

RELATIONSHIPS AFTER RUPTURE - Part 1 - Responsibility Changes



A brain injury can significantly change a couple's relationship. After severe, moderate, or complicated-mild brain injury, both survivors and their spouses or partners must often change many parts of their lives. The following life changes typically affect intimate relationships:

- Changes in responsibilities
- Changes in relationship roles
- Changes and challenges in communication

Brain injury survivors often have new personality traits, challenges, fears, and limitations. Survivors are often surprised by how these changes also mean that they will feel and behave differently in their relationships. These changes have led many spouses to say they feel like they are "married to a stranger."

The intimate partners of survivors may have new concerns or fears related to both the incident that caused the injury and the new behavior traits of the survivor. Also, partners often change the focus in their lives in order to manage the multiple challenges that arise for their family after an injury.

These changes in the survivor's personality and the life focus of both partners often result in a feeling that partners do not know what to expect from one another. Uncertainty can increase stress and anxiety within the home.

How Are Relationships Typically Affected?

Part 1 - Responsibilities

After rupture, survivors must focus their energy on getting better and developing new skills. As a result, the assignment of responsibilities in the home must change. This means that everyone in the family is involved in learning new skills and taking on new jobs.

How do responsibilities typically change?

Survivors often give up many responsibilities, including work expectations and household chores, while they focus on getting better. Partners often must take on many responsibilities formerly managed by the survivor, such as:

- Yard work and physically maintaining their home through chores and repairs
- Managing household finances
- Planning and organizing activities for the family

There are also new tasks for both survivors and their partners, such as managing the health care of the survivor.

What happens when responsibilities change?

Any time people have to take on new responsibilities and learn how to handle new tasks, they will also experience more stress. In addition to the stress of injury and recovery, the stress of changes in responsibilities can increase tension between partners. Partners who have significantly more responsibilities will also have less time for other things. In contrast, survivors who are focusing on getting better may feel like they have more time. This can result in different expectations about how much time partners have to spend together.

Tips to improve relationship issues related to responsibility changes:

- Be understanding about each other's new responsibilities. This can have a positive impact on a relationship. Although it is natural to focus on oneself when a person is overwhelmed, partners must take time and effort to note all of the new responsibilities their partner is managing. Noticing and talking about these challenges can reduce tension within your relationship.
- "Thank you!" Make a commitment to yourself to thank your partner at least once a day for attempting to manage new responsibilities.
- Schedule opportunities to take breaks from responsibility. These breaks may be short and may not be as frequent as desired. However, when couples and families schedule time off for each adult family member and honor that commitment both practically and emotionally, thankfulness and respect are more likely to grow in the relationship.

* See Part 2 (Changes in Relationship Roles) in the September Knuckle-Up Issue

this issue

Page 1

Relationships

Page 2

Donna's Diary

Knuckle Ball 2015

Page 3

Beth's Blog

Fantasy Camp

Page 4

Zombie Walk

SNIS Annual Meeting

Stroke for Strokes

Page 5

Grief Through a Caregiver

Caregiver Support Group

Page 6

Trusting your Physician

Kendall's Crusade

Page 7

Board of Directors

Contact Us

FISH OR CUT BAIT!

by: Donna Poole - JNF Patient Advocate



Donna's Diary,

"Fish or cut bait" means to decide one way or the other. Young adults living on North Haven Island off the coast of Maine have a fish or cut bait moment when they decide whether or not to remain on the island. Kimmee Poole created a multi-media piece about some of them as they debated their decision. Among others, she interviewed a young man, a wonderful artist with cerebral palsy. <http://freerangenonfiction.com/freshly-hatched/freshly-hatched/the-salt-series-fish-or-cut-bait-by-kimmee-poole/>

Why would a man who has difficulty controlling his movements become an artist? Theoretically, struggles can enhance creativity, and so can "island" life.

Aneurysm and AVM survivors are on an island of sorts. Unlike the people in the documentary, our fish or cut bait moment doesn't come when we decide whether or not to stay or to go. Leaving is not an option. This is our fish or cut bait moment: will we merely survive, or will we live creatively?

My last fortune cookie said: "We are here to create not merely to survive." Will this difficult experience make us better or bitter? Will we stagnate, or will we discover inventive ways to cope and to help others through their darkness? Fish or cut bait!

For aneurysm and AVM survivors the resolution to live creatively is a daily, sometimes an hourly one. Discouragement and depression lurk in our shadows, but light and hope also beckon.

Our support rooms not only help thousands of people survive, the rooms have taken on a creative life of their own. They hum with life twenty-four hours a day. We meet there often. We pray each other through defeats. We cheer the victories. We laugh; we cry; we talk. We find friends. In helping others find creative ways to cope and thrive, we create a better life for ourselves.

KNUCKLE BALL...A PITCH FOR LIFE

SAVE THE DATE

The Sixth Annual

KNUCKLE BALL

A Pitch for Life

Benefiting brain aneurysm, AVM and stroke research and awareness

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

SNIS
FOUNDATION

www.joeniekrofoundation.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 Earp of [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!

THE PATH BEFORE US



By: Beth Barnes - BA Survivor and JNF Advocate

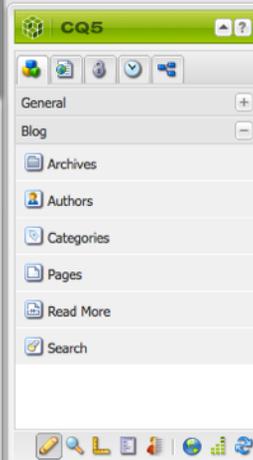
Before my [brain aneurysm](#), I didn't think about them. It isn't something people often research such as cancer or diabetes. And then it happened to me. After my surgery, I just took care of healing, well that and growing my hair back!

And then about 5 months after the "Event" I began to have questions. Even my co-workers, who were clinicians didn't have the answers I was seeking. Being overjoyed because you survived a life and death procedure is sometimes shadowed later by the feeling that you are alone and no one understands. As much as our brilliant neurosurgeons and primary care providers try, it takes another survivor to understand the "I have an achy head headache."

So much about our brain is unknown. How much time does it really take to heal? Does it ever stop? What about our "dents" or as I call them, "the battle scars." Do they every truly dissipate? Will they always be there?

I am particularly fond of saying on a beautiful clear blue and sunny 85 degree day, that we are going to get rain. And being right 3 hours later. These are only some of the topics that another survivor can understand. I never thought that I would find a [support group](#) such as the one JNF has. It has brought much sun to break up the dark clouds in my life. It has allowed many of my questions to be answered. Our marvelous, brilliant, gifted neurosurgeons "fix" our heads, and our support groups manage to "fix" our hearts!

For the ones that have walked this path before us, it may have been a lonely road, and many of them paved the way for us. For the ones that are walking it now, we have managed to light those paved roads. For the ones that will come after us, there is the brightness. I think one of the responsibilities I have as a survivor is to make sure that I reach out and help educate, but mostly to make sure that I can give the gift of [#metoo](#) to another survivor.



Nov 1-6, 2015
REGISTER TODAY

Don't miss this once in a lifetime opportunity to play with the pros! The camp includes three days of baseball, plus an 18 hole golf scramble. Cashman Field, home of the AAA New York Mets is where you'll find your very own personalized locker, complete with home and away uniforms, bats, balls, a full time clubhouse assistant and trainer, plus all the extras needed to play like the pros. Campers will be hosted at Green Valley Ranch Resort and Casino. Price includes transportation to/from airport, hotel accommodations, all meals, all equipment, uniforms, personalized locker, golf fees, Photograph/Autograph day and more! *Airfare not included

TOP 10 REASONS TO PARTICIPATE

#10 - The Resort: We stay at a family-friendly, world-class resort and casino.

#9 - The Ballpark: We play at Cashman Field, Triple-A home to the New York Mets. Imagine stepping up to the plate as you hear your personal walk-up song and your face staring back at you from the big-screen.

#8 - The Play: Our campers love to play baseball, which makes for games that are competitive and always fun.

#7 - The Uniforms: Professional uniforms make you look good. At home, they also look great in a frame on your wall, especially after the coaches autograph them.

#6 - The Coaches: George Brett, Andre Dawson, Ozzie Smith, Gaylord Perry, Rollie Fingers, Vince Coleman, Bert Campaneris, Dave Rozema and other MLB greats coach and hang out with you for five days.

#5 - Individual Attention: All campers are guaranteed a fair-share of attention. If you want extra attention, assign yourself a "cool-sounding" nickname. Put it on the back of your jersey in lieu of your last name—just to make sure that it gets noticed.

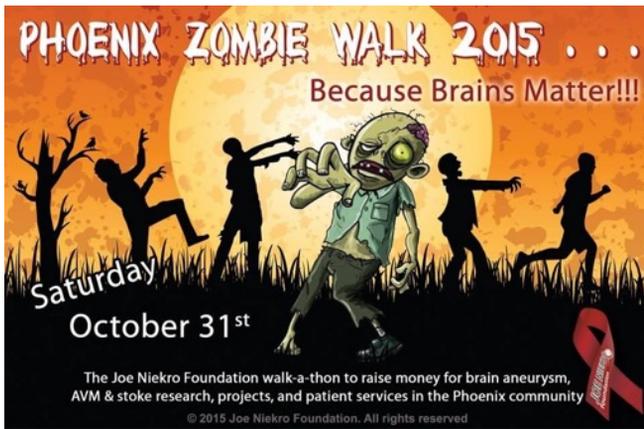
#4 - Kangaroo Court: Each day begins with Kangaroo Court, one of baseball's most revered but little publicized traditions. There, the many who are guilty of indiscretions against our national pastime during the previous day are held accountable and fined accordingly. Nothing is sacred, and nothing goes unnoticed. Be prepared to laugh hard, and laugh often.

#3 - The Camaraderie: Love baseball? What better way to spend five days than with others who share your passion? Bring your family, too. The fun doesn't end when camp does. You'll have memories and stories to tell for the rest of your life!

#2 - The Dream: Many of us have dreamt of becoming a big-leaguer. Attend every year, see old friends and make new ones. And where, for a few days, your dream becomes a reality.

#1 - The Cause: The camp proceeds support the Joe Niekro Foundation's mission of aneurysm, AVM and hemorrhagic stroke research and awareness funding.

[Click here to get signed up for this year's Fantasy Camp](#)



Sign Up - Join us, walk for a survivor that you love. Or better yet, start a team and invite your friends.

Fundraise - Ask your friends, families and neighbors to support your lifesaving efforts.

END THESE HORRIBLE CONDITIONS- Every dollar we raise puts us one step closer to stopping brain aneurysms, AVMs and hemorrhagic strokes, once and for all.

Sponsor

Company involvement is key to eliminating brain aneurysms and AVMs . Become a sponsor and let your employees and customers know that you are committed to eliminating these horrible conditions.

Volunteer

Will you take your commitment to the next level and become a volunteer? If you are more than 14 years of age and dedicated to eliminating brain aneurysms or AVMs, then we need your help to make Zombie Walk...because brains matter a success!

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!

Zombie Walk...because brains matter is a powerful and inspiring opportunity to unite as a community to honor brain aneurysm/AVM survivors, raise awareness about steps we can take to reduce the risk of having a hemorrhagic stroke, and raise money to help the Joe Niekro Foundation lead the fight against these devastating conditions with groundbreaking genetic research.

Will you walk for those who no longer can walk and alongside those who are learning to walk again?

Registration is FREE!!
 PLEDGE PAGE IS NOW OPEN!
 Or to learn more about the event
[Create a Pledge Page Here](#)

JNF A BIG HIT AT SNIS ANNUAL MEETING

The 12th Annual SNIS Annual Meeting was held this past July 27-31 in San Francisco.

From sessions that spanned the full spectrum of neurointerventional surgery, to a strong slate of abstracts that reflected our vision for research, this year's meeting helped us assess the full picture of where the field of Interventional surgery is, the new treatments being explored and what's in store for the future.

While in SF, the JNF hosted an impromptu **support group** meeting and had a tremendous turnout. Microvention, Medtronic and Stryker Neurovascular all showed their support by attending and demonstrating their various treatment devices. Thank you to all that participated and helped make this night a great success.



"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

\$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

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.

GRIEF THROUGH A CAREGIVER'S EYES

by: Marcy Mudd - Parent of a BA Survivor

Did you know that caregivers also go through the stages of grief -- just like survivors? If you are a caregiver and haven't done anything for you lately, please read this and then run - don't walk - to the nearest salon, golf course, cigar/wine shop, church, ball field, or gym. Go to the place that restores you. Just don't wait as long as I did to take care of you.



The Joe Niekro Foundation has a helpful caregiver information page located [here](#). For the record, I did not do numbers 1, 2 or 4.

"Make sure you take care of you, and take a break." **As caregivers, how many times have we heard this?**

When my daughter Madeline was in the ICU, her team of doctors was kind enough to ask if I wanted a temporary gym pass. Apparently, they noticed that I was always wearing running shorts and a T-shirt. While I was a runner in my younger days, running shorts were comfortable and I could wear them 24/7, literally. Most moms will tell you they rarely left the ICU. I was no different. Even though I couldn't help Madeline, I wasn't leaving her side, either. During her 3-week stay in the hospital, I went home only twice to gather her things. The rest of the time, I had my sister or a friend rummage through my closet (laundry included) for more running shorts.

For the three weeks of her inpatient rehab, I left twice for groceries and once to color my hair. I got some strange looks and even a comment when I returned to the rehab unit so my hair must have really needed it!

When Madeline and I finally returned home my well-meaning friends tried to coax me out of the house for "just one drink." I can count on one hand the number of times I went out with a friend during Madeline's first year home. She was recovering remarkably well for her type of rupture. She was in a full-day rehab program and I returned to work. I joined my bike-riding friends for two rides but begged off after that. What was wrong with me? Bike riding was my release, my love, and my passion. I knew I was a bit depressed but I also knew I wasn't ready to help myself out of it. I told myself to go catch a movie or go for a walk, but instead I stayed home.

Fast forward to the summer of 2015 and a text from one of my best friends, Chris. She lives on the lake and invited me to join her on her new boat. I love the water; I grew up boating on the lake. With that simple invitation from Chris, it was as if a switch had flipped in my head and I was ready. I practically danced around the house giggling because I was going to the lake. Chris did not invite Madeline and I felt a little guilty about that -- but not enough to ask if she could join us.

I spent the day on the water with Chris. The sun and the breeze lifted the fog from my head. And, it was as if I was reborn. I knew at the end of that day that I couldn't -- and didn't want to -- go back to hiding in my house.

This summer, I also bought some new running shoes and reconnected with my running-bike-riding best friend, Kate. We started walking together and this has re-energized and reignited my passion for exercise. I let the aneurysm take away that part of me for a while, but I am proud to say I'm back!

As we enter the final months of summer, Chris and I have a few more lake days planned and I've reloaded my "running" playlist on my phone. Kate and I are still walking and I've added more miles to my solo walks as a way to keep myself challenged.

So, [#TakeThatAneurysm](#). You did not beat this caregiver either. I feel like the old me again. And, it's good to be back.



The [Brain Aneurysm/AVM Caregiver Support Page](#) was created for caregivers to turn to others with similar issues in attempt to deal with their isolation, powerlessness, alienation and the feelings they believe nobody understands. This chat room is a safe haven to be among other caregivers or family members in similar situations to express fears, challenges, successes and failures in an atmosphere in which everyone is loved and accepted by all.

This forum of mutual acceptance, understanding can play a vital role for caregivers by providing emotional and moral support.

JOIN THE JNF MISSION - MAKE A DIFFERENCE TODAY!

HOW TO TRUST YOUR PHYSICIAN!



Probably the most complicated and anxiety-provoking decision patients with **unruptured brain aneurysms** have to make is whether to undergo an invasive surgical procedure. It takes a tremendous amount of courage to proceed with the process where you are completely powerless and at the mercy of the treating physician who will have devices in your head that have the possibility of causing significant harm. Of course, the only reason why one would agree to go through this is with the belief that there exists an underlying problem that is of even greater concern and potential risk.

What used to make this process easier was the fact that the physician essentially made the decision of what was best for the patient. You were simply under the care of the physician who would take care of you. Such an approach is largely unheard of these days. With so much information readily available online, including reviews from others who have used similar services, the patient/consumer feels compelled to take on the decision-making burden. However, taking on this decision-making burden is as empowering as it is anxiety-provoking. One's ability, without any prior medical education, to understand a complex medical diagnosis and treatment options is obvious finite and usually superficial.

Friends or family in the medical field whom you can truly trust are often seen as valuable resources to provide references for second opinions, advice, suggestions and reassurance. It is difficult though, for a friend or family member who you are having an informal conversation with, to have sufficient information and perspective to provide a truly professional consultation. Information available online from medical or hospital websites such as WebMD also seem trustworthy, but lack the ability to provide exact relevance to any particular patient's unique situation.

As a physician, I have tremendous respect for most of my colleagues. I marvel at how they care for patients, contribute to research, lead administrative challenges, and still be personable, affable and fun to be around. I also see, on a regular basis, the effects conflicts of interest have on my colleagues and myself. Whether it is fee-for-service, concern for litigation, a competitive practice landscape, ties to industry, preoccupation with the newest treatments, or having overbearing financial responsibilities, there are many interests that may, at times, have greater influence over a physician than what might be best for the patient. Patients need knowledgeable doctors to help care for them. Patients should also be aware of the many conflicts of interests that currently exist and may interfere with the care they deserve. With this awareness, it may be easier to use your intuition in deciding whether to trust the recommendation of the physician you are seeing.

KENDALL'S CRUSADE

On October 25, 2014, young 5th grader Kendall learned she had a Grade V **AVM**. Kendall is now on a mission to teach people about Arteriovenous Malformations (AVM) as she embarks on a journey to treat and hopefully obliterate hers.

As part of her journey, Kendall joined a friend on the golf course this past August 3rd, who was determined to play 100 holes from 7A-5P, all to raise awareness for AVMS.

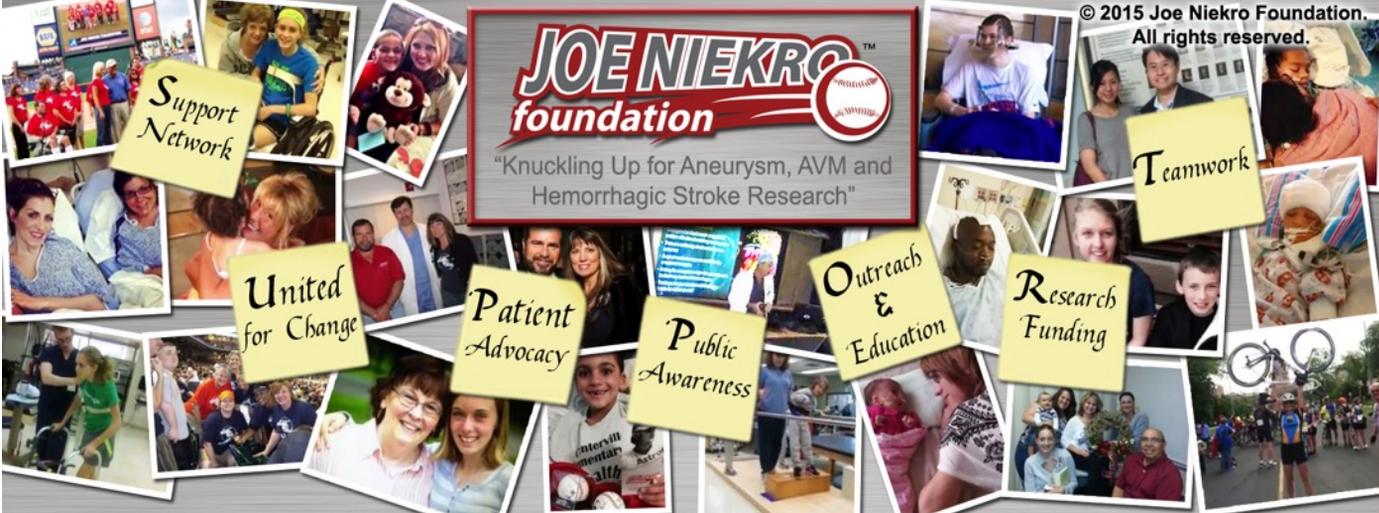
Kendall helped raise a little over \$2,000, thanks to the help of some very generous friends... but that's not all. Thanks to another generous donor, that \$2,000 was matched and she will be donating it to Joe Niekro Foundation to help find a cure for AVMS.

There's more to this story... \$400 of what was raised started out as \$10 from a friend as part of a pay-it-forward effort. That \$10 quickly turned into \$200, which was then doubled to \$400.

Congrats on a hugely successful effort and thank you for showing others what giving is all about.



Kendall and her friend Rory, with Mark Peterson (right) were all smiles after completing 100 holes.



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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