, bed, toilet and car. I have a condition called myositis ossificans, which is a huge growth of bone in the hip on my affected right side. No doctor will operate because it requires seven hours of surgery and months of rehab. We run two support groups in Florida, and no one we’ve met has a similar problem. I’m told it either happened from a fall when the stroke hit, or from not being turned enough when I was comatose for three months.

How it happened is no longer important to me. What is important is how difficult it is for my wife, who is my caregiver, to lift and seat me so many times a day. We had a hoya lift for awhile, but that, too, was most difficult.

Does anyone else have this problem? And if so, how do you cope with it?

Harry Hochler, Survivor
Margate, Florida

I want to thank the people who write about their stroke experiences. I liked “Stroke — Not for Sissies” by Mary Prill in the September/October 2006 issue.

My husband is my caregiver and is incredible. He works full time, takes care of me, runs the house and takes me to medical appointments. It is very rough. I am a young survivor and would like to see articles on intimacy after stroke, also how to find your purpose after stroke.

Jan Shaughnessy, Survivor
Scituate, Massachusetts

I am writing in response to “Playing Around with Recovery” in the September/October 2006 issue. I am a Certified Therapeutic Recreation Specialist working on an inpatient rehab unit, and I use leisure and recreation activities like those described in the article to get patients back into what they like to do. For instance, I often use one-handed cardholders to help patients continue to play cards when they don’t have the use of both hands. Recreation therapists have a lot of experience in adapting activities to meet patient needs. I found it frustrating that the author did not address the role a recreation therapist plays in the rehabilitation of stroke patients.

Bonnie Hauser, CTRS
South Bend, Indiana

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.
In the largest, most comprehensive study of its kind to date, researchers supported by the National Institutes of Health (NIH) showed clinical improvements out to one year when stroke survivors who had lost function in one arm were given a two-week dose of constraint-induced movement therapy (CIMT).

Steven Wolf, Ph.D., Professor of Rehabilitation Medicine at Emory University, led a multi-center team that tested the effects of CIMT in 222 patients. The study, published in The Journal of the American Medical Association, was funded by the National Institute of Child Health and Human Development (NICHD) and the National Institute of Neurological Disorders and Stroke (NINDS).

“This study provides the strongest evidence to date that constraint-induced movement therapy can help stroke patients regain lost arm function,” said NIH Director Elias A. Zerhouni, M.D. “This is welcome news for stroke patients and those who care about them.”

CIMT involves training the weakened hand and arm through repetitive exercises, while restraining the unaffected hand and arm with a mitt like a boxing glove. The theory behind the hand restraint is that it forces the wearer to use the affected hand and arm.

“We now have an intervention that is beneficial for between 5 and 30 percent of the stroke population. CIMT should be considered as a valuable form of rehabilitation, and opens the door to further explorations,” Dr. Wolf said.

Dr. Wolf’s study involved people who had weakness in one arm caused by a stroke within the prior three to nine months. About half of the trial participants received customary care, ranging from no treatment to standard physical therapy, while the other half received CIMT.

Study participants wore the restraint during several hours of training every day for a period of two weeks. They were evaluated immediately after treatment, and again four, eight and 12 months later, through a series of tasks designed to measure arm dexterity and questions about how well and how often they used the impaired arm in daily activities.

Compared to the group that received customary care, the CIMT group showed improved function of the stroke-affected arm in timed tasks and in self-reported daily use. At the earliest evaluations, some participants were unable to perform certain tasks, but those who received CIMT were more likely to regain the ability to perform those tasks by the end of the year-long study period.

Previous neuroimaging studies have revealed that CIMT stimulates increased activity in the part of the brain that controls the rehabilitated arm. “The work of Dr. Wolf and his colleagues shows that it’s possible to harness this remarkable plasticity in the brain to significantly improve the lives of patients,” said John Marler, M.D., Associate Director of Clinical Trials at NINDS.
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 symmetry
• Walk with greater confidence and ease over uneven surfaces

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

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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Rx only
States Begin to Take Stroke Care Seriously

Maggie Ferment was only 32 when she had a stroke. She awoke in a hospital room, unable to speak, with those around her talking about stroke. It took her three years of hard work to reclaim her life and return to work as a nurse. Treatments available today for stroke can make what happened to Maggie a thing of the past.

Speed is crucial to stroke treatment. The creation of stroke systems of care gives each patient seamless transitions from one stage of care to the next with the highest quality at each step. A few states have already pushed to improve stroke care and have established networks of primary stroke centers.

A program in Massachusetts took off after the state Department of Public Health approved regulations in 2004 creating primary stroke service hospitals and requiring ambulances to take most stroke patients to those 68 hospitals. New Jersey also established primary stroke centers and appropriated $3 million in grants to help hospitals with upgrades. The movement to advance stroke care through legislation at the state level continues throughout the United States in 2007.

Illinois has introduced legislation that will create primary stroke centers. The legislation is sought by Stroke Survivors Empowering Each Other, a statewide stroke advocacy group founded by the American Stroke Association. Other states looking at stroke legislation include North Carolina, Pennsylvania and Nevada.

These important measures will pass only if legislators hear from their constituents that building strong stroke systems of care is important. To learn more about stroke legislation and how you can take action, visit www.americanheart.org/yourethecure and become a member of the American Stroke Association's You're the Cure network.

Depressed Stroke Patients Often Not Treated for Depression

Despite a high rate of depression, few stroke survivors take antidepressants, according to a study in Stroke: Journal of the American Heart Association.

“Stroke patients suffering from depression have been found to have reduced quality of life and a higher rate of death, so it is important to identify and treat depression after stroke,” said Seana L. Paul, B.Sc. (Hons), lead author of the study and researcher at the National Stroke Research Institute in Victoria, Australia.

From May 1, 1997, to April 30, 1999, researchers identified those who had a stroke among 306,631 people in the North East Melbourne Stroke Incidence Study (NEMESIS). Researchers excluded those who had suffered a subarachnoid hemorrhage (bleeding in the brain).

Nurse researchers visited the 289 participants (51 percent men, average age 73) in their homes five years after their stroke. During the interviews, the researchers assessed participants for depression and asked about all medications they were taking, including antidepressants.

Researchers found that at five years after stroke:

- Nearly one in five stroke survivors were suffering from depression.
- Only 22 percent of those with depression were taking an antidepressant.
- About 28 percent of those taking antidepressants were still depressed.
- 72 percent of those taking antidepressants were not depressed, which could mean the medication was successful in this group.

“We have confirmed that depression is common even up to five years after stroke, and that the majority of those taking antidepressant medication were not depressed,” Paul said. “This provides indirect evidence that antidepressants are effective in treating depression in stroke patients.

“The low treatment levels found in this study may indicate that physicians are unwilling to prescribe treatments that have not been demonstrated to be an effective and safe treatment for depression among stroke patients,” Paul said. “Another factor may be that depression among stroke patients is not being diagnosed.

“We know that stroke survivors who are not depressed live longer, higher-quality lives than those who are depressed. Consequently, educating physicians, stroke survivors and their families about the risk of depression after stroke may increase identification of depression and lead to improved treatment.”
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.


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In July 2004 I submitted a story to Stroke Connection about the stroke I had in October 2001. In re-reading it recently, I saw the feelings of disappointment, fear and bitterness that, at the time, I didn’t recognize I was experiencing.

On October 14, 2006, I celebrated the fifth anniversary of that event. My choice of “celebrate” might seem strange. Why do I think of it as a celebration?

At first I was devastated; it really threw my life off balance. In hindsight I must say that it is the best thing that ever happened to me. After the initial shock, dismay, fear and the pain of not knowing, the veil has lifted, bit by tiny bit — slowly at first but definitely a little more each day. I somehow was able to build on my successes, instead of lamenting the failures. Now I look at the stroke as getting me un-stuck because it jolted my world and forced me into different orbits.

I still don’t play guitar very well but I enjoy trying. My left hand still has little feeling, mostly pain, but I use it as much now as my right hand. A simple headache no longer results in worrying. People have told me that if I didn’t share the event with them they would never know. That is quite liberating.

I found a good job that provides full benefits and gives me the freedom to pursue other interests, like reading, writing, cooking, etc. I am lucky to be able to telecommute from home, although I drive up to 500 miles a week. Just having medical benefits is a great consolation in itself. It took four years to find a job that suited me and my needs; there were five other attempts.

I do whatever I want now. I’m not afraid to drive. I just put a radiator in my truck last week, and I noticed that I’ve learned to use the hand, instead of ignoring it. I do check the temperature of things with my right hand before touching or grasping them with the left. It’s still tough to pick up a coin from the table with the index finger and thumb, but it can be done and I enjoy the challenge. I feel more powerful now than ever before.

The event was an awakening of sorts, a fresh start, a new way of viewing the world. I’m happy now and look forward to all the things that life offers. I am no longer on medication but do take an 81 mg aspirin every day. Twice in the past five years, I’ve felt odd, and out of fear went directly to the emergency room, but both ended up to be nothing. Once in awhile, I trip over my tongue and I still type mostly right-handed, but I feel normal every day.

All I can say is it has helped me to view the event as a fresh start and a new way of looking at the world. I do believe time heals all wounds. Notice that I refer to the stroke as the event rather than my stroke. I take no ownership of it, it’s just something that happened. Earlier you might have noticed the wording my successes and the failures. I take ownership only of the positives.

I know having a positive attitude is almost impossible in the beginning, but when the veil finally lifts, the sun shines in.

Christopher Happ, Survivor • Phoenix, Arizona

Editor’s Note: To read Chris’s original story from the November/December 2004 issue, visit our Web site at www.strokeassociation.org/strokeconnection.
“ITB Therapy℠ has given me independence to continue doing the things I’ve always enjoyed.”

Mary C., stroke survivor
Day of stroke: Dec. 15, 2001
Day she began receiving ITB Therapy℠: May 8, 2003

Five years ago, a blood clot in Mary’s uterus reached her brain, causing her to sustain a stroke. She lost the use of her left arm and leg and experienced paralysis on the left side of her face.

After six months of physical therapy, Mary’s left foot remained turned inward on its side, making each step treacherous. Severe spasticity left her left leg muscles tight so she couldn’t bend at the knee or hip.

Mary’s doctor believed Medtronic ITB Therapy℠ (intrathecal Baclofen Therapy) could address the spasticity in her leg, joints, and arm and help her regain an active lifestyle. With ITB Therapy, her foot returned to a more natural angle and the muscles in her legs loosened up.

A recent study revealed ITB Therapy significantly improves stroke survivors’ spastic hypertonia, functional independence and quality of life. The most common adverse events in this study were accidental injury, somnolence, dizziness, and hypotonia.

Today, Mary is back at work as a part-time pastor and enjoys water aerobics, Pilates classes and attending her son’s cross-country and gymnastic meets.

To hear another stroke survivor’s story, to learn more about ITB Therapy and the results of recent research into the treatment, please participate in an upcoming Movement for Living teleconference:

March 21
The teleconference is held at 7 p.m. Eastern, 6 p.m. Central, 5 p.m. Mountain, 4 p.m. Pacific.

Embrace the possibilities
Call 1-888-743-8348 to register. There is no cost to participate in this teleconference.
Find out more at www.YourLifeAfterStroke.com/sc or talk to your doctor.


This story captures one individual’s experience with ITB Therapy. Results vary; not every individual will receive the same benefits. Side effects can occur. For complete prescribing information, please refer to the following patient information.
PATIENT INFORMATION

Lioresal® INTRATHECAL (baclofen injection 40 mg/20 mL, 10 mg/5 mL, 10 mg/20 mL, 0.05 mg/1 mL)

Completely read this information before you start using Medtronic ITB Therapy® (Intrathecal Baclofen Therapy). This information does not take the place of thorough discussions with your doctor. You and your doctor should discuss ITB Therapy before you begin receiving the therapy and at regular refill appointments.

Q: What is Lioresal® Intrathecal (baclofen injection)?
A: Lioresal Intrathecal is a liquid form of baclofen, and is commonly used to treat severe spasticity. Liquid baclofen is used for injections and infusion into the intrathecal space (the fluid-filled area surrounding the spinal cord), using an implantable drug delivery system.

Q: What are the signs of rapid or abrupt withdrawal from intrathecal baclofen?
A: Increase or return in spasticity, itching, low blood pressure, lightheadedness, and tingling sensation are often early indications of baclofen withdrawal. It is very important that your doctor be called right away if you experience any of the above symptoms.

In rare cases, severe symptoms may occur. These symptoms include high fever, altered mental status, spasticity worse than before you started ITB Therapy, and muscle rigidity. It is very important that your doctor be called right away if you experience any of the above symptoms.

Q: What can I do to prevent baclofen overdose or abrupt discontinuation of intrathecal baclofen?
A: It is very important that you keep all of your refill appointments. This may require some planning prior to traveling. Maintaining a regular refill schedule will ensure the pump does not run out of medication and that any potential problems with the infusion system are diagnosed and corrected. Additionally, you should be aware of what your pump alarms sound like. If you hear an alarm, contact your doctor immediately.

Furthermore, it is very important that you know and understand the signs of baclofen overdose. Also be sure to tell your doctor right away if you experience any unusual symptoms, side effects, or changes in your condition.

Q: What are the symptoms of baclofen overdose?
A: Although rare, it is possible for you to receive too much medication (overdose). A baclofen overdose may cause drowsiness, lightheadedness, respiratory depression (difficulty breathing), seizures, loss of consciousness and coma. If you experience any of the above symptoms, it is very important that you or your caregiver contact your doctor right away.

This provides a summary of the most important information about Lioresal Intrathecal. If you would like more information, talk with your doctor. You can ask for information about Lioresal Intrathecal that is written for healthcare professionals. You also can get more information by visiting www.spasticity.com.

Rx only.
Lioresal® is a registered trademark of Novartis Pharmaceuticals Corporation.
Some Thoughts on Surviving

After my stroke in December 2003, my caregiver, who loved me, meant well when she took on the assignment to get me better. Unfortunately, her good intentions were not enough, and my needs were depriving her of her own life. She viewed my behavior as unacceptable even though my doctors told her my stroke prevented me from behaving differently. I think the real question is, who is the victim? The one with the stroke or the loved one affected by it? When my caregiver said “I have no life!,” I was confused because I thought I was her life.

Caregivers become frustrated because they expect more from the survivor, which puts us in a difficult position: Not only do we have to cope with our deficits, we have to make our caregivers happy. Not always an easy task. It’s not always so much a matter of personality change, it’s a matter of priority change.

How can clothing be important when you have difficulty with your vision? It’s inevitable that people are depressed when so much gets taken from them. Crying is a relief from depression. Lexapro helped me. Being grateful for what you have instead of sad because of what you don’t have can help relieve depression.

We survivors can’t help what happened. We can’t change the carotid artery blockage. We have to live with what we have. Our major choice is to survive or not to survive. I found out the world did not stop revolving while I was absent for awhile. My grandchildren still want their grandpa to play with them; my lover still wants me to make love. Perhaps, the stroke was a tragedy, but I’m going to get through it.

Richard Steinberg, Survivor
Boynton Beach, Florida

A Poem for Janie

I recently wrote a poem for Janie Anderson, the daughter of a friend. Janie is age 38 and had a stroke three days after giving birth to her first child, Nathaniel.

Janie related deeply to this poem. She particularly liked my calling prosthetics “armaments.” It gave her a whole new orientation to something she dislikes.

Princess and Warrior

It is July 2006, Tempe, Arizona.
On Mondays, Wednesdays and Fridays, he has the privilege of escorting her to the clinic for physical therapy.
What more could a father wish for than to spend precious time with his oldest daughter?
A daughter who, at 39, is still his little princess; one of the lights of his life.
Entering, his eyes move to the poster.
He knows the words by heart now — “The body is silent, but the spirit stirs.” He understands this so well.
The father then watches as his princess turns into a warrior and prepares to enter battle.
She straps on her armaments, prosthetics of plastic and metal, that replace muscles and tendons made quiet by a stroke.
The princess digs deep, summons her courage and, once again, transforms into a soldier.
Steely eyed. Ready to take on the enemy; the enemy who has no heart, no conscience, no remorse.
Not content to merely wear her “Purple Heart” and seek sympathies, she locks and loads, bravely moving again into the heart of darkness.
Taking back her life one step, one movement and one minute at a time, she whispers her soldier’s mantra, “Patience, patience, patience.”

Bill Hamelau, concerned friend • Charlotte, North Carolina
Don’t call David Layton if you’re having a pity party. His attitude will ruin everybody’s sad time.

If you’ve read Stroke Connection for very long, you may recognize David’s name and face: He’s been our most prolific contributor, appearing in eight magazines since 2002. From the very beginning, while he was still in the hospital, he had the mindset to make the most of life after stroke. You can see this in this excerpt from his first Readers Room submission in the November/December 2002 issue:

I had a massive cerebral hemorrhage three years ago causing left-side paralysis. Because my left arm seemed like someone else’s arm, I told myself this was God’s Arm. At night, alone and afraid, I have received much comfort by pulling this heavy, warm arm across my chest and telling myself that God is embracing me in His love by holding me in His Arms.

David actually had two bleeding strokes within an hour in June 1999, the second one while in the emergency room. He was age 55.

The strokes left him in and out of consciousness for three weeks, a time his wife Charlotte remembers vividly. “David’s stroke put me on a roller coaster of feelings, and I do not like roller coasters. Seeing my husband of more than 30 years in a weakened state was very hard. Accepting that the stroke was a life-changing event was even more difficult. With the support of God, friends and family, we were able to learn to accept the new normal.”

In those first months, the Laytons felt the need to talk with a survivor with whom they could discuss the possibilities of recovery and gain hope for the future, but there was no one to talk to. After regaining his strength and mobility, David started visiting other survivors. Seven years later he’s visited over 2,000 patients and many of their family members, and he has even recruited two other survivors to help.

“We’ve noticed that quite often the family members are more worried about the patient’s future than is the survivor,” David said. “Of course, we can’t make guarantees, but we can show possibilities and try to give that needed hope and encouragement. One stroke family nicknamed me ‘Dr. Hope.’ That was really special.”

In addition to bringing hope to survivors at the hospital where he received treatment, David decided to educate the public about stroke and prevention. “After I got out of the hospital, I read everything I could about stroke,” he said. “I learned that most strokes are preventable.”

To get that message out, he started making presentations about stroke awareness and prevention. He began in his local church, and then gave the speech in other churches, at civic groups and then on TV and radio.

“In 2002, our local Greensboro, N.C., American Heart Association started a speaker’s bureau, and I joined,” David said. “They started booking some presentations for me and recording the number of people I was speaking to.” With a way to keep track, David set a goal of reaching a million people with his message.

He met his goal this past September — actually 1,198,808 people at the time of this article. He accomplished it by doing TV and radio interviews, what he calls “specials.” “I’ve done nine TV specials, including being filmed at the fitness center — to demonstrate the importance of exercise — and on my sailboat — to show that there is enjoyable life after stroke. I’ve also done eight radio specials, 10 health fairs and 37 speeches to churches and business and civic groups.”

In between his patient visits, speaking engagements and media appearances, David and Charlotte have taken three Caribbean cruises. “Each one was just a little more fun than the last,” he said. “This year we have enjoyed seeing more of our own state, North Carolina. With mountains to our west and the coast a few hours to the east, we have a lot to see and enjoy here at home. Last
November we bought a new house just 5 minutes from our grandchildren.

“I still love sailing, but I’m very busy with other things that I feel are more important at this point in my life,” David said. “I will sail again. I want to teach my grandchildren, Jonathan and Christina Marie, the thrill of sailing when they’re old enough to crew for me.”

It wasn’t just his lifestyle that changed after the strokes. “My priorities in life changed,” he said. “God and family and a genuine concern for others moved to the top of my list. The stroke has slowed my life — left-side paralysis and walking with a cane will do that — but it has given me the opportunity to learn patience and perseverance. I like the new me better than the old.”

“David’s attitude has changed,” Charlotte said. “He has become much more aware of the needs of those around him, and he’s made a quantum leap in patience.”

Achieving his million-person goal didn’t cause him to rest. There are millions more to reach. Since September, he and Charlotte recorded a 30-minute TV special in Morehead City, N.C., where they discussed stroke from the point of view of both survivor and caregiver. That video is scheduled to run 12 times on cable in that area.

“I can’t really imagine 1,198,808 people,” David said. “It’s beyond my comprehension. However, I am excited by the thought that if only 1 percent of those who heard me improved their lifestyles because of something they learned, that’s 11,988 people! Every day I thank God for sending me back to life and giving me this ability and the opportunity to do what I do.”

Of course, like all caregivers, Charlotte Layton had her own experience of stroke survival, which she sometimes shares during interviews. Her advice to caregivers is to get information. “Learn all you can to understand your new situation in life. Deal with each day as it comes. Sometimes it may be hour by hour. Remember, you are not alone and your situation is not unique. There are people who want to help. Call on them, whether it’s healthcare professionals, friends or family. Prayer helps, too. And start a journal as soon as possible!”

She suggests six ways to use a journal:

1. Write down the time and dates of doctor visits. A written record will provide you with some organization for your questions and concerns. Doctors will ask if you have any questions, so be prepared — keep your questions in your journal and make notes of how the doctor answered.

2. A journal also helps you keep up with important information, like medical descriptions and prognosis, as well as notes to yourself. It becomes an ongoing to-do list.

3. Keep billing updates in the journal where you can easily review them. This provides you with additional information as well as helps you stay on top of the financial side of the hospitalization.

4. Make notes of meetings with the benefits/insurance specialists. Many of the decisions about care are made here, so it helps to learn the terminology of the condition.

5. Use your journal to keep a record of the calls, cards and visits you have received. This is helpful when sending updates to family and friends. E-mailing progress reports in a group e-mail will save repeating updates by phone.

6. Record any and all improvements in your survivor’s condition. This is a good reminder to both patient and caregiver of progress, and it can serve as motivation when progress seems to have reached a plateau. It can also come in handy when talking to your insurance company about continuing therapy.
Has Congress Changed Your Will?

Several recent laws have taken effect that could significantly impact your estate and retirement. Do you know how these laws will affect you? The American Heart Association’s brochure, Has Congress Changed Your Will? can help answer such questions as:

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The first clue that Seema Agarwal-Harding had a rare disease called fibromuscular dysplasia came in an exotic land. She had a stroke at the airport in New Delhi, India.

It was October 2004, and her flight to Mumbai (formerly Bombay) had been delayed. A senior education adviser for Asia and the Near East for the U.S. Agency for International Development (USAID), she was visiting her native India as part of a team negotiating development projects with Indian organizations.

“At 4:55 p.m. I felt fine, a little tired so I bought some tea. Waiting in line I felt a strange tingling in my arm, and by 5:05 my head was bursting,” said the 48-year-old mother of two. “The room was spinning, and I was losing my bearings. I started to sweat.” She collapsed into the arms of two co-workers.

She was “rushed” by ambulance through the notorious New Delhi traffic to one of the city’s best hospitals, where an MRI showed a subarachnoid hemorrhage (bleeding from a blood vessel on the surface of the brain into the space between the brain and skull) that precipitated multiple strokes. But a diagnosis is not necessarily an explanation, and no one could explain the burst artery.

For two weeks the doctors puzzled over her case, tentatively deciding on a type of vasculitis called Takayasu’s arteritis. This very rare blood vessel disease occurs in only two to three cases per million people.

She was medivaced from India to the Johns Hopkins neurology ICU in Maryland. There leading experts from the Johns Hopkins Vasculitis Center eventually ruled out the Takayasu’s diagnosis after four months of tests and diagnostic work. Using magnetic resonance angiography (MRA), the doctors finally determined Seema had fibromuscular dysplasia (FMD).

While FMD is more common than Takayasu’s arteritis, it is often misdiagnosed and mistreated. FMD is a blood vessel disease that has no unique symptoms and can only be diagnosed with advanced imaging techniques. The first accurate description of FMD occurred in 1958, according to Dr. Jeffrey Olin. Dr. Olin is a professor of medicine at Mount Sinai School of Medicine and Director of Vascular Medicine and the Vascular Diagnostic Laboratory in the Zena and Michael A. Wiener Cardiovascular Institute of The Mount Sinai Medical Center in New York City.

STRING OF BEADS

Pam Mace of Rocky River, Ohio, was diagnosed with FMD in 2001, many months after having a transient ischemic attack (TIA) at age 37. She joined the Fibromuscular Dysplasia Society of America (FMDSA) soon after to raise awareness of this disease. “FMD causes the arteries to narrow, blocking blood flow,” she said. “It often affects arteries to the kidneys, causing the sudden onset of high blood pressure, or blocking blood flow and causing the destruction of kidney tissue. If FMD affects the carotid...” (continued on page 18)
FMD changed the direction of Pam Mace’s life. Once an ER nurse, she now works part-time and focuses her efforts on raising awareness of FMD in the medical community.
or vertebral arteries, people may experience dizziness and chronic headaches or even neurological symptoms such as stroke or TIA. My symptoms were caused by bilateral carotid artery dissections (tears or rips).”

“The name ‘fibromuscular dysplasia’ refers to the fact that the fibrous tissue and muscle layers in the middle of the artery wall grow in an abnormal manner and deform the artery,” said Dr. Richard Hughes, an associate professor in the neurology department at the University of Colorado Health Science Center in Denver. “This makes the normally smooth tube a bumpy tube.”

The most common forms of FMD produce this bumpy tube, which in the angiography produces the characteristic “string of beads” appearance. This is due to changes in the architecture of the artery wall that cause the arteries to alternatively become narrow and dilated. A less common but more aggressive form of FMD may cause the vessels to become severely narrowed without the “string of beads” appearance.

“FMD cannot be diagnosed without some type of imaging tests such as duplex ultrasound, magnetic resonance angiography (MRA), CT angiography (CTA) or catheter-based angiography,” Dr. Olin said. “Its general prevalence is not known, but it occurs much more frequently in women. It’s usually diagnosed when something happens that makes you suspect it and a diagnostic image is made. Sometimes it is discovered incidentally during an imaging test performed for an entirely different reason.”

IN FMD, TIA MAY BE A SYMPTOM

For Pam Mace, it was dissected carotid and vertebral arteries that began the medical odyssey that would eventually lead to her FMD diagnosis. A follow-up MRA showed aneurysms in both carotid arteries, a fact confirmed by the opinion of a second neurologist, who urged her to see a vascular doctor. “He ordered an angiogram so he could visualize my arteries,” Pam said. “At that point it had been seven months since my TIA and none of my symptoms was better. I still had terrible headaches and a drooping eyelid.

“Within minutes of starting the angiogram the doctor saw the classic ‘string of beads’ formation in my renal artery, which indicated I had FMD. That explained the sudden onset of high blood pressure that I’d experienced when I first went to the ER. Although I was a nurse, I had never heard of this disease, but I finally started to feel like I knew what was causing all of my problems.”

There is no cure for FMD. For Pam, treatment included stents in both carotid arteries because of the damage caused

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A leading authority on FMD, Dr. Jeffrey Olin estimates that he has seen fewer than 200 patients with the disease but said that there is no way to know how common it is.
by the dissections. “Stents are not approved by the FDA for this purpose,” said Pam, “but I really had no choice.” It had been more than two years since she had first gone to the hospital with “the worst headache of my life” and unequal pupils.

A leading authority on the disease, Dr. Olin estimates that he has seen fewer than 200 patients with FMD but said that there is no way to know how common it is. “The most common presentation is a young woman with high blood pressure because FMD most commonly affects the renal arteries,” he said. “Those with the disease in the carotids can often hear the swooshing noise in their ears. This is caused by turbulence of blood flow, and if a physician listened with a stethoscope, they would hear this noise called a bruit. FMD is often confused with an inflammatory disease of the blood vessels — vasculitis.”

Mattanjah de Vries was diagnosed with Horner’s syndrome when he first visited his doctor with a severe headache, unequal pupils, sensitivity on one side of his face and a drooping eyelid. “These symptoms can occur when nerves to the face get pinched or when a carotid artery is dissected because the nerves are close to the artery,” said Mattanjah, a professor of physical chemistry at the University of California — Santa Barbara. “Normally doctors look for a tumor in that situation, but my CT scans didn’t show anything. The medicine they gave me wasn’t helping my headache. In June 2006, the doctor ordered an MRA, and that showed a carotid artery dissection as well as FMD.”

He was treated with blood thinners, and a later MRA showed that the dissection was healing nicely. “I am trying not to let this diagnosis change my life too much,” Mattanjah said. “I’m careful about exercises that strain my neck, or getting a massage. This is a new experience of fragility that I’ve never had before.”

CAUSE IS STILL A MYSTERY

The vascular physicians who work with FMD have not found its cause. “There is no evidence of an environmental component, although FMD occurs more commonly in individuals who were smokers,” Dr. Olin said. “I don’t know how valid that is because I have seen many patients with FMD who never smoked. There is no preponderance in any part of the world, and weight doesn’t seem to be a factor.”

“Since women in the 20–50 age group represent the majority of cases, many researchers think there is an important hormonal component to FMD,” Dr. Hughes said. “Maybe hormones accelerate the changes of FMD, or maybe it makes their FMD more likely to be symptomatic, (continued on page 20)
and therefore diagnosed. Still, men get this, too, so the hormonal theory cannot be the only explanation.

“There is another theory that the artery or arteries involved are made susceptible to the FMD changes because of some sort of wear and tear, or a viral irritation. The idea is that the artery tries to heal but overdoes it.”

There is some evidence of a genetic cause. However, relatives may have different arteries involved, different levels of severity or not develop FMD at all. Not all individuals with FMD have a family member who has the disease.

**LIFE AFTER DIAGNOSIS**

For Pam Mace, FMD has changed everything. She now works as an ER nurse on a per diem basis, which allows her to make her own schedule so she doesn’t get overworked. Her nursing background has been a plus in her work with FMDSA.

Unlike Mattanjah, her carotids did not heal, which required the stenting. A year after her first stent was placed, she was still having spasms and noise in her ears, as well as unequal pupils. “I was afraid to fly again or do anything for that matter,” she said. “I had already given up running — I had been a marathoner — golfing and scuba diving. At one point I was told not to have my hair washed at a beauty salon because of the position you are in. I was instructed not to do anything that would raise my heart rate or blood pressure.” A second stent was placed in 2002, and FMD was also diagnosed in her right renal artery at that time.

Seema Agarwal-Harding’s life has also changed as a result of her FMD diagnosis. “During the course of my illness, I felt like a burden or even an invalid, less than what I was before in the eyes of others. It forced me to regain myself through rebuilding my own self-esteem. It hurt that I was no longer considered by some to be the beautiful, capable, intelligent person I once was.”

“FMD created a sense of doubt, uncertainty and loss. I had to grapple with who I had become, what I am capable of today. I lost a lot of self-confidence. For a time I could not walk, read or write, let alone drive or cook or analyze professional papers. It was devastating. I still felt the same on the inside, but everybody treated me differently. I was now a sick person.

“To regain myself, I set about trying to do little things. I started writing a memoir, working on a quilt for my son, cooking occasionally, and listening to books and music. By doing these small acts, people around me became convinced that I would be okay after all. Six months after my illness, I returned to work full time, resuming my work in international education and traveling once more to developing countries.

“But two years later I am in a different place,” Seema continued. “I have now reconciled myself to the fact that I do indeed have a life-threatening disease that will not go away. I am more accepting of that fact. I have given up my career as a U.S. diplomat, designing and implementing education projects around the world. I am focusing on cherishing my life with family and friends. “My life is no longer about ambition or success or glory at work, it is more about the value of my time spent on things that really matter — my precious children, my parents, time writing and reflecting on my life and contributions that I have made and that I might still make for those less fortunate than I, and for my children.”

“It’s been six years since I dissected,” said Pam Mace, “and it was only about a year and half ago that I started to move on with my life. Every now and then I worry about having stents in my head. With FMD I will always be at risk of a stroke, but I take every precaution I can: I watch my diet, walk, take my medication, and I never miss a doctor’s appointment. And I have lots of doctors — a primary care physician, a neurologist, a vascular specialist, a nephrologist for my kidneys and a cardiologist. At age 42, I have already had five angiograms, but I have gone from weekly doctor visits to yearly checkups.

“There are many aspects of this disease, and no one fully understands it. And few doctors have heard of it, so I have shifted my focus to raising awareness of FMD. It is my hope that one day everyone will be aware of this very special ‘string of beads’.”

“It is my hope that one day everyone will be aware of this very special ‘string of beads’.”

— Pam Mace
COMMON SYMPTOMS

The signs and symptoms of fibromuscular dysplasia depend on the organ the affected artery supplies.

If the affected arteries lead to the kidneys, patients could experience high blood pressure, ischemic renal atrophy (where the kidney shrinks) or, in rare circumstances, kidney failure (when FMD progresses in both kidneys). The renal arteries are the most commonly affected blood vessels in the body.

If the affected arteries are the carotid and vertebral arteries, patients may complain of dizziness, temporary blurring or loss of vision, vertigo, neck pain, ringing or whooshing noises in the ear, TIA or stroke. FMD patients are also at an increased risk for intracranial aneurysms.

If the affected arteries lead to the intestines, liver or spleen, patients may experience abdominal pain after eating, and unintended weight loss. FMD in the arms and legs can cause limb discomfort with use (claudication).

DIAGNOSING FMD

Diagnostic imaging is the only means for diagnosing FMD. CT angiography, MRA (magnetic resonance angiography), duplex ultrasound and catheter-based angiography are all effective ways to diagnose FMD. In the most common form of FMD, called medial fibroplasias, these imaging methods show a distinctive “string of beads” appearance. Because FMD is not commonly encountered, not all healthcare professionals know what to look for.

COMMON MISDIAGNOSES OF FMD

Because FMD is uncommon, it is often misdiagnosed as:

Vasculitis — an inflammatory condition of the blood vessel walls

Atherosclerosis — buildup of plaque on artery walls causing “hardening of the arteries”

Traumatic dissection — rupture of an artery

Buerger’s disease — an inflammation of the arteries, veins and nerves in the legs caused by smoking and leading to restricted blood flow. Left untreated, Buerger’s disease can lead to gangrene and ultimately amputation of the affected areas.

TREATMENT OF FMD

There is no cure for FMD, and there is no set protocol for treating it. Treatment often involves attempts to increase blood flow through the affected vessel. The kind of treatment used depends largely on which arteries are affected as well as the severity of the symptoms. Balloon angioplasty is most frequently used to open the renal (kidney) and carotid arteries. Unless there is a dissection of the artery, stents are usually not required. Most people with FMD take some sort of antiplatelet agent (usually aspirin) every day.

POSSIBLE CAUSES OF FMD

The cause of FMD is not known, but several theories have been suggested. Because it has been identified in multiple members of the same family, including twins, some experts believe it has a genetic cause. However, not all individuals with FMD have relatives with the disease.

Because FMD is more common in women than men, some investigators have suggested that hormones play a role. This theory is supported by the fact that most women are premenopausal when diagnosed.

Other suggested causes include tobacco use, abnormal development of the arteries that supply the vessel walls with blood resulting in inadequate oxygen supply, and the anatomic position of the artery within the body. It is possible that many factors are involved in the development of FMD.

For more information, contact:
Fibromuscular Dysplasia Society of America
PO Box 999
Hudson, OH 44236
330-653-8416   www.fmdsa.org

Source: “Important Facts You Should Know” published by the Fibromuscular Dysplasia Society of America, Inc.
Have You Heard the One About...

by Jim Batts

DeYip (Louie) Loo of Canton, China, came to America as a teenager in the 1930s to work on his father’s farm in Minnesota. Two years later he was a busboy at the Nanking Restaurant in Chicago when the great 20th century magician Harry Blackstone Sr. dropped in, chatted with Louie and offered him a job. His boss, thinking about all the dishes the boy was breaking, urged him to take it.

Louie did, and for a time was Blackstone’s personal valet and his assistant on stage. This launched a show-business career that has featured magic salted with good humor — a run that extended over several decades. He was the first professional magician to perform on The Bozo Show, which gave him his big television break in 1961.

Before Louie became a U.S. citizen, he was in the Army Quartermaster Corps in World War II, serving in Korea, the Philippines, Okinawa and Japan. After being discharged, Louie polished his magic act while touring with Red Skelton’s 1949 tour entertaining service personnel.

After returning from the war, Louie started his own one-man act, which included Chinese-English jokes. This gentle wit is reflected in an ad he ran periodically in Variety, the show-business newspaper. Its punch line plays off an old joke about eating Chinese food: “Louie Loo, No. 1 Chinese Magician — A half hour later you want to see this act again.”

He was still performing in various venues when he collapsed with a massive hemorrhagic stroke as he was doing yard work at home in 1998. He underwent emergency brain surgery he wasn’t expected to survive, followed by almost a year of intensive rehabilitation.

He has recovered sufficiently to perform with his family three times since the stroke.
THE FAMILY’S KEY ROLE IN LOUIE’S RECOVERY

Treasured family dynamics that have passed the test of time are at the heart of his wife, Arlene’s, and his daughter, Mai-Ling’s, drive to help Louie progress as a stroke survivor.

“My parents were always loving,” Mai-Ling recalled. “I am an only child, and they always had my best interests at heart. They strengthened me in every possible way to be the best Mai-Ling I can be.” When the stroke came, “being the best” meant taking care of Louie at home.

“We knew he wouldn’t do well anywhere else,” Mai-Ling said. It’s where he felt the best physically and psychologically. He’s surrounded by his familiar life, the things that make him happy. We created a home that was safe but also workable to encourage him to improve.” This included putting up photos and special things that would trigger his memory.

“We created a ‘magic’ room full of items so he can look around and enjoy,” Mai-Ling said. “We even made the transition of having him sleep in the recliner, then to the couch, to sleeping in the master bedroom with Mom. It makes him happy, because it’s living life as normally as he can, and comfortably.”

Louie sometimes uses a wheelchair outside the house due to terrain issues or challenges to his endurance. Other than that he walks all over the house, something he wasn’t able to do when he first came home.

Louie often sits at the dinner table and bird-watches how it really took time and patience to see through how he would improve.

“I think with my Mom and me, it was the challenge that boosted us to care for him the best way.”

Q&A WITH MOTHER/DAUGHTER CAREGIVERS

Arlene Loo and daughter Frances Mai-Ling are what you might call dedicated realists. They see how stroke has changed husband and father, but they recognize the real Louie Loo is unchanged. They hold to that reality and reinforce it every day. We asked Arlene and Mai-Ling to share their views about the demands and rewards of giving care to a loved one.

SC: What is the hardest part about care giving?

Arlene: Seeing the stroke every day. Certain frustration from the survivor when they are capable of doing something that is not impaired, but don’t. An example is not answering when spoken to.

Mai-Ling: Seeing the stroke every day, and having to accept it. Knowing that he was always doing something and now he can’t do as much.

SC: What is most satisfying?

Arlene: Seeing him get stronger every day.

Mai-Ling: Watching him improve every day. Hearing him talk about his plans and things he wants to do (like raising chickens, going fly fishing and building magic, doing shows and so forth). (continued on page 24)
SC: Where do you go for support?
Arlene: My family, because we can support each other.
Mai-Ling: I go to my Mom for support mainly, because we can talk things out. Other than that, my journal and my bedroom wall. (My wall is great because it doesn’t talk back to me.)

SC: Where do you go for strength and recharging?
Arlene: Home activities, going out as a family, spending time in public places like coffee shops or bookstores, resale shopping and rummage sales.

SC: Where do you get the best information about stroke and recovery?
Arlene: Stroke Connection, medical TV news, magazines.
Mai-Ling: Magazines, newsletters, Internet, TV.

SC: What advice do you have for someone faced with caregiving responsibilities?
Arlene: Take each day as it comes. Every day is different.
Mai-Ling: Don’t forget to breathe. Keep a journal and write everything down. I have an online journal where I write public entries and “friends only” entries. A journal offers a place to vent or just jot down your thoughts, and if it’s online, people can respond if you want. Also, talk to yourself out loud. You’re bound to come up with a resolution for situations that are bothering you. Stand up for what you do and be proud. Ask for advice from people in similar situations. Talk to your care receiver. Enjoy the time and appreciate it.

SC: What keeps you going?
Arlene: Working with Dad. Spending time with him. And knowing that he has come a very long way since his stroke, beating the odds.
Mai-Ling: My Mom and Dad. Seeing him improve. Our family’s humor. How we work together as a family. Hobbies. My passion for music and the creative arts. Always creative, constantly thinking up ideas. As a performer, I like to make the public aware about stroke and heart disease and connecting with people who can already relate and meeting and getting new people involved.

SC: And a word from Dad?
Louie: For caregivers — Be present and be patient. For care receivers: Take it easy. Be kind. Don’t get mad at them. Be thankful for being alive.

MUSIC and MESSAGE: a double reward

People get more than they expect when they buy one of Mai-Ling’s CDs featuring her pioneering alternative-classical piano stylings. They get lifesaving information about stroke and heart disease, including the risk factors for each.

Go to one of her performances, and you’ll likely learn about stroke and the American Heart Association’s Go Red For Women initiative to make women more aware that heart disease is their No. 1 health threat.

Since her father, Louie, had a massive hemorrhagic stroke in 1998, she has donated part of every CD sale to the American Heart Association and its division, the American Stroke Association, to help fund research and education about cardiovascular diseases. “We as a family are always in ‘advocacy’ mode,” Mai-Ling explained. “My Mom and I wear our Go Red For Women pin on our jackets (or purses, etc.) daily and give them out to people if they are not aware of them.”

This past Christmas, Mai-Ling offered a special limited edition of her “Chronology” CD sold at a special price with a specific amount donated to the American Heart Association. It included a Go Red For Women pin, a sign-up card and a Learn and Live bracelet.

For these and other efforts, Mai-Ling received the 2006 American Heart Association Heart and Stroke Heroes Award. The citation reads, “For your outstanding efforts to create a healthier community, safe from the devastation of heart disease and stroke.”

Mai-Ling’s commitment to giving is an example of the phrase “like mother, like daughter.” Arlene has been an American Heart Association financial supporter for many years. She gave money before and after her own mother and an aunt died of heart attacks, then even more so after her husband had his stroke.

For more information about Mai-Ling and her music, visit www.mai-ling.net.
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

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Jim (not his real name), one of my stroke patients, recently presented with me to a class of physical therapy students. Because of his profound aphasia, Jim has great difficulty expressing his ideas through speech. As he struggled to think of the words to tell the students the cause of his aphasia, an automobile accident that led to massive bleeding on the left side of his brain, Jim pantomimed a driving motion with his arms and eventually got the idea across.

One student asked Jim why he gestured. Was it to get the idea across in the form of a pantomime? Was it to help him get words out? Jim astutely responded that it was both. Sometimes Jim, like many patients with aphasia, resorts to using gestures when he is stuck trying to think of the word he wants to say. And sometimes use of a gesture seems to increase the likelihood that the actual word will come out.

This is not unlike the gesturing that all of us do in the course of conversations to embellish a message and to think of words. It is a natural step in communication to incorporate gestures.

Individuals with aphasia often need to use gestures to enhance communication in the course of a conversation. Although many with severe aphasia naturally attempt to use gestures, others struggle to say words and must be encouraged to use gestures.

The use of gestures is not without its complications, however. The left hemisphere of the brain that controls
the ability to think of words and sentences is also the side of the brain that tends to control our ability to perform learned, skilled limb movements. Examples are pantomimes (for example, making a stirring motion to indicate a spoon) and other familiar gestures, like a salute.

Disruption of the ability to use skilled limb movements is termed limb apraxia. Even though one of the arms, usually the left, is not paralyzed, people with severe limb apraxia have great difficulty using that arm to produce recognizable, meaningful gestures. Sometimes they wave their hand in unrecognizable motions, and it is impossible to determine what idea they are trying to express.

Limb apraxia can cause other problems as well, at times posing a safety risk. The same people who produce meaningless gestures may have great difficulty using tools and utensils during daily activities. In a study several years ago, we found that individuals with limb apraxia often have difficulty with routine tasks such as eating. Some people had such awkwardness using eating utensils that they gave up and ate their food by shoveling it on a slice of bread or simply by hand.

Individuals with limb apraxia can also find it quite difficult to manage tools such as razors and sharp knives and should be closely supervised when using them.

In our recent studies of aphasia and limb apraxia at Old Dominion University, we have shown that, with therapy, people with severe limb apraxia can improve their ability to use recognizable gestures to communicate. Frequently the ability to say words improves as well. In those individuals who do not increase their use of spoken words, the communication improvements as their gestures increase can be remarkable.

A physician of one of my patients, Jerry, called to say he was pleased and amazed at the improvements Jerry had made since participating in our speech therapy research. What we knew from our research was that Jerry really had not improved his speech. Rather, he had dramatically improved his ability to produce meaningful, recognizable gestures.

We had videotaped Jerry as he participated in conversations with his wife before and after his speech therapy. When we analyzed those conversations, Jerry used many more meaningful gestures to express ideas following therapy than before therapy. I suspect that Jerry’s physician had picked up on the improved communication afforded through his increased use of gestures in conversation.

Unfortunately, not all words can be expressed through gestures. Some research has shown that use of a complex non-meaningful limb movement, like reaching and turning a lever with the left hand, can also help a person recall words during speech therapy. Such a movement can be used during conversation, no matter what the topic.

It is not clear whether it is the rhythm of the movement or the ability of the movement to engage other parts of the brain to improve language recovery. But these preliminary studies suggest that complex limb movements, not just pantomimes, have the potential to enhance communication attempts in individuals with aphasia and limb apraxia. Given these findings, caregivers might encourage individuals with aphasia to make a circular motion of the left hand, as many people naturally do during speaking, to facilitate activation of words during speaking.

Many times people with aphasia want to speak but may not be willing to try gestures, at least in the beginning. One of my patients with severe aphasia was absolutely insistent that she wanted to speak and did not want to practice gestures at all. I had to work gently and diligently to get her to see that not only could gestures be an effective means to communicate some ideas, but also gestures have the potential to promote the ability to get out spoken words. Once she understood that gestures might be able to help her recover her speech, she started to incorporate them in her communication attempts.

Communication partners need to encourage individuals with aphasia to use gestures whenever possible. Partners can model the use of pantomimes to provide an example of how gestures can naturally and successfully facilitate the flow of ideas in conversation. Although not all ideas can be expressed through gesture, gestures can improve communication, particularly in those with severe aphasia who have limited abilities to express themselves through spoken words.

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.
As soon as I awoke the adrenaline started pumping like I just had a latte with a double espresso shot. You see, this would be the day I take public transportation and leave para-transit behind. I would be independent, on my own, free to go wherever and whenever I wanted! I felt like Steve McQueen in the movie “The Great Escape.”

I never understood the word para-transit. If paramilitary means kind of military, and a paralegal is kind of a lawyer, then does that make para-transit kind of transit? Instead of taking me where I want to go will they kind of take me where I want to go?

New York City’s para-transit system, Access-A-Ride, was well intentioned. The idea was to provide the disabled with low-cost transportation. However, the system almost goes out of its way to be inconvenient. This can turn regular people into para-people. Who are para-people? Para-people are the three D’s: the Disillusioned, the Demented, and the Depressed.

It’s like a Sergio Leone movie on wheels. They cut costs so much the buses were less reliable than Pat Brady’s jeep Nelly Bell on the old Roy Rogers show. It should be called carbon monoxide-a-ride. I was always surprised when I arrived at my destination alive.

I probably should be more delicate here, but it’s hard to lavish praise when you’re stranded at home and unable to get to therapy. Or when you’re stranded at therapy and unable to get home. Or when you’re stranded in Brooklyn and forced to take a “fly by night” car service with one over-worked driver who’s falling asleep at the wheel on the FDR drive!

Or … well, you get the idea.

However, there is an upside. One of my first post-stroke jokes was an Access-A-Ride joke I tried out at group. Okay, here it is: “If I was on death row, my last wish would be to take Access-A-Ride to the electric chair, because I know I’d never get there.” It sounds pretty lame now, but it killed in group even though half the people didn’t show up, which wasn’t unusual because most of us used Access-A-Ride.

Public transportation would change everything for me. Finally, no more hassles. I thought I’d start with the bus and work my way down to the subway. I figured bus people were less aggressive than subway people — mostly mothers, kids and elderly women. How bad could that be? However, I didn’t realize that the elderly women actually took control of the bus. It was like a senior wilding. They came in packs.

As the bus got crowded they’d start to talk about me so loud that everyone could hear. “Look at him. Glued to that seat. Men aren’t what they use to be. Years ago a man would get up and give a poor, elderly woman a seat. Not today. They have no shame!” I became the pariah of the bus. Dirty looks and swears were thrown in my direction. My problem wasn’t having any shame. My problem was standing up on a moving bus!

There’s an old Buddhist saying: “It’s not the destination. It’s the journey.” I guess if you’re a stroke survivor the journey will always be an adventure!
If you are unable to speak due to aphasia, and have Medicare Part B, you may be entitled to a LingraphicaExpress. The Lingraphica makes it easy to communicate with friends and family. And you can practice as much as you want. Call our toll-free number to find out if you qualify. 1-888-274-2742.

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Gene Gladhill
Stroke Survivor

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Recover more speech
and movement today!
Three and a half months after Jan’s annual mammogram, she received a bill for the full cost of the procedure. Was her health insurance plan rejecting the claim? She double-checked her coverage, and then sent an e-mail inquiry to her plan’s customer service department.

An e-mail to customer service confirmed that the plan would pay. The claim was just slow to pass through the system, causing the confusion.

“Each insurance company has a customer phone service number and, frequently, an e-mail address,” says Doris Crosby, an accounting associate with Friends Homes at Guilford, a retirement community in Greensboro, N.C. Crosby is one of the employees who handles insurance matters for the residents there. The customer service number is a good place to start when trying to get answers, she said. “Sometimes it may be an error where they processed the claim incorrectly.”

In Jan’s case, the answer was simple, and she didn’t need to worry about the plan not paying. But what happens if the plan actually rejects your claim? Under the Employee Retirement Income Security Act of 1974 (ERISA), if the claim is denied, the plan administrator is required to notify you in writing within 90 days with a detailed explanation. ERISA sets standards to protect participants and their beneficiaries for most pensions and health insurance plans in private industry.

Filing an Appeal

You can appeal and ask for a full review if the health insurance plan denies the claim. Your plan administrator must tell you how to appeal and when it must be done, usually within 60 days. The administrator may be someone who is part of the plan, your employer who provides the plan or a third party. If you don’t know, ask your employer or call the plan’s customer service number. You can also call the customer service number if you are covered by a private health insurance plan.

If you are covered by Medicare, your appeal rights are on the back of the Explanation of Medicare Benefits or Medicare Summary Notice that is mailed to you from a company that handles bills for Medicare.

“Each insurance company has certain steps, such as asking for doctors’ notes, therapy records and a letter,” Crosby says. “It varies company to company.”

Make your appeal letter as short as possible, but be sure to include all the important details, including any new information that arises later. Send the letter by certified mail. A sample letter can be found at http://info.insure.com/health/letterofappeal.html

During the appeal process, carefully document every conversation, letter and e-mail related to the appeal, and keep them organized.

Should the review take longer than 60 days, the health insurance plan must send you written notice, and a decision is
Finding a Health Insurance Advocate

If you decide to appeal a rejected health insurance claim but want an advocate to help you, where do you find one? Many states have independent review boards with the power to resolve disputes. The consumer counseling division of your state department of insurance can provide information about how your case can be reviewed.

If you are going through rehab, live in a retirement or nursing facility or have Veterans Administration benefits, an insurance advocate may be close at hand.

“We call on behalf of the resident,” says Doris Crosby of Friends Homes at Guilford in Greensboro, N.C. “We talk to the (insurance company) representative to see what the problem is.”

Another source of information that can point the way to finding an insurance advocate is:

• Families USA of Washington, D.C.
  Families USA can answer consumers’ questions about Medicaid, Medicare and private insurance. A free program locator on its Web site, organized by state, directs consumers to other agencies and organizations that can help.

One of Families USA’s stated functions is to “serve as a clearinghouse for information about the healthcare system.”

Families USA, (202) 628-3030
www.familiesusa.org

Following the Steps
Here’s a quick summary guide of the necessary steps for appealing a rejected claim:

• Read the specific reason for the denial of the claim. If you don’t understand why you have been denied, check with your health plan’s customer service.

• Your plan administrator will tell you how to submit your denied claim for a review. Be sure you keep all of your records, including the names of people you talk to and what they said.

• Mail your written appeal by certified mail to the appropriate person, being careful to include all documents and other evidence supporting the claim.

• If your appeal is rejected, you may be able to ask for another review by an independent panel. You can contact the U.S. Department of Labor concerning your rights under ERISA, or contact your state insurance department. Other options include asking an insurance advocate for help or hiring a lawyer.
Friends’ Health Connection

Friends’ Health Connection is a nonprofit organization that offers a worldwide support network linking people with the same health problems on a customized, one-to-one basis. In addition, there are educational programs that encompass a variety of health, wellness, motivation and lifestyle topics. They’ve been connecting people based on age, health problem, hobbies and interests since 1988. Family members, friends and caregivers of people with health problems are networked as well. Their goal is to enhance people’s lives through friendship, where participants can share experiences, comfort, encouragement and support. There is a fee involved.

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New Brunswick, NJ 08903
Toll-free: (800) 48-FRIEND (483-7436)
Direct: (732) 418-1811
Fax: (732) 249-9897
E-mail: info@friendshealthconnection.org

American Association on Health and Disability

The mission of the American Association on Health and Disability (AAHD) is to contribute to national, state and local efforts to prevent additional health complications in people with disabilities. Through research and advocacy they are working to identify effective intervention strategies to reduce the incidence of secondary conditions. They are also working to alleviate the health disparities between people with disabilities and the general population. AAHD was founded in response to the ADA. In 2000, AAHD modified its mission to focus on the prevention of additional health complications and secondary conditions in people with disabilities. Their Web site has many helpful links to state-specific disability information as well as access to a wide variety of information for people with disabilities. For instance, they recently published a great amount of information pertaining to sexuality and people with disabilities. A free e-newsletter is available.

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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.

Talk to your doctor about PLAVIX.
For more information, visit www.plavix.com or call 1-800-294-7068.