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WHAT IS AN AVM?

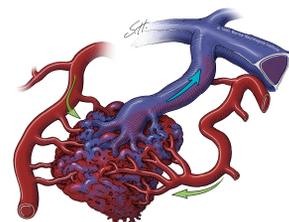
An **arteriovenous malformation (AVM)** is a complex tangle of abnormal arteries and veins linked by one or more direct connections called fistulas or shuts. This tangle of abnormal arteries and veins is referred to as a nidus. Normally, as the high-pressure arterial blood is pumped through a capillary bed there is a gradual decrease in blood pressure before reaching the venous system. With an AVM, the capillary bed is absent and the high-pressure arterial blood bypasses normal brain tissue and is pumped directly into the normally low-pressure venous system.

There is typically high blood flow through the nidus of the AVM, but it is a cause or effect of the abnormal blood vessels, or both. One thought is that the high-pressure blood from the arterial system gravitates towards the path of least resistance. Another thought is that the AVM itself recruits blood vessels.

Ultimately, the arterial blood rushes through the AVM, instead of working through available capillary beds, which feed the surrounding brain tissue, increasing blood flow through the nidus. This re-direction of the arterial blood away from the brain tissue and through the AVM is referred to as shunting.

Over time, the high blood flow and shunting of high-pressure arterial blood through the AVM causes the feeder arteries and veins making up the AVM to dilate or expand. This dilation weakens veins making them susceptible to hemorrhage and the arteries susceptible to aneurysms.

AVMs are thought to be congenital, arising from developmental derangements at the embryonic stage of vessel formation, at the fetal stage. However, this has never been clearly established and they may arise after birth. AVMs are usually single, except when associated with hereditary hemorrhagic telangiectasia (HHT).



- AVMs occur in <1% of the population, about 1 in every 200-500 people and their cause is unknown
- AVMs are thought to be due to abnormal development of blood vessels in utero and may be present since birth
- The average age of an AVM rupture is 17 years old
- About 12% of people with an AVM experience symptoms
- Each year, 2-4% of people with an AVM have a hemorrhage
- About 2% of hemorrhagic strokes are related to an AVM
- More than 50% of people with an AVM will have an intracranial hemorrhage

Symptoms May Include

- Seizures
- Headache
- Stroke-like symptoms (weakness, paralysis, numbness, tingling, vision, balance and hearing problems)
- Bleeding

How Are They Diagnosed?

Most AVMs are detected with either a computed tomography (CT) brain scan, a magnetic resonance imaging (MRI) brain scan or a cerebral angiogram.

Treatment is offered to try to prevent bleeding from the AVM. Your doctor will recommend the best treatment for you and this will be determined by the size and the location of your AVM.

To read more about AVMs, [click here](#)

INFLUENCED BY BRITTANY

by: Donna Poole - JNF Patient Advocate



Donna's Diary,

The media labels people born between 1979 and 1994 the "Entitlement Generation;" the group of people who believe the world owes them something. Brittany La Fontaine shatters that label. Brittany caught my attention when she posted an inspiring message in our [Young Adult Brain Aneurysm/AVM Survivor's Group](#). She asked, "Have you ever just looked up and felt how blessed you are for being able to do chores or show your own emotions, for being able to take a shower, or brush your own teeth?"

Brittany was at work when she had her first seizure. Soon she was having ten seizures a day. Doctors discovered Brittany had an [AVM](#), located in the cerebellar region, close to her brainstem. In 2015, Brittany underwent embolization and a craniotomy. Brittany shared, "At just twenty-two years old, I learned what it was like to lose everything. I suffered two strokes, and they found a ruptured aneurysm and a

second AVM. I relearned to walk, talk, eat, breath, shower and all the basics. I wasn't able to move my fingers. I told my doctors before the end of the year, I will be doing a 5k." I still face some difficulties. I'm half blind; I can't see unless I shut my left eye. I suffer from PTSD which keeps me from getting good sleep. I walk "drunk" with no balance/coordination. I can't speak certain words or letters. I have to take 18 pills a day. I still have seizures every few months. So I know what it's like to lose everything you once knew. I know the pain, the loss. But I believe I am here for a reason. I want nothing more than to inspire others. I am beyond lucky to be able to do what I can now. I guess the determination I have and desire to inspire is what keeps me going."

On July 4th, Brittany fulfilled her promise of running a 5K. "I can't even begin to describe the feeling. The pain was worth it. I will never be that person again. I will never take advantage of my ability to walk and jog again."



KNUCKLE BALL...A PITCH FOR LIFE COMES TO PHOENIX

SAVE THE DATE

The Sixth Annual
KNUCKLE BALL
A Pitch for Life

Benefiting brain aneurysm, AVM and hemorrhagic stroke research and awareness at Barrow Neurological Institute

SATURDAY, OCTOBER 17th, 2015

Emcee:
TAMALA JONES
Actress/Brain Aneurysm Survivor

All tables hosted by MLB, NBA and NFL All-Stars

6:00pm / JW Marriott Desert Ridge - Phoenix
Black Tie

HONORING

Joseph Zabramski, MD
Joe Niekro Medical Humanitarian of the Year

Ms. Petrice Schuttler
Joe Niekro Humanitarian of the Year

JOE NIEKRO
foundation

www.joeniecrofoundation.com/events/knuckleball

On **October 17th, 2015**, athletes from all over the country will come together, in association with The Joe Niekro Foundation and The Society of NeuroInterventional Surgery Foundation, to support brain aneurysm, AVM and hemorrhagic stroke research and awareness, for the **6th Annual Knuckle Ball...A Pitch for Life** at the JW Marriott Resort in Phoenix, AZ.

The black-tie evening, hosted by actress and brain aneurysm survivor, Tamala Jones, will feature a festive reception, silent auction, formal dinner, event program and LIVE auction (plus a few surprises in between). The gala, coordinated by [Teonna's Floral Design and Studio Production](#) is the foundation's biggest fundraising event of the year and pays tribute to those that have lost their lives to these fatal conditions, while honoring the survivors who are fighting everyday to recover.

We are proud to announce that **Petrice "T.C." Schuttler will be honored as the Joe Niekro Humanitarian of the Year** for her outstanding commitment and contributions to the Phoenix community. Petrice has devoted her life to improving the lives of others and we are incredibly excited to present her with this year's award. The **Joe Niekro Foundation Medical Humanitarian of the Year** recipient, **Joseph Zabramski, MD** will be recognized for his research and continued advancements and treatment studies of brain aneurysms, AVMs and hemorrhagic strokes.

Please join us as a for this unforgettable event. [Click here](#) for tickets and more information.

Every donation matters and every dollar counts. Help [support our mission](#) and make a difference today!

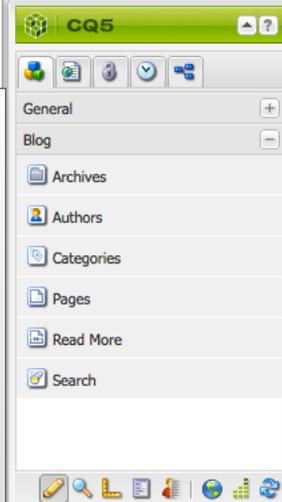
JUST SAY THANK YOU

When was the last time you watched the sunrise and said thank you? The last time you were just happy to be alive? Most people become complacent about life. We take for granted the small gifts we are given on a day to day basis but remember the big ones. I can speak as a survivor with great confidence that other survivors can agree with, we don't take life for granted. When our lives changed on that fateful day in our life, we no longer remained complacent.

On July 14, 2010, I had made my peace with my life, and I placed my life in the hands of my Wizard. When I remember opening my eyes and there was a coherence to my abilities, I thanked God, I thanked my neurosurgeon, I thanked my family, my friends, my medical "entourage".

But on the 21st of July that year, I watched the sun come up. With my bald head, with my coffee in one hand and my thankfulness in the other, I was relieved, happy, and gracious.

I work in an emergency room, and so I know first hand that life can change in a second. Never are we guaranteed a happily ever after. But as this anniversary date approaches I know that I will watch the sun rise and be full of joy. Because I have the ability, the opportunity and the chance to make sure I appreciate all of my gifts, whether they are wanted or not, and all of my lessons, no matter good or bad. I'd say that for me, I beat the odds that day in 2010. And maybe, just maybe, it's my sign that I have work yet to do, people still to thank, and some educating to be had! In the meantime, have some coffee, watch the sun come up and live your life with a smile. Because we don't know where tomorrow leads us. And you know had I not made it, I'm not certain I would have been happy with how it ended. I'm doing my best to change that, every single day, every single anniversary, every single second!



"STROKES FOR STROKES"

A Golf Outing Benefiting the Joe Niekrö Foundation™
 "Knuckling Up for Aneurysm, AVM and Hemorrhagic Stroke Research"
 The Club at Flying Horse ~ Colorado Springs, Colorado

Monday, August 24th, 2015

Join us to promote awareness and raise money for aneurysm, AVM and hemorrhagic stroke research by participating in this benefit outing.

Registration Opens: May 20th, 2015
 Registration Deadline: August 10th, 2015

Registration may be paid through the website
 OR mailed...along with registration form:

Make checks payable to:
 Joe Niekrö Foundation
 c/o Lisa Simms

2204 Rocking Horse Ct.
 Colorado Springs, CO 80921
 **Attendance will be confirmed

Schedule of Events:

7:30am - 9:00am - Registration and continental breakfast
 7:30am - 3:00pm - Beverage cart available
 9:00am - 1:30pm - Golf
 1:30pm - 3:00pm - Lunch/Reception
 Entry Procedure: Register on the website or with Lisa
 Entry Deadline: August 10th, 2015

ALL registrations must be completed and paid in full to be accepted.
 Participation is limited.

(No refunds will be given for cancellations after August 15th, 2015)

Please contact Lisa Simms lisasimms1@gmail.com or 248-444-1936 for questions or further information.

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\$250 per player
 \$900 per foursome

Hall of Fame: \$2000

- 18 hole Foursome with
 Goose Gossage
 - Business Logo on cart
 - (4) Goose Gossage
 autographed baseballs

Knuckle Ball: \$1500

- 18 hole Foursome
 w/cart
 - Business Logo on cart
 - (4) Goose Gossage
 autographed baseballs

No-Hitter: \$1250

- 18 hole Foursome
 w/cart
 - Business Logo on cart

STROKES FOR STROKES

Join us Monday, August 24th at the private 18-hole Tom Weiskopf Signature Course, Flying Horse Golf and Country Club in Colorado Springs for the 1st Annual [Strokes for Strokes](#) Golf Tournament.

- 18 hole golf scramble
- Continental breakfast
- "Ballpark" buffet luncheon
- Putting contest
- Hole-In-One contest
- Silent/Live Auction
- Autographed "SWAG" from Hall of Fame pitcher, Goose Gossage (designated sponsorship levels)

Entry Deadline – August 10th, 2015. All registrations must be completed and paid in full to be accepted. No refunds will be given after August 15th. For questions or sponsorships, email lisasimms1@gmail.com.

[Download Registration Form](#)

[Click here](#) to see a complete list of our support group locations

MODEL SEARCH WINNERS ANNOUNCED

After reviewing thousands of submissions and hearing the incredibly passionate stories, we are thrilled to announce the winners of the [Brain Aneurysm Survivor Model Search](#). You certainly didn't make it easy to choose as each story was more moving than the next.

Congratulations to these seven beautiful faces that will be representing survivors across America! Our goal is to put a face on [brain aneurysms](#) and [AVMs](#) and help remove the stigma associated with brain illness while encouraging survivors to share their experiences and help save lives. Each and every one of you who entered is a winner and we thank you for sharing your stories.



Monica Sauls



Cindy Mann



Dulce Isler



Felicia Harrison



Jaime Moore



Melanie Taylor



Sandra Marante

[Click here](#) to read their amazing stories

SHOPPING WITH A CAUSE!

Attention all Amazon.com shoppers!!!! Shop [Amazon Smile](#) and your purchases will help support The Joe Niekro Foundation. When first visiting www.smile.amazon.com you will be prompted to select a charitable organization. Simply type The Joe Niekro Foundation in as your charity of choice and then shop away!

Eligible purchases at AmazonSmile will result in a 0.5% donation of the purchase price to The JNF. Thank you for your support!

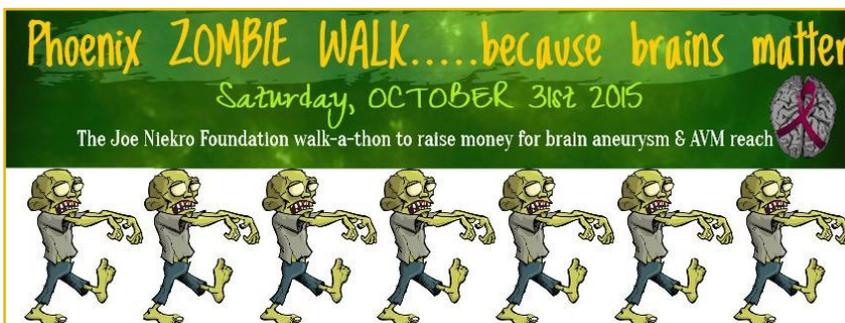
Shop at AmazonSmile
and Amazon will make a donation to:
The Joe Niekro Foundation

[Get started](#)

amazonsmile

WALK LIKE A ZOMBIE????

What are your plans for Halloween 2015? Well, look no further, we've got some fun for you...The [Phoenix Zombie Walk](#)...Because Brains Matter! Celebrate this October 31st as you walk in honor, memory and support brain aneurysm, AVM and hemorrhagic stroke victims across the country. Indian Steele Park will host the walkers, who will be entertained by the spirit of Halloween. Come in costume, or just come as yourself – either way...WE WANT YOU!



Last year's walk-a-thon saw over 160 walkers and raised nearly \$10,000...but its our goal to double this year's participation and we know we can do it with your help! Funds will be used to support [brain aneurysm](#), [AVM](#) and [stroke](#) research, projects, and patient support services in the Phoenix community.

Join us as we Support the Fighters, Admire the Survivors, Honor the Taken and Vow to Never Ever Give up Hope.

ANNIE VS. ANEURYSM!!!...WHAT'S IN A NAME?

by: Marcy Mudd - Parent of a BA Survivor



July 3, 2015, is the two-year anniversary of Madeline's **aneurysm** rupture. I have typed the word aneurysm so many times you would think I could type it in my sleep. But no, it still doesn't flow on my keyboard. Right off the bat some people referred to her rupture as an "annie." That really bothered me. I said I would never reduce it to a nickname. Ruptured aneurysms are horrible, horrible, life changing events. It is disrespectful to use a nickname for something so powerful. I remember when I first joined the **JNF support group** there was a discussion about this. Survivors felt passionate each way. I didn't join that discussion. I am not a survivor and it just didn't feel right to give my opinion, although I felt very passionate about respecting the word aneurysm.

Fast-forward to July 3rd, her two-year anniversary. I have changed and grown immensely in the past year. There are two reasons for this. One, I have watched my daughter not just survive, but THRIVE! She has taken every heartache, every struggle and every battle and turned them into positives by sharing her story and trying to help other young survivors. She wears her scars proudly on her head, never trying to cover them. The second reason I have grown so much this year is my involvement with our **JNF support groups**. Every day I read about survivors who don't ever give up. Despite their deficits they are on our support pages every day trying to help each other. It humbles me to read their stories.

Annie vs aneurysm- what *is* in a name? And have I changed my opinion? Yes I have! I can't put my finger on one specific event that led to it, perhaps just my growth over the year? But now I think that "annie" is the perfect word. "Annie" doesn't minimize what an aneurysm rupture can do to your body and your soul. YOU have the power to decide what a rupture does to YOU. Do you just survive or do you thrive? For me, the word "annie" now means taking **back** your power. For me there is just something positive about saying the word "annie." I am not afraid of it anymore. "Annie" no longer feels like it is minimizing the aneurysm. However, I am not the survivor and out of respect to our survivors I would never use the word on our pages if it makes them uncomfortable. My role is to support our survivors. I will continue to use the word aneurysm on our support pages because it is all about our warriors. But for my journey and my path I have turned a corner and in my head and in my heart it will now be "annie." #TakeThatAneurysm!

ROAD TO RECOVERY

Support is a vital part of recovery and many of America's hospitals do not offer ongoing support and education after a patient is discharged. This means that thousands of individuals are left with unanswered questions, no support, guidance or continued care outside of the basics allowed through their insurance. It is our goal to bridge this gap and encourage collaboration across the country, resulting in more comprehensive support programs for survivors and their families. To help solve this barrier, we have created "Road to Recovery," a guide to help you through the recovery process, addressing issues such as depression, denial, social reintegration, questions to ask your doctor, coping with disabilities, nutritional brainpower, exercising your brain and much more. Participants in our support groups receive a packet upon their first visit, and several hospitals throughout the country and now handing out this information to their patients to let them know support is available. If you would like more information on obtaining a Road to Recovery Booklet, please contact kimberly@joenikrofoundation.org.

SURVIVOR NETWORK
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"Committed to supporting patients and aiding in the research, treatment and prevention of brain aneurysms, AVMs and hemorrhagic strokes."

JOIN THE JNF MISSION - MAKE A DIFFERENCE TODAY!

ABSOLUTELY! KATY!

by: Vicky Russell - Stryker Neurovascular

At Stryker, my job is to educate the community, EMS and physicians about recognizing stroke and the many treatment options available. There are certain hospitals called "Comprehensive Stroke Centers" that have the most treatment options and it is important to know when to go straight to one or when to transfer a patient there.

This story hits close to home for me. Nicola and Kirsten are two of my best girlfriends from junior high. All three of us are in the age bracket to have a ruptured [brain aneurysm](#) and we are women, which puts us at an increased risk compared to men.

Back in March, I had just returned from "brain training," when I got a message from a close friend letting me know that Nicola had just been hospitalized due to a ruptured brain aneurysm. Nicola who suffers from migraines, was under tremendous stress and working on planning a wedding for a client when suddenly everything got blurry. She said "my head" and the next thing she knew she was on the ground. Her handyman, who was nearby called 911. This headache was the worst headache of her life and she had severe nausea. EMS arrived and took her to Conroe Regional in Conroe, TX. They immediately did a non-contrast CT and determined a bleed in her brain. Because they did not have the capabilities to treat her beyond imaging, they needed to transfer her to a comprehensive capable hospital. It was now late in the afternoon on a Friday and she was immediately transferred to Methodist Hospital. Surgery was performed the next morning by Dr. Richard Klucznik, an interventional neuroradiologist. Before she was put under, Nicola remembered pleading with the staff to make sure she survived for her three children, who had lost their father a few years earlier. Nicola was at Methodist for three weeks after surgery. Following her procedure she awoke neurologically normal.

Just as Nicola was being released from the hospital, I learned that my dear classmate Kirsten had also experienced a ruptured aneurysm just two months earlier. Kirsten's began as an excruciating headache that had been going on for nine days. She could also hear noise in her head and suddenly became extremely nauseated. She later called 911 and told them "I think I'm having a stroke." Still coherent, EMS felt her symptoms were due to the flu. At that point, she felt embarrassed, so stayed home.

At 46, being a female, having nausea and a sudden, severe headache, other possibilities should have been considered like [subarachnoid hemorrhage](#). Later Kirsten went to a local urgent care clinic to get Tamaflu and a nasal swab. Her swab came back negative and she was told to wait 14 days before she would feel better. Nine days later, she felt another sudden, severe headache in front of her mom, and she was taken to Houston Methodist West Hospital in Katy, and a CT determined she had subarachnoid hemorrhage. She was then transferred to Memorial Hermann in the medical center.

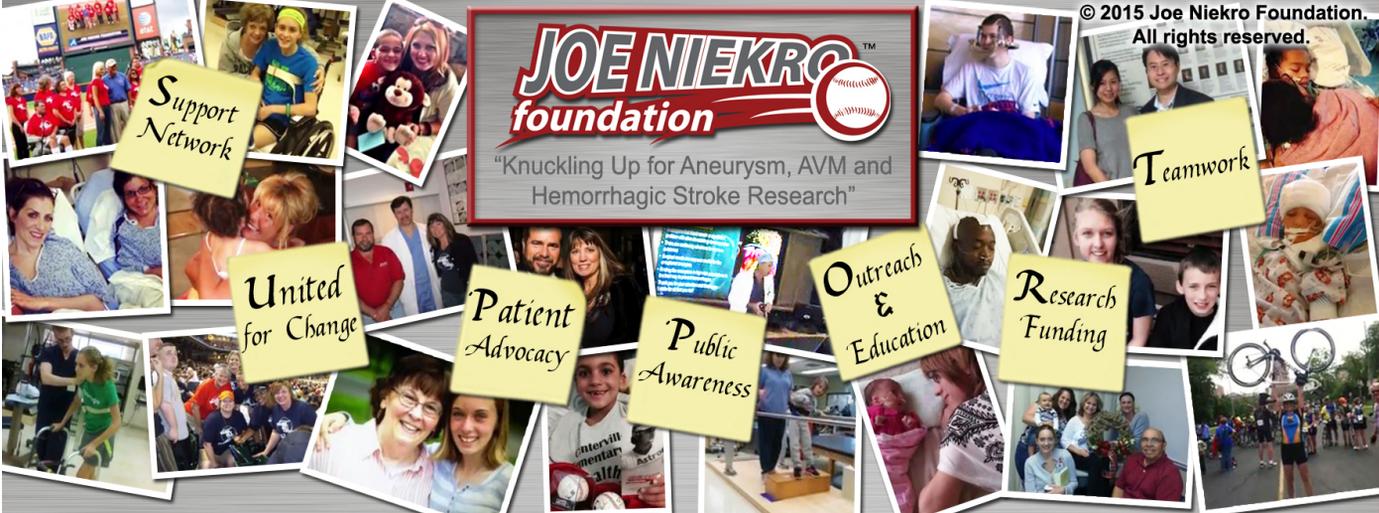
Dr. Mark Dannenbaum, a vascular and endovascular neurosurgeon coiled her ruptured aneurysm the next morning. They also discovered that she had three other aneurysms that had not ruptured and needed treatment. Kirsten was lucky that after all the delays she had no complications or deficits. In April she had her second aneurysm coiled and while I am writing this, she is having her third one [clipped](#). Dr. Dannenbaum recommends that anyone with concerns over diagnosis, management, or even simple questions should reach out to a physician at a comprehensive stroke center for specific advice, and never be ashamed to seek evaluation in emergency department.

Dr. Klucznik, stated that if you are having a sudden onset "the worst headache of your life," to call 911. It's the kind of headache that comes on immediately. Patients need to go to an ER at a stroke center for a CT and evaluation by specialists who offer both coiling and clipping as opposed to an urgent care center.

The fact that the three of us grew up together and both of their ruptured aneurysms occurred a couple of months apart and my job is to educate the community about this, we felt it was imperative to do something to make a difference. I hope their story makes you aware of how precious life is and to recognize the signs and symptoms of this kind of stroke.



Brain Aneurysm Survivors, Nicola Weems (left) and Kirsten Roll Kosack



JNF Thank you for your support!

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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 regiments brought before the support group are informational in purpose only and do not represent an endorsement or recommendation of any kind."

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