

this issue

Page 1

Stroke Prevention

Page 2

Donna's Diary

Joe's Locker

Page 3

Understanding Aphasia

Amazon Smile

Page 4

Marcy's Memo

Chen's Corner

Page 5

Beth's Blog

2014 Grant Recipients

Page 6

Board of Directors

Contact Us

STROKE PREVENTION GUIDELINES

About 795,000 people in the United States have a stroke every year. Of those, roughly 610,000 are first or new strokes. This prevalence makes knowing how to prevent a stroke extremely important, and these recently updated stroke prevention guidelines can help.

New guidelines for preventing stroke recommend evaluating someone's risk based on numerous factors, including:

- Cholesterol levels
- Blood pressure and age
- Eating a Mediterranean diet along with nuts
- Increased blood pressure monitoring for people with hypertension and prehypertension

The guidelines, published in the journal *Stroke* were last updated three years ago. They reiterate long-held recommendations, which include:

Overall Stroke Risk. A tool that assesses a person's risk of having a stroke within 10 years based on factors including cholesterol, blood pressure, weight, age, and whether the person has diabetes can help identify people who might not receive treatment on the basis of any one risk factor, according to the guidelines. People at a high risk of stroke should start cholesterol-lowering statins as well as make lifestyle changes.



Blood Pressure. People with high blood pressure, or hypertension, should get regular blood pressure screening and work to lower their blood pressure through lifestyle changes and medication. They should also monitor their blood pressure at home. People with prehypertension should get annual blood pressure screenings and make lifestyle changes. Overweight and obese people should lose weight to lower their blood pressure and reduce their stroke risk.

Diet. A Mediterranean diet supplemented with nuts may lower the risk of stroke. A DASH-style (Dietary Approaches to Stop Hypertension) diet, which emphasizes fruits, vegetables, low-fat dairy foods, and a reduction of saturated fat intake, is recommended to lower blood pressure. Reducing your intake of salt and increasing your intake of potassium also are recommended.



Smoking. Community-wide or statewide bans on smoking in public places can reduce the risk of stroke and heart attack. Abstain from or stop smoking. If you do smoke, a combination of counseling and drug therapy is recommended.

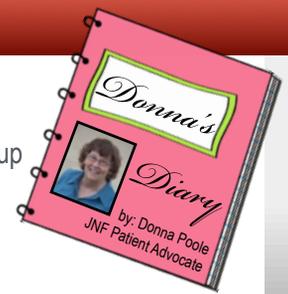
Exercise. Healthy adults should get at least 40 minutes of moderate to vigorous aerobic exercise three or four times a week. Physical activity can reduce your risk of stroke.

What does this mean for you? If you have questions about these guidelines and whether you should be doing anything differently, especially when it comes to medications, ask your doctor. Your doctor can help you figure out what's best for you based on your individual risk factors and medical history.

*stroke.org - 12/29/14

A NEW FOCUS

Bill Vaughan said, "An optimist stays up until midnight to see the New Year in. A pessimist stays up to make sure the old year leaves" Some people are more than ready to say goodbye to 2014. Many in our [online support group](#) faced difficult challenges this year. Some anticipate the New Year with hope; others look ahead with dread.



I am ready for this new year. The prospect of a new year makes me smile because there are many days ahead, and I haven't messed up any of them—yet. John and I usually begin our new year the same way. We stay at home and try to keep awake long enough to watch the Times Square Ball Drop. We kiss, we pray, and we sleep. Sometimes, before I fall asleep, I think of changes I hope to make in the coming year.

In 2015, I want a new focus. I see my ophthalmologist again in January. During my last visit, he explained why I am losing some vision; my brain now communicates too slowly with my eyes. The first thing I asked was if glasses might help. He smiled and said they would not. The problem is not with my eyes; it is with my brain. The second thing I asked was what caused the problem. Was it my aneurysm surgery, my small vessel brain disease, or my stroke? He answered, "Yes." My third question was, "Will it get worse?" He replied, "We don't know."

My one eye that constantly has blurry vision is irritating. I had double vision for several months after my stroke, and that is annoying too. Several members in our JNF [Aneurysm/AVM Support Group](#) deal with double vision, or loss of vision, caused by a rupture or by their treatment.

Some things are difficult to accept. We may not be able to change our physical eyesight, but we can adjust our emotional focus. "We can't control the wind, but we can adjust the sails." It isn't just aneurysm/AVM survivors who have troubles; everyone does. It is easy to focus on the negative. Focusing on blessings is challenging

Years ago I had a friend who mastered the art of focusing on blessings. She and her husband had four teenage boys, and barely enough money to survive, when a baby girl joined their family. When I took a gift for the baby, I saw an old, worn pan sitting in the middle of their table. I was curious. When on subsequent visits I noticed the pot was still there, I asked about it. "Oh, that's our blessing pot," my friend replied. "Every time something good happens to one of us, we write it on a piece of paper and drop it in the pot. When we get discouraged, we pull out a few blessings and read them."

A blessing pot is a tangible reminder to change focus. This year John and I decided to make our own version of a blessing pot. We plan to write down good things that happen and put the slips of paper in a Mason jar. Next year on New Year's Eve our stay-at-home party will have a bit more zing. As we struggle to stay awake to watch the ball drop, we will pull papers from the jar and read the wonderful things that happened in 2015. If you choose to make a blessing jar, please don't forget to include The Joe Niekro Foundation on one of those slips of paper. Happy New Year! I wish for you a year full of blessings. Don't forget to notice them!

JOE'S LOCKER

A very special thank you to those that supported Joe's Locker this past holiday. Your gifts put smiles on many faces this past Christmas and we are incredibly grateful for your donation. Joe's Locker supports children with aneurysms, AVMs and/or hemorrhagic strokes. Here are just a few of the families that your donation helped. Left to right: Avery Rouhoff, Justin King and Shannon Schey

SUPPORTERS

Suzanne Antonelli	David Migliore
Mary Bratt	Madelon Peterson
Robert Crotty	Donna and Jim Poole
Art and Betty Howe	Aneeta Dayal Valdez
Judy Hudek	



If you are interested in having us help you get a support group started, contact

Kimberly@joeniekrofoundation.org

WHAT IS APHASIA?



Many brain injury survivors likely experience some form of aphasia. Aphasia is a neurological disorder caused by damage to the portions of the brain that are responsible for language. Primary signs of the disorder include difficulty in expressing oneself when speaking, trouble understanding speech, and difficulty with reading and writing. Aphasia is not a disease, but a symptom of brain damage. Most commonly seen in adults who have suffered a stroke, aphasia can also result from a brain tumor, infection, head injury, or dementia that damages the brain. It is estimated that about one million people in the United States are currently suffering from aphasia. The type and severity of language dysfunction depends on the precise location and extent of the damaged brain tissue.

There are two broad categories of aphasia: *fluent* and *non-fluent*.

Damage to the temporal lobe (the side portion) of the brain may result in a fluent aphasia called Wernicke's aphasia. In most people, the damage occurs in the left temporal lobe, although it can result from damage to the right lobe as well. People with Wernicke's aphasia may speak in long sentences that have no meaning, add unnecessary words, and even create made-up words. They usually have greater difficulty understanding speech, and are often unaware of their mistakes.

A type of non-fluent aphasia is Broca's aphasia. People with Broca's aphasia have damage to the frontal lobe of the brain. They frequently speak in short phrases that make sense but are produced with great effort. People with Broca's aphasia typically understand the speech of others fairly well. They are often aware of their difficulties and can become easily frustrated. People with this aphasia often have right-sided weakness or paralysis of the arm and leg because the frontal lobe is also important for motor movements.

In some instances, an individual will completely recover from aphasia without treatment. In most cases, however, language therapy should begin as soon as possible and be tailored to the individual needs of the patient. Rehabilitation with a speech pathologist involves extensive exercises in which patients read, write, follow directions, and repeat what they hear. Computer-aided therapy may supplement standard language therapy.

It is also imperative that family members help with the rehabilitation by simplifying their own language, repeating the content of words to clarify meaning, minimizing distractions, avoiding correcting the person's speech and allowing the person plenty of time to talk. Just these few steps will not only help the patient, but give them greater confidence to keep moving forward in their recovery.

YOU SHOP...AMAZON GIVES!



Shop Now

ATTENTION ONLINE SHOPPERS! If you are like the millions of Americans who shop on Amazon, why not make your dollars count?

AmazonSmile is a simple and automatic way for you to support The Joe Niekro Foundation every time you shop, at no cost to you. The website is operated by Amazon so you'll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com. The difference is that when you shop on AmazonSmile (smile.amazon.com) 0.5% of the purchase price is donated to JNF.

On your first visit to AmazonSmile, select The Joe Niekro Foundation as your donation recipient before you begin shopping. From there on, your selection is remembered and then every eligible purchase you make on AmazonSmile will result in a donation to The Joe Niekro Foundation. What are you waiting for???? Go shopping!!!!

If you are interested in having us help you get a support group started, contact

Kimberly@joeniekrofoundation.org.



LETTING GO OF THE PAST

by: Marcy Mudd
BA Survivor Parent



Ready or not 2015 is here. Traditionally this means making a new year's resolution trying something new, and the opportunity to make a fresh start. But sometimes before you can say hello to something new, you must let go of something old.

I knew from the [JNF Facebook support group](#) that many aneurysm survivors lose friends during recovery. Friends move on because they just can't deal with the changes in you after your aneurysm. Our rehab therapists also warned me about this and I prayed of course that it wouldn't happen to Madeline. But it did. I watched as her friends stopped texting, took her out of their group messages, and then eventually stopped including her altogether. It absolutely shattered my heart.

I can plaster her wall with positive quotes and text her funny pictures but I can't take away the heartache of a lost best friend. I can tell her that it isn't her fault. I can tell her that someday she will find new friends, but I can't fill that huge gaping hole in her heart where L... was. My words were not enough. I didn't know how else to help her until her therapist recommended that she write L... a letter. A letter that was never meant to be sent. Pour out your heart and your feelings on paper and then let it go. Send it up in a balloon, light it with a match, or throw it in the river. Find a way to symbolically let go of the pain.

Our therapist was adamant that Madeline needed to let go of the past before she could move forward. This hit me like a ton of bricks. I needed to write my own letter too. L... called me her second mom and she spent many many hours at our house through the years. I missed her sassiness and spunk and our house was quiet without her. I am an adult and I realize she is only 17 but realization doesn't take your pain away, you still need to deal with it.

The end of 2014 was the perfect time to face our pain and write our letters. We each wrote our own letter and then sealed them in an envelope. I wanted to throw mine into the river and watch it float away, but I also didn't want to add to water pollution and Madeline really wanted to burn them. So on January 1, 2015 we stood in our driveway and had our letting go ceremony. No tears were shed that day. Instead, we cheered and said goodbye to the past. Now bring on the new year!

TRANSPARENCY IS EASIER SAID THAN DONE

by: JNF Medical Advisory Board Member,
Michael Chen, M.D.

Mrs. Levitt and Dubner point out in their best-seller, "Freakonomics: A Rogue Economist Explores the Hidden Side of Everything." There is usually more to something than what's obvious, and they use everything from real estate agents to sumo wrestlers to ice hockey players to illustrate this.

Similarly the doctor-patient relationship may be more complicated than most patients would care to or like to believe. The purpose of this month's column is not to point fingers, assign blame or create fear. I would simply like to point out an issue doctors face that may quietly influence the care you receive as a patient. Transparency is easier said than done. But I think patients might be better served by being aware of these issues, and hopefully have an appropriate amount of skepticism when seeing their physicians. When interacting with, or researching your physician, pay attention to some details that may shed light on any potential conflicts of interest that may or may not be complicating your care.

See if you can get a sense of the incentive structure your physician works under. I know, sounds too complicated and personal than possible. But there are a few general rules you might be able to use. Traditionally, surgical or procedural practices have incentive structures that disproportionately reward the performance of procedures compared to conservative medical management options.

Some physicians, particularly in private practices, may have equity and a potential to collect revenue from the services they provide outside of their direct medical care, such as imaging or ancillary testing. Other physicians are involved to varying degrees, in the development of novel drugs or devices, and may have additional reasons to offer them to patients. Yet other physicians are offered fixed salaries irrespective of how many procedures they decide to do. Physicians who do not perform procedures may be biased towards more conservative options, and have higher amounts of fear when discussing invasive procedures.

Every physician probably responds a little different to each of these influences. What I think is important for the patient to realize is that these conflicts of interests exist, are not usually made explicit, do not affect all physicians the same way, but could potentially influence your health care. We all know that unnecessary medical procedures exist in our current health care system. The extent to which these conflicts of interest contribute to the prevalence of unnecessary procedures is difficult to generalize. Being aware of these issues is a good first step. If your intuition suggests that conflicting interests may be complicating your physician's care of your brain aneurysm, it might be worth taking pause and obtaining a second opinion.

CHEN'S
O
R
N
E
R



Need Support??? Visit the JNF [Online Support Group](#) for survivors and caregivers



It is a new year, and while I didn't make any resolutions, I do have some goals for this year. Awareness is one of my goals this year. To increase education and awareness of aneurysms and AVM's. As much as our [online support group](#) has grown, there are still so many that we haven't reached.

It doesn't carry the stigma that it did so many years ago, yet a large percentage of people don't know what they are, until it happens to them or someone close to them. Look to the person on your left, now look to the person on your right. Do you know that the incidence of reported ruptured aneurysms is about 10 in every 100,000 persons per year (about 30,000 individuals per year in the U.S.). It can happen to anyone!

I was shopping in a local grocery store last year, and a friend of my daughter was the cashier. When she realized who I was she said "oh, you look great after your lobotomy and your hair grew back!". Really? I had no words at that point. I wondered how to even explain it.

We have had an influx of new members, and often we will see the statement that their family doesn't understand. It is difficult for another to empathize if they do not grasp the definition.

While I am delighted by hearing "me too" from so many members because it means that they are not alone, I am also saddened. For me it means that someone else has suffered from this condition.

Can you explain what a [brain aneurysm](#) or an [AVM](#) is? I didn't understand it until I lived through it. So, with the help of other survivors, neurosurgeons, medical staff, hospitals, friends and loved ones, we will strive to educate and do our part to make awareness a priority! I am pretty excited, and hope that you each make it one of your goals too!

We have online support groups for [survivors and caretakers](#), a [parents page](#) and a [teen room](#), and so many support groups that are established and new ones starting up! So no one has to walk alone. Make "me too" your tagline and get involved!

And it is a fresh year, and as my Mom used to say "Today is the first day of the rest of your life"- Make it a great one!

JNF GIVES \$90,000 IN RESEARCH GRANTS

JNF is pleased to announce the following [research grant](#) recipients:



Barrow Neurological Institute - \$50,000 Phoenix, AZ

Dr. Joseph Zabramski and Dr. Yashar Kalani
Project Title: *Deconstructing the vascular tangle-A molecular biopsy of cerebral arteriovenous malformations*

SNIS Foundation - \$20,000

The Joe Niekro Research Fund

Project Title: Now accepting applications for this seed funding
[Click here](#) to download the application

University of Michigan - \$20,000

Ann Arbor, MI

Dr. Aditya Pandey

Project Title: *Intraventricular injection of noncellular cerebrospinal fluid from subarachnoid hemorrhage patient leads to ventricular enlargement and periventricular injury*



JNF Board Members (shown here from left to right) Bill Michels, Kimberly Chapman, JNF Founder Natalie Niekro, Gary Simms and Linda Michels present Barrow Neurological Institute and Drs. Yashar Kalani and Joseph Zabramski with a \$50,000 research grant

Have you gotten your awareness band yet? [Click here](#) to start sporting your support of brain aneurysm, AVM and hemorrhagic stroke research.



SURVIVOR NETWORK
UNITED FOR CHANGE
PATIENT ADVOCACY
PUBLIC AWARENESS
OUTREACH & EDUCATION
RESEARCH FUNDING
TEAMWORK

“Knuckling Up for Aneurysm, AVM and Hemorrhagic Stroke Research”

Designed by Carol Stout

Board of Directors

Executive Director -
Natalie Niekro
Chairman of the Board –
Gary Simms
Treasurer - Larry Simon
Suzanne Antonelli
Dave Bergman
Kimberly Chapman
Bill Michels
Linda Michels

Medical Advisory Board

Felipe Albuquerque, M.D.
Gavin Britz, M.D., MPH
Robert D. Brown, Jr, M.D., MPH
Michael Chen, M.D.
Orlando Diaz, M.D.
Donald Frei, M.D.
Robert G. Grossman, M.D.
Hani Haykal, M.D.
Joshua Hirsch, M.D.
Richard P. Klucznik, M.D.
Italo Linfante, M.D.
Demetrius Lopes, M.D.
Cameron McDougall, M.D.
Kristin M. Mascotti, M.D.
Philip Meyers, M.D.
Aditya S. Pandey, M.D.
Aman Patel, M.D.
Peter Rasmussen, M.D.
Robert F. Spetzler, M.D.
Nedaa Skeik, M.D.
Michael Ulrich, M.D.
Ronald E. Woosley, M.D.
Joseph Zabramski, M.D.
Y. Jonathan Zhang, M.D.



Thank you for your support!

The Joe Niekro Foundation was established in 2008 in honor of the founder's father, Joe Niekro, who lost his life from a sudden ruptured brain aneurysm on October 27, 2006. The astonishing lack of public awareness and under-support of research of such a widespread and often fatal condition led to the launch of a crusade to educate and encourage awareness about cerebral disorders. The Joe Niekro Foundation is committed to supporting patients and families, research, treatment and awareness of brain aneurysms, AVMs and hemorrhagic strokes. We provide education on the risk factors, causes and treatments of these conditions while funding the advancement of neurological research.

Every donation matters - every dollar counts. The Joe Niekro Foundation is a registered 501 (c)3 which means your donations are 100% tax deductible.

"The Joe Niekro Foundation isn't a clinically trained organization and all therapy regimens brought before the support group are informational in purpose only and do not represent an endorsement or recommendation of any kind."

[DONATE TODAY](#)



[Click here to subscribe to the Knuckle-Up Newsletter](#)

[Join our Patient Support Group page](#) • [Join our Parent Support Page](#)