

JNF AVM FUNDED GENETIC STUDY BEGINS

The Joe Niekro Foundation recently granted St. Joseph's Hospital/Barrow Neurological Institute the initial seed grant for their research study - *Genetics of Arteriovenous Malformations*. We are excited to announce that the study has begun enrollment and we are currently recruiting patients. The goal of this study is to identify genetic alterations resulting in the development of arteriovenous malformation (AVM) in the central nervous system.

Detailed Description:

The study will include AVM patients and members of their nuclear family. All patients will donate a sample of saliva (5 mL) or blood (10 mL). Basic demographic and clinical parameters will be collected, including ethnicity, age at first presentation, symptoms at presentation, history of subsequent symptoms, treatment history, Spetzler-Martin AVM grade, medication history, and other pertinent medical information. In patients undergoing AVM resection, a small sample of the AVM will be collected for concurrent genomic analysis. Family members will donate saliva (5mL) and document their relationship to the patient (i.e., parent, sibling, child, etc.). Nucleic acids will be isolated from the saliva/blood samples, and genetic sequencing will be carried out. When a surgical sample of the AVM is available, nucleic acids will be obtained and transcriptome profiling will be performed. Identification of genetic alterations common to patients with AVM and not present in samples from parents and siblings will greatly aid in identification of pathways associated with AVM formation. Candidate sequences will be chosen by differential expression ($p < 0.05$) and fold-changes. Once identified, mechanisms for the rapid detection of marker sequences will be developed and their predictive value tested in future collections.

Eligibility:

Inclusion Criteria:

- Age between 6 and 60 years inclusive
- Diagnosis of AVM or nuclear family member of a patient with AVM
- Grants access to saliva, blood, and/or tissue

Exclusion Criteria:

- Age less than 6 years or greater than 61 years
- Nuclear family members who do not share the same parents as the AVM patient

Study Population:

Male and female persons with AVM and their immediate family members

Contacts and Locations:

Choosing to participate in a study is an important personal decision. Talk with your doctor and family members or friends about deciding to join a study. To learn more about this study, you or your doctor may contact the study research staff using the Contacts provided below. For general information, see [Learn About Clinical Studies](#).

If you are interested in participating in this study, please contact:

Joseph Zabramski, MD
Yashar Kalani, MD, PhD
602-406-3181

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SEEING TEARS THROUGH TEARS

Donna's Diary

by: Donna Poole - JNF Patient Advocate



Dear Diary,

Survivors' struggles are real. Calendars fill up with fun things like neurosurgery and neurology appointments, angiograms, physical therapy, CT and CTA scans. We matter, but we aren't the only ones who matter.

Physical or emotional stress can make us either more sensitive or more oblivious to the needs of others. When our own struggles overwhelm us we can get tunnel vision. We may forget to look around and see who else is hurting, who else needs help. In our desperate need to be understood, we must remember to understand. In our crying need for help, we can't forget to give help. If we aren't careful, our struggles can make us selfish.

So many need help, even if it's just someone to listen and care. We live in a beautiful world, but, at times, it's also a brutal world.

In our small, rural community many are hurting. Yesterday our friend's dad had a fatal accident. He was operating his tractor when a sudden storm hit causing the tractor to roll into a ravine.

A little 18 month old girl from our area wandered into the road and was killed by a truck driver who had taken his eyes off the road for a split second. Our son was first medical responder on the scene.

The family of the toddler knew the truck driver's remorse; and in their own hurt, they recognized his hurt. Through their own tears, they saw his tears. The family then begged the District Attorney to drop any charges against the driver, of which he did.

Our tears can blind us to the tears of others, or they can make us tenderer, more aware, more generous with our love and help. The choice is ours.

WORLD SERIES Legends

WILLIE HORTON
AL KALINE
MICKEY LOLICH
JACK MORRIS
ALAN TRAMMELL
LOU WHITAKER

Rick Leach, Scott Lusader, Dan Petry, Dave Rozema, Pat Sheridan, Jon Warden, Pio DiSalvo and more

Join us to honor World Series Legends from the 1968 and 1984 games

Thursday, June 11th
6:00 PM
Motor City Casino
2901 Grand River Avenue

Reception, Dinner, Cocktails, Auction and Panel Discussion

To purchase tickets, visit joeniekrofoundation.org

Presented by The Joe Niekro Foundation to benefit brain aneurysm, AVM and hemorrhagic stroke research, treatment and awareness

JOE NIEKRO SYMPOSIUM

REGISTER NOW

HOUSTON METHODIST
CEREBROVASCULAR SYMPOSIUM
NEUROLOGICAL INSTITUTE



June 12-13, 2015



SECOND ANNUAL CEREBROVASCULAR SYMPOSIUM & HANDS-ON WORKSHOP

Friday, June 12, 2015

Joe Niekro Foundation Symposium
Structured Didactic Sessions:

Location: Houston Methodist
Research Institute Board Room
(2nd floor)

8 - 8:20 a.m.

Registration and breakfast

8:20 - 8:30 a.m.

Guests with Guests

8:30 - 9:10 a.m.

Alan West - Natural history of ruptured and unruptured aneurysms

9:10 - 9:50 a.m.

Jonathan Zhang - Treating dilemmas for wide neck aneurysms

9:50 - 10:30 a.m.

Richard Mori - Optimizing the use of flow diverters

10:30 - 11:00 a.m.

Break and exhibits

11 - 11:40 a.m.

Sean D. Lavine - Controversies in management of ruptured and unruptured aneurysms

11:40 a.m. - 12:20 p.m.

Daniel McDougall - Recent advances in neuro-anesthesia

12:20 - 1:20 p.m.

Lunch break

1:20 - 2 p.m.

Richard Klucznik - Advances and updates on stroke trials

2 - 2:40 p.m.

Orlando Diaz - Trends in use of interventional devices in stroke intervention

2:40 - 3:20 p.m.

Shahid Mirza - Pearls for use of novel anticoagulants

3:20 - 4 p.m.

Break and exhibits

4 - 4:40 p.m.

Christal Karmali - CFDs and 3D aneurysm modelling: an overview

4:40 - 5:20 p.m.

Eugene Golovinski - Third circulation: do we know it well?

5:20 - 5:30 p.m.

Guests with Guests

5:30 p.m.

Adjourn and closing remarks

6:30 p.m.

Assemble at the lobby of Marriott

Transportation provided

Chuy's Tex-Mex Restaurant

2706 Westheimer Rd,

Houston, TX 77098

Register online at
houstonmethodist.org/cerebrovascular-course

LOOKING BACK ON THE LAST FIVE

Five years looms on my horizon. 5 years of scratching, clawing, growing, healing, accepting. I have been through hell and back. I survived a brain aneurysm, a divorce, the loss of my brother, my father and my friends.

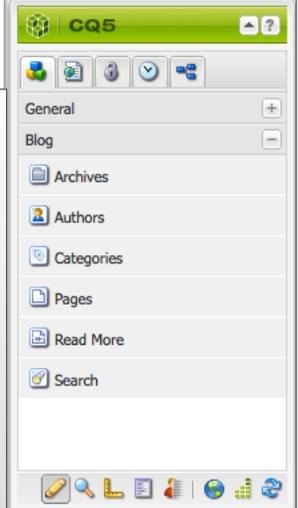
But through it all, I found out what I was made of. I found my truth, plus a few other "finds" that I am still trying to figure out.

My visible scars are healed. But the inner scars are the reason I become sad, frustrated, and angry all within the same minute. Add that to being a female and the facial expressions are fun to watch, or a bit scary, take your pick.

I have found strength, acceptance, humility, and unity in our [JNF aneurysm/AVM support group](#). In those early morning hours that have developed since the surgery, I have found myself. One of the most hurtful things that I heard after my surgery was from my ex husband. He said that I was brain damaged, all screwed up and that it was too bad my surgeon did a good job. It has taken all of the last 5 years to live those statements down. If I sound like I am bragging...I am. I walked out of ICU 5 days after a 16 hour brain surgery. The 6th day I was doing laundry. The 2nd week I was driving and mowing the lawn. But I also can't forget what I lost... the vision in my right eye, my marriage, and my courage.

But my gains are far bigger than my losses. I could roll around in self pity, but I liken that to rolling in mud, and I am not a fan. I am stronger, smarter, more resilient, and both more AND less tolerant of certain things. I love bigger, stronger and harder. My faith, family, friends, my neurosurgeon... they all played a part in this. My reason for being and my lessons here are obviously not finished. If that were the case, my surgery wouldn't have been a success.

I try to tell everyone to remember that we are not the same person we once were. There are changes, some big, some small. Some you can see, some only we can see as survivors. Five years may not seem like much to you. But I have lived a thousand different scenarios in them. And for those 1,825 days, I am incredibly thankful. As for the bad days, I wonder if the next 1,825 will be quite as interesting? Remember...be thankful for every day, for we never know when it could be our last!



FATHER'S DESERVE MORE THAN JUST ONE DAY

by Natalie Niekro - Founder/Joe Niekro Foundation

It's June which means Father's Day will soon be here. Every year, I find myself feeling thankful and blessed, yet melancholy as I reminisce on the wonderful memories of my father. On June 21st, we will honor our Dad's; although I believe, Dad's should be honored every day! After all, they are the one's that have always been there, have become our heroes, have lifted us up when we needed it most, brought that great joy to our each and every day, and have never failed to let us know just how much we are loved. My Dad was and will always be my hero. I truly treasure every moment that we shared and will never forget his unconditional love. Dad had that wonderful ability to make you feel as if you were the only one in the room - while at the same time, making sure everyone around felt his presence, love and enthusiastic energy. God truly blessed my life with an amazing, loving and unforgettable Father. Be sure to take a moment this Father's Day..and every day, to let your Father know just how much he means to you because you just never know when your last words with him will come. I LOVE YOU DAD!

Happy Father's Day to all the Dads out there who continue to be our heroes!

What Makes A Father

*God took the strength of a mountain,
The majesty of a tree,
The warmth of a summer sun,
The calm of a quiet sea,
The generous soul of nature,
The comforting arm of night,
The wisdom of the ages,
The power of the eagle's flight,
The joy of a morning in spring,
The faith of a mustard seed,
The patience of eternity,
The depth of a family need,
Then God combined these qualities and
When there was nothing more to add, He knew His
masterpiece was complete,
And so, He called it ...
FATHER!*

Author - Margi Harrell

DOES AGE PLAY A FACTOR IN TREATMENT?

Recently, I took care of a woman in her mid 80s who had a large brain aneurysm discovered by accident after she fell and hit her head. Fortunately, her scan did not reveal any blood, or other serious injury. But what we were left with was an 8 mm aneurysm at the internal carotid artery bifurcation, and the decision of treatment. She had no active medical issues, good cardiac function, no significant vascular tortuosity on imaging, and an aneurysm neck that was relatively narrow, making for a potential embolization procedure.

Besides the typical issues that are included in the decision to treat unruptured brain aneurysms when caring for much older patients, the imprecise and awkward estimation needs to be made as to life expectancy and quality of life. This unique type of medical decision-making is becoming increasingly common as people live longer and more medical imaging is being performed.

We rather quickly covered the more customary concerns, such as the aneurysm diameter. According to the literature, this anatomic information would qualify as high risk for future rupture. But because this aneurysm was discovered by accident and she was in her mid eighties, there was the distinct possibility that she had lived with this aneurysm for quite some time, perhaps even a decade or so. The technical aspects of the procedure were reviewed, and fortunately, it appeared to be a relatively straightforward procedure. The real question really boiled down to whether our current notions of how concerning or dangerous the aneurysm was, based on its size and anatomy, needed to be adjusted in any way because of the patient's age.

The information we often have is frustratingly limited. There are no reliable warning signs on the neurologic examination, bloodwork, or imaging that reliably help us predict if something harmful is truly imminent. She is already past the average life expectancy of a woman in North America. She is quite active on a daily basis and her personality is one of someone who deeply cares for her family and their activities. Given how she has been living, we all generally agreed that she could very well live at least another five years.

We took our time. We allowed time for the patient and family to deliberate on the issues we brought up. Certain questions were repeated. We showed pictures. We talked about our prior experience. We talked about published case series looking at outcomes from elective preventative aneurysm treatment in patients older than 70 years old.

Fortunately, the procedure went well, she was discharged home the next day, and hopefully our efforts helped her live a longer, more functional life. We will never know for sure if what we did was the right decision. But given the limited information available to us at the time, I would like to think this was the best decision.



"STROKES FOR STROKES"

A Golf Outing Benefiting the Joe Niekro 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 Niekro 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 lisaesimms1@gmail.com or 248-444-1936 for questions or further information.

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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 lisaesimms1@gmail.com.

[Download Registration Form](#)

SURVIVORS TO BE FEATURED IN NATIONWIDE AD CAMPAIGN

In an effort to raise awareness of a sudden and fatal illness that claims nearly 500,000 lives annually, The Joe Niekro Foundation recently teamed up with actress and brain aneurysm survivor, Tamala Jones ("ABC - Castle") and luxury hat maker Canada Bliss, in a model search for brain aneurysm survivors.

The Brain Aneurysm Survivor Model Search was looking for survivors age 18 and older to appear in advertising for *Tamala By Canada Bliss*, Jones' signature line of hand-crocheted hats. Participants were asked to submit a 500 word essay and two photos. Thousands of entries were received and we are excited to announce the beautiful faces that will be representing brain aneurysm survivors across America on June 26th.

The model search is the start of Jones' personal aneurysm early detection campaign and survivor self-esteem initiative that seeks to educate the public on the warning signs and symptoms of brain aneurysms by encouraging survivors to share their stories and show post aneurysm successes.

"This is more than a model search, it a message to survivors that by sharing our stories we help save lives," says Jones who suffered a ruptured brain aneurysm at age 23. "For a long time I did not discuss my brain aneurysm out of fear, so I understand the silence of survivors but now we are giving them not only a voice, but faces too."

"We are thrilled to be collaborating with Tamala, Canada Bliss and survivors across America. This is a wonderful testament to survivors everywhere that awareness is beautiful and chic," said Joe Niekro Foundation founder, Niekro Niekro. "What an incredible day it will be when we get to witness these courageous survivors representing a platform that is so vitally important to our mission."

Luxury hat maker Canada Bliss worked with Jones to create the signature line *Tamala By Canada Bliss* to help raise awareness of brain aneurysms. The company is now taking its altruism a step further by placing survivors chosen via the model search in advertising for the brand. Proceeds from the sales of *Tamala By Canada Bliss* benefit brain aneurysm awareness and research.

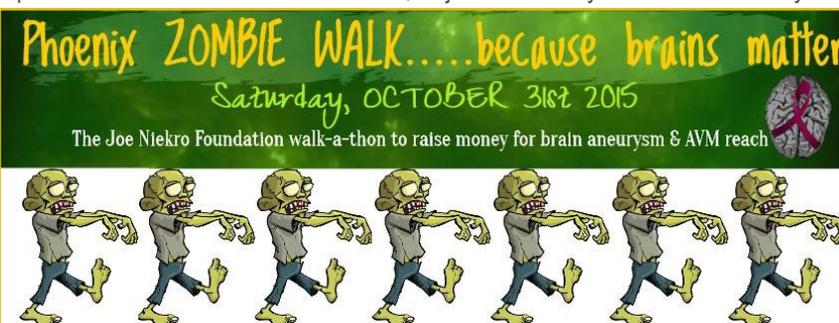
"One of the central values of Canada Bliss is celebrating the simple joys and diversities of life. Being part of the Brain Aneurysm Survivor Model Search embodies all of these values," said Karen Viloría-Miguel the CEO of Canada Bliss. "It is a privilege to be involved in supporting brain aneurysm survivors; honoring their struggles and celebrating their lives."

With women being 50% more likely to suffer an aneurysm than men Jones, Viloría-Miguel and Niekro are the ideal advocates for this cause. Approximately 30,000 Americans suffer a rupture each year, that is roughly one rupture every 18 minutes. Those numbers outpace more well know illnesses like breast cancer and ALS.

LOOK FOR OUR WINNERS IN THE JULY KNUCKLE UP ISSUE

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.

TAKE THAT ANEURYSM!!!!...I DID IT ON MY OWN!

by: Madelon Mudd - BA Survivor



If you read my mom's [Knuckle-Up May article](#), you would have seen how she said she was going to mail my graduation announcements the first of the month for my May 17th High School graduation date. Well, on May 17th, I did the thing that many people (including myself) doubted I would ever do. I walked across the stage and got my high school diploma (well actually I got an empty folder). I had to go back to the principal's table and pay a \$10 parking ticket before they were going to give me the real thing... Oops, short term memory probs.

How did graduating from high school make me feel? It was an overload of emotions for sure. The strongest emotion for me was relief. Relief from the stress of being placed in a chemistry class that required too much memorization of facts that I will NEVER use again. Relief from the anxiety of having teachers who didn't understand me or my limitations. And finally, relief from the fear that my short term memory loss would keep me from graduating.

I was ready to be done with teachers who DIDN'T follow my accommodations, especially one of my special education teachers who tried to force me not to use my notes on a quiz. She even slammed her hand down on my desk and said to me "What's the point?" The point is, I would much rather have the ability to study and memorize facts. The point is, I don't like having short term memory loss. It's scary.

For my final project in my Senior English class, we had to tell what we had learned in our four years of high school. By the way, I loved this teacher, props to Victor Abundis for being one of the very few teachers who got me. Of course I had to include my aneurysm rupture in my story. My rupture happened the summer after my Sophomore year. My high school life was literally cut in half and I lived two separate lives. My first two years of high school I was just a normal teenager. I was driving, I had boyfriends, and I had lots of friends. My last two years of high school were very different. I had rehab, rehab and more rehab and then I even had driver's rehab. I didn't have any boyfriends and my "friends" walked away. But, like Bob Marley said *"You don't know how strong you are, until being strong is your only choice."* I am not a quitter and now I tell my story proudly. It is who I am. Here is a link to my final project.

<https://www.youtube.com/watch?v=tY8wtR0yn-g&feature=youtu.be>

High school didn't turn out quite the way I had envisioned it would. But, it is only one chapter in my life. The rest are yet to be written. So here we are, nearly halfway through June and guess where my announcements are still sitting? Yep...in the corner where Mom left them last month! XOXOXOXOXO Love you Mom!



JNF WELCOMES NEW BOARD MEMBER

W. Patrick Dreisig is a shareholder practicing in Butzel Long's Bloomfield Hills office. He is a Vice President of Butzel Long and serves on the firm's Board of Directors. He is co-chair of the firm's Finance Committee and Global Automotive Industry Group and a member of the firm's Business Law Practice.

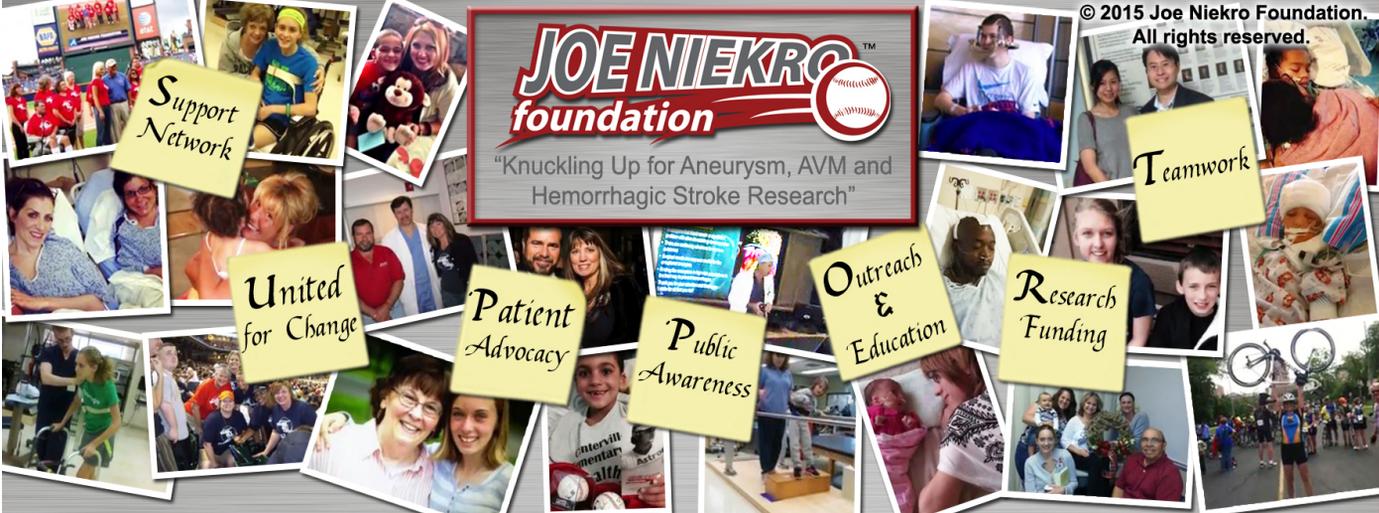
Pat focuses his practice in general business law and transactional matters, including mergers and acquisitions, divestitures, joint ventures, recapitalizations, debt and equity finance transactions, venture capital transactions, supply agreements, intellectual property development and licensing transactions, customer and supplier workouts, entity selection and formation, corporate governance and business succession.

He practices extensively within the automotive supplier industry. He is highly experienced in representing automotive suppliers in structuring and negotiating long term supply and other commercial arrangements with automotive manufacturers and other suppliers.

Pat received his B.A. degree, with distinction, from the University of Michigan in 1974 and his J.D. degree from Wayne State University in 1977, where he served as an editor of the Wayne Law Review in 1976-77.

Mr. Dreisig is a member of the Business Law Section of the American Bar Association and the State Bar of Michigan. He has also served as a member of the Legal Issues Council, and as past counsel to the Chief Purchasing Officers Council, of the Original Equipment Suppliers Association. He is listed in The Best Lawyers in America.

Welcome to JNF Pat - thank you for your service!



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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