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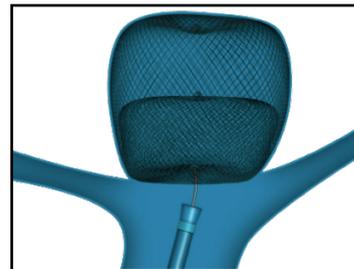
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## NEW BRAIN ANEURYSM TREATMENT TECHNOLOGY

Joe Niekro Foundation™ Medical Advisory Board Member, Dr. Donald Frei of Swedish Medical Center, is leading the study of an investigation device called WEB to treat [brain aneurysms](#). Swedish is one of the 20 sites across the country doing trials on this new technology.

Building on the experience with [endovascular embolic coils](#), the WEB™ enables physicians to treat a broad range of intracranial aneurysms in an innovative new way with the familiarity of an intra-saccular approach and established biomaterials.



The device is already approved in Europe, and doctors just put it into the first patient in Colorado. "Brain Aneurysms are deadly, and if we can come up with better and safer and more effective ways of treating brain aneurysms, we absolutely should do that," said Dr. Don Frei with Radiology Imaging Associates.

The new technology is a tiny metal mesh sphere that expands inside the artery to seal off the aneurysm. It is a revolutionary treatment for challenging [ruptured](#) and [unruptured](#) aneurysms. The initiation of the WEB study represents an important milestone for this exciting technology platform and a critical STEP towards improving outcomes in a patient population with significant unmet needs.

The idea — if blood can't get in, it can't rupture. "We have no idea if this device is going to be better than what's out there already and that's what the study is going to try to find out," said Frei.

The study will enroll 139 patients at hospitals across the United States and in Canada and Canada.

[Click here](#) to see how the WEB™ treatment is performed.

## FDA PANEL EVALUATING NEW TREATMENT DEVICES

On April 17, 2015, the FDA will discuss the current knowledge regarding the conduct of clinical studies and evaluation of clinical study data for flow diverter technology. This is a growing clinical approach thought to be safer than previous methods for treating large aneurysms.

The committee will seek expert opinion on scientific and clinical considerations relating to the study design and existing clinical studies, for flow diverter technology.

Flow diverters are an endoluminal treatment option for intracranial aneurysms. They are similar to traditional stents but with a significantly higher mesh density. The working principle is that the high-mesh density reduces flow rate into the aneurysm which promotes blood stasis and occlusion of the aneurysm. Flow diverters are advantageous for the treatment of large/giant wide-neck aneurysms and offer an alternative to other interventional techniques or surgery.

The treatment uses flow-diversion devices, introduced in 2011. A tiny catheter is threaded through the aneurysm's parent blood vessel, moving past the aneurysm without having to enter its sac. The flow-diversion device is then deployed across the neck of the aneurysm to reduce blood flow to it. This method makes it unnecessary to go into the aneurysm, which risks its rupture. Previous treatments included surgery or "[coiling](#)," which involve the use of a stent. [Continued on page 2](#)

## WAIT FOR IT!

"Spring has returned. The earth is like a child that knows poems" (Rainer Maria Rilke).

All those dark, cold months we waited for you, April! You took a long time coming, but one look at your sweet, childlike face and we forgave you. You are here now, and that's what matters.

Things change quickly in April. In our part of the country nature's most obvious change is during the 30 days from April 15th to May 15th. That doesn't mean nothing was happening before this; buried under the snow and ice, the spring flower bulbs only seemed dead. They were waiting for the return of warmth and new life.

"Bulbs have biological clocks that tell them when to sprout roots, stem, sprout leaves, flower and then finally when to die down and go into dormancy. Spring blooming bulbs have to be planted in fall when they are fully dormant. In fact they are longing for moisture and soil...as soon as you plant them, they start to develop their embryonic leaves and flowers. They quickly push out roots from their bottoms and, a little later, stem from their tops. The stems grow until they are just beneath the soil's surface and then they halt! They are stopped when the soil temperature drops. But even when it is not freezing their biological clock tells them to protect themselves against the winter cold. Generally speaking, spring blooming bulbs start to grow when temperatures rise, usually in early spring."



Waiting is part of recovery. Some of us aneurysm/AVM survivors are still in the "winter of our discontent." It seems nothing is happening. That doesn't mean nothing ever will. Changes we don't yet see may be occurring.

A friend had an acoustic neuroma removed from the base of her brain. For eight years she was unable to completely close one eye, even when she was sleeping. After eight years her eye suddenly cooperated and closed.

I asked members of our [Brain Aneurysm/AVM Support Page](#) to share improvements they've experienced after the first few years of recovery. One person's sense of smell returned after five years. Other comments they shared were:

- "Surgery 14 years ago but able today to do things that I couldn't do yesterday"
- "Emotions getting back to normal after 25 months"
- "Dreaming again after 17 years"
- "Regular sleep patterns after 8 years"
- "Surgery 18 years ago - learned to run after 3 yrs - a few years ago learned to skip again - but only on right side"
- "Confidence level increasing"
- "Big improvement in taste after 5 years"

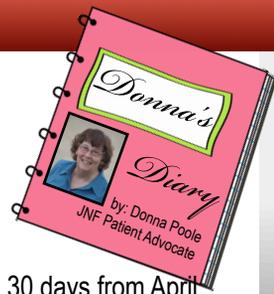
Our surgeons and neuropsychologists can't really predict long range outcomes. We may never get back to 100% of normal, but "normal" changes over the years. If I considered "normal" to be my physical and mental abilities at 25, I would be nowhere near that at 66, even without a stroke, small vessel disease, an aneurysm and a craniotomy.

Survivors are in all different seasons of recovery. We may have to accept that in some areas we will always be in winter, but I don't think we should give up too soon. We can keep working and praying. Even years later, our recovery may surprise us the way April does after every hard Midwest winter. Wait for it!

## cont. - FDA PANEL EVALUATING NEW TREATMENT DEVICES

The market for flow-diversion devices will grow from \$12.6 million in 2013 to \$60 million by 2020, according to market research firm iData Research. An increasing number of providers are using flow-diversion devices, raising questions about possible overutilization given the low rate of ruptures.

FDA intends to make background material available to the public no later than 2 business days before the meeting. If FDA is unable to post the background material on its Web site prior to the meeting, the background material will be made publicly available at the location of the advisory committee meeting, and the background material will be posted on FDA's Web site after the meeting. Background material is available at <http://www.fda.gov/AdvisoryCommittees/CommitteesMeetingMaterials/MedicalDevices/MedicalDevicesAdvisoryCommittee/default.htm>.



## JNF ONLINE SUPPORT GROUPS

The Joe Niekro Foundation™ is excited to introduce [The Brain Aneurysm/AVM Caregiver Support Page](#). This 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. It was created as a sanctuary for caregivers. A place where you as a caregiver can come and say whatever is on your mind without fear of what your survivor may take away from it. But sometimes, just sometimes, you need to voice what you are thinking or afraid of. This is the place for that. 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.

*“When you are a caregiver, you know that everyday you will touch a life or a life will touch yours.”*

*Anonymous*



**Patients Page** - Brain Aneurysm/AVM Support Group sponsored by The Joe Niekro Foundation  
[www.facebook.com/groups/aneurysmavm](http://www.facebook.com/groups/aneurysmavm)

**Parents Page** - Parents of Brain Aneurysm/AVM Children Support Group sponsored by The Joe Niekro Foundation  
[www.facebook.com/groups/ParentsBAVM](http://www.facebook.com/groups/ParentsBAVM)

**Young Adult Page** - Young Adult Brain Aneurysm/AVM Survivors Group sponsored by The Joe Niekro Foundation  
[www.facebook.com/groups/youngadultaneurysmsurvivors](http://www.facebook.com/groups/youngadultaneurysmsurvivors)

**Caregiver Page** - Brain Aneurysm/AVM Caregiver Support Group sponsored by The Joe Niekro Foundation  
[www.facebook.com/groups/caregiversbrainaneurysm](http://www.facebook.com/groups/caregiversbrainaneurysm)



**Beth's blog**

by Beth Barnes : JNF Patient Advocate

There can be such utter joy in being a survivor, and there can be despair. You can feel just like the "old you" one day and the next you feel as if you took 5 steps back. Your life can be in your control with carefully planned events and then spiraling out of control the next moment.

It is a delicate balance that a survivor maintains. Perhaps it's as a spouse, a parent, a child, a friend. We often tend to overdo because we try so hard to return to who we were. Because we want to make it better and easier for the other people in our life.

But we do ourselves a huge disservice, and to the people who saved our lives. It is important to take time for yourself, to take that nap you need, to recognize that maybe that headache isn't going anywhere because there is a change in that barometric pressure.

My life changed again in the last month. I had to reevaluate the job I had taken. It caused undeniable stress and an unbelievable exhaustion. Even for someone like me who has the oddest sleep patterns. It was yet another change. But because of being a survivor, not in spite of, I made some changes! And I'm happy with them.

I guess my point is that while it may be difficult to change, sometimes it is necessary to our existence. Don't be afraid to have days where you mourn your other life, but don't forget to be happy about your new one!

I, for one, plan on some more changes. But maybe I will start with a new hair color, at least for now!

The present changes the past. Looking back you do not find what you left behind.  
 Kiran Desai, The Inheritance of Loss

[Check out Brainstorming with Beth every Sunday in the JNF Online Support Group](#)

## SAYING GOODBYE TO A DREAM by: Madeline Mudd (BA Survivor, with mother Marcy)



I am a synchro skater. Skating has been my whole entire world since I was in the 7th grade. I am the happiest when I am on the ice. In fact, I was on the ice when my aneurysm ruptured. I was one of the lucky ones. I was able to walk 3 weeks after my rupture. I was allowed to skate again at 4 months. Everyone one was shocked that I was allowed to return to the ice. I'll never forget how it felt to glide across the ice again! It all came back. I had not forgotten how to skate.

Fast forward to one day in rehab when Robin (my speech therapist) sat me down and asked what my plans were for college. I responded immediately, without hesitation, "Miami University in Ohio to skate for one of their elite teams." Her reaction of shock confused me, I didn't understand that this prestigious school would be out of my reach.

I was in complete denial. I still didn't understand the severity of my damage. I thought I would be able to just pick my life back up and everything would go back to normal. This little "brain thing" was just going to be a small bump in the road of my life, yeah maybe I'd have to take few summer school classes and write stuff down but no, my life wouldn't change *that* much.

Robin and I often talked about life. She became a trusted friend and one of my biggest supporters. She could relate to my struggles and how my life had changed because she herself had beat cancer in high school. We had a lot in common. Then one day when she asked me again about college it finally hit me smack across the face. I was like Robin. She could not go to Notre Dame and I could not go to Miami. She had been gently nudging me toward this for some time. But I had to discover it on my own.

Just because I finally *understood* it didn't mean I was ready to *accept* it. I spent many hours by myself, sitting, absorbing, realizing and trying to understand that my dreams of skating in college were not going to happen. I'm not sure when I turned the corner from denial to acceptance but I did. This past season was a struggle. I couldn't keep up with all the constant footwork changes and that was stressful for me. It took me months and months to learn the program. I finally came to understand that I could not do this at the college level.

I understand that it is okay for me not to skate in college. Synchro taught me the most important lessons in my life. It taught me teamwork and patience. It taught me how to work hard and persevere. Synchro also taught me how it feels to win and how to loose with dignity and grace. But I didn't loose this battle. I won. There are many other aneurysm survivors that are not as fortunate as me. I am blessed to have my health. I am one of the lucky ones. I can't waste my time being sad. I'm happy that I have the ability to go to college! #TakeThatAneurysm

Check out Milestone Monday's with Marcy at  
[www.facebook.com/groups/aneurysmavm!](http://www.facebook.com/groups/aneurysmavm!)



### WORLD SERIES LEGENDS

JUNE 11th, 2015

Motor City Casino  
 2901 Grand River Avenue  
 Detroit, Michigan 48201



Join us June 11th as we honor World Series Legends from the 1968 and 1984 games, plus pay tribute to the brave souls we have lost in the Detroit Tigers organization.

Panel discussion with former Tiger legends:  
 1968 Athletes: Mickey Lolich, Willie Horton, and more to come  
 1984 Athletes: Jack Morris, and more to come  
 Master of Ceremonies: Eli Zaret

5:30 p.m. VIP Cocktail Reception  
 6:00 p.m. Strolling Dinner and Cocktails  
 7:00 p.m. Panel Discussion with Detroit Tigers

[Click here for more info & to purchase tickets](#)

## ROCKIN' WEST FEST ROCKED IT!

The 1st Annual [Scottsdale Rockin' West Fest](#) was a huge success, raising over \$12,000 which will be used to support Arizona aftercare patients for [brain aneurysm](#), [AVM](#) and [hemorrhagic stroke](#) patients. Pinnacle Peak Patio Steakhouse & Microbrewery served as the venue for this Western Show and Concert on March 28th.

There was entertainment for the entire family including Western music, Western film and TV celebrities, cowboy poetry, action packed events, exhibitors selling unique Western merchandise and more.

Patrons kept their toes tappin' and fingers snappin' with music from Jerry Riopelle, Jon Chandler, Jimmie Ray & Cyndi Cantrell's Tribute to Johnny Cash, and local bands Nowhere Fast and Tommy Rocks.



Some of Hollywood's best known western film stars including Bruce Boxleitner, Jim Clark, Martin Kove, Paul Pape and Peter Brown were on taking pictures, signing autographs and chatting with attendees.

The event was hosted by brain aneurysm survivor, Robin Hardin, and her husband Rex who are members of the [Phoenix Support Group](#).

*Pictured above from left to right: JNF Founder – Natalie Niekro, JNF Support Group Coordinator – Kimberly Chapman, Phoenix Support Group Member – Jackie Peters (with her two girls) and San Diego Support Group Facilitator – Carol Stout.*

## JNF & CNY GRANTS CROUSE NEUROSCIENCE INSTITUTE

The CNY Brain Aneurysm Awareness Campaign, in conjunction with the national Joe Niekro Foundation™, hosted its annual [Melt Away the Winter Blues](#) fundraiser in February at Barbagallo's Restaurant.

More than 200 people attended that evening to support the group's mission as well as the work of honoree Eric Deshaies, MD, medical director for Endovascular and Cerebrovascular Neurosurgery at the [Crouse Neuroscience Institute](#).

Net proceeds of more than \$13,000 from the event were donated to the [Crouse Health Foundation](#) and are now benefitting Crouse's aneurysm, AVM and hemorrhagic stroke patients through treatment and research. Mary Albanese and Mary Cook (center), members of the CNY Brain Aneurysm Awareness Campaign, joined Dr. Deshaies and Crouse Health Foundation President Carrie Berse (far left) in the Witting Surgical Center recently, where they presented the event proceeds.



## JNF WELCOMES NEW BOARD MEMBER



Terry Oprea is an award-winning media veteran with 37 years in the communications business. He's President & CEO of the integrate marketing firm MCCI – Mort Crim Communications, Inc. Terry's career has included major positions with Post-Newsweek Television, Time-Life Broadcasting, Public Television, and NBC Elections.

He's written, developed, and produced dozens of cover stories and business articles for publications, broadcast entities and other public-facing organizations. During his tenure with public television, Terry served on the Board of Directors of Frontline, the international award-winning PBS documentary series. Over the past 20 years at MCCI, Terry has taken a front seat in the amazing transition from a print and broadcast-based media and marketing culture to one that heavily depends on digital, web and mobile communications. The firm has been recognized nationally for its expertise regarding integrated marketing communications, content development, and media messaging.

Terry is winner of numerous national awards for excellence and is active not only in serving his national and international clientele, but he is an active philanthropist, serving on a number of business and community organizations.

Welcome to the JNF Family Terry!



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

**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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