

## this issue

### Page 1

National Caregivers Month

### Page 2

Donna's Diary

### Page 3

A Mother's Perspective

### Page 4

Brains Matter

Celebrating Caregivers

### Page 5

Chen's Corner

Familial Link Risks

### Page 6

Board of Directors

Contact Us

## NATIONAL CAREGIVERS MONTH

November is National Caregivers month, a service worth noting, as family caregivers give a notable \$450 billion worth of uncompensated care to loved ones annually, according to the Family Caregivers Alliance. Family caregivers continue to be the largest source of long-term caregivers, providing care to a family member who is ill, disabled or aged. With more than 7 million stroke survivors living in the US today, caregivers play a critical role in many of their wellbeing.

## national caregivers month

### Caregiving by the numbers:

**65.7**

**million** number of caregivers in the US

**29**

percent of the adult US population who are caregivers

**66**

percent of caregivers who are women

**48**

average age of a female caregiver

**51**

percent of caregivers are between the ages of 18 and 49

**63**

average age of a person caring for someone aged 65 or older.

One-third of these caregivers also are in poor health.

Source - Family Caregivers Alliance

Caregivers play a variety of roles that often go unrecognized.



As November is National Family Caregivers Month, please join us in paying tribute to those selflessly caring for friends and family across the country.

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

## Donna's Diary

# LET'S TALK TURKEY

by Donna Poole  
JNF Patient Advocate



Who doesn't love the smell of a kitchen on Thanksgiving! Pumpkin pie and homemade rolls cool while turkey and stuffing keep warm in the oven. One cook whips the potatoes as another thickens the gravy.

I remember the almost forty Thanksgivings we spent at my sister Eve's house. Sisters and brother-in-laws, kids, grandkids, and friends filled every corner of that home with love and laughter. I recall the year our then two year old son, looked with wide eyes at the tables full of food. He pointed and shouted, "I want dis and dat and dese and dem and dose!"

Eve will not be here when we bow our heads and give thanks this Thanksgiving. This summer she ended her six-and-a-half year battle with ovarian cancer and went home to God. During those years Eve was an unspoken sermon. Without a word she taught everyone around her to face adversity with gratitude. Even when cancer invaded her brain and took her sight, Eve kept a positive attitude.

Attitude is everything. We can't help what happens to us, but we can control our reaction to it.



I'm grateful for the people in my life who taught me to look at adversity and face it with gratitude. When my father-in-law had been on dialysis for about five years and his health was horrible, I asked him if he ever had a good day. He looked surprised and said, "Why, Donna! I have a good day every day!" He meant it too: people called him "Mr. Sunshine".

I asked [aneurysm](#) and [AVM](#) survivors if gratitude helped them recover and adjust to deficits. Here are a few responses:

*"Gratitude went far in helping me with my recovery! When I paused to think about how very blessed I was, I found that I became more grateful, which then made me want to push that much harder during my recovery process!"*

*"I am grateful every day, and that is a very powerful feeling. I realize the value of being given opportunities and the value of living life to the fullest. I also think I came to appreciate the value of spending time with loved ones, and just appreciating the beauty of nature. I have even more of an appreciation of how beautiful this planet is, and how amazing people are! We've all been given a second chance for a reason."*

*"The experience has made me appreciate every moment. Not to say that I haven't felt sadness or some depression along the way, but gratitude brings me out of it pretty quickly."*

*"So thankful to just be here--my attitude has changed and that's for the better."*

*"I am thankful for the little things and I take the time to enjoy them. I try to make time hanging out with my family and friends; I now know how important it is."*

Attitude is contagious. Visit the [Joe Niekro Foundation support group](#) during a January blizzard, an August sizzler, or on Thanksgiving Day itself, and you will find an attitude of gratitude. We appreciate having a place to learn, and to give and find support. Many survivors and caregivers say they don't know where they would be today without the JNF.

Zig Ziglar said, "When you combine love, integrity, and skill, you create a legacy." So, as we give thanks for many things on Thanksgiving Day, we thank Natalie Niekro for the legacy she created. We also send grateful hugs to Kimmothy Lane for our online support group. It helps thousands of us face adversity with gratitude.

This Thanksgiving, and every day, lets be thankful and commit to an attitude of gratitude.

## THE PEACE OF ACCEPTANCE...A MOTHER'S PERSPECTIVE

By: Marcy Mudd

The morning of July 3, 2013 my daughter Madeline texted me from the ice rink and said the ice was very crowded so she had gone on a Starbucks run and was now back to skate the last session. Ten minutes later the rink called to say she had collapsed and 911 had been called. My daughter had suffered a ruptured aneurysm and like many of you, she had no warning signs.

By the grace of God, many prayers and her strong will and determination, she beat all the odds and walked around the KU NICU the day she left. But, we were just beginning our long and bumpy road of recovery. Many things were a blur that first day, but I vividly remember the doctor (in a very somber voice) telling us that if she survived, brain recovery would be a long and bumpy road.

She recovered physically first. Did I mention I pushed her wheel chair into the hall when we got to the rehab center, and refused to go get it when we met her PT? But cognitively she still had a long way to go. Again, blissful ignorance on my part made me think she would heal and then she would jump right back into her regular life. I figured short-term memory loss, no problem. I would buy some sticky notes and she would set some phone alarms and this whole brain injury thing would be behind us.

Yes, I had read about long-term deficits, and how you need to accept the new normal, but as a parent I could not accept it. She worked at our figure skating pro shop called Edgewise Sports Supply. This girl could multi-task with the best of them. She could fit skates, sell dresses, and she loved to rhinestone. Her boss regularly relied on her to run the store for a few hours while she slipped away to a yoga class.

In our small community of synchro skaters Madeline's story had spread from coast to coast so her boss, and our dear friend, was anxious for Madeline to come back to the store. No one prayed harder for Madeline than her boss Stephanie. She just needed to have Madeline back because she loved her much. Nothing made me happier than Madeline back at Edgewise where she belonged.

But then the wheels fell off. Not only does Madeline have major short-term memory loss but also a deficit in Executive Function and a large dose of ADD. Steph called one Saturday and explained that Madeline was interrupting, couldn't focus, and couldn't remember what to do. I cried buckets that day and thought our world would never be the same, but I also understood exactly what Steph was saying. I tried everything to make it work at Edgewise, and so did Stephanie. She made lists for Madeline and I made sticky notes for her to put on the counter. I simply could not accept that Madeline wasn't able to work there.

So how did I come to the acceptance part? Madeline has just started her senior year of high school and with the stress of school, Edgewise and trying to remember the steps of her synchro program, she was more anxious than ever. I knew I had to take something off of her plate. The only thing that I could take off was Edgewise. It all became clear to me. Stopping work was not a set back, but rather a step forward in the progress. Her brain was not ready and that was ok. As her mom I had to learn to accept her pace of recovery.

So what did we do today on her first Saturday of sleeping in? We spent the afternoon together on the couch watching National Geographic cat stories. We are both very relaxed. Cats make her happy so that makes me happy. Recovery is a day by day process and we must be patient and help our loved ones understand IT'S OKAY!

**STROKE DOESN'T DISCRIMINATE.**

**KNOW YOUR NUMBERS.**  
Reduce your risk by doing the following:

1. Manage blood pressure
2. Lower cholesterol
3. Lose excess weight
4. Regulate blood sugar

**KNOW WHERE TO GO.**  
The University of Kansas Hospital - the first and only Advanced Comprehensive Stroke Center in Kansas City.

Learn more at [kumed.com/stroke](http://kumed.com/stroke).

**Madeline, 16, stroke survivor**  
Read Madeline's story.

If you are interested in having us help you get a group started at your hospital, contact

[Kimberly@joeniecroftoundation.org](mailto:Kimberly@joeniecroftoundation.org).

## BRAINS MATTER

by Beth Barnes  
JNF Patient Advocate



November is a cold, bleary month. The leaves are no longer beautiful fall foliage, Indian summer days are a thing of the past until next year. But for many survivors it can be a time of year that can bring sadness mixed with joy, especially with the onset of the holidays.

In the whirlwind of the season you are seeing friends and family you haven't seen. And that's when it starts. Perhaps it's Aunt Lucy at Thanksgiving dinner who asks the questions that we all try to set aside and forge on. The "oh honey, you don't look like you had that brain thingy operation". Or you run into friends from high school or college, and they search to see your scars. "Oh you look great even though..."

Holidays can often be difficult for anyone. And we become short, hurried, and don't think about what we say. Survivors won't often tell you what all of our fears are. After all, we made it through brain surgery. Hah! Little did we know that's the easy part.

If you were to look closely at a survivor, you would see a myriad of emotions, with the smile quickly in place. We know we had that "brain surgery thingy" and please, "you look good even though..." is tacky! Give us a hug and say hi. Ask how we are doing but focus on hearing what our reply is. We are rebuilding our lives in ways that are the new normal for us. That also means integration of the past. And just like a lot of people, stress is a partner in our world, holidays included! So be thoughtful and perhaps deflect the question that Aunt Lucy asks, and let's not focus on how we look but how we feel.

It's November, the month of Thanksgiving. I'm grateful for the gifts in my life, for the family and friends I have, for the JNF and everyone that it blankets. But don't forget to be thankful on a rainy April day. It's just as important then as it is now. Happy Thanksgiving!

## TOP TEN WAYS TO CELEBRATE NATIONAL CAREGIVER MONTH

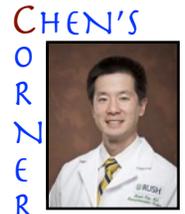
- 1) Offer a few hours of respite time to a family caregiver so they can spend time with friends, or simply relax.
- 2) Send a card of appreciation or a bouquet of flowers to brighten their day.
- 3) Encourage local businesses to offer a free service for family caregivers through the month of November.
- 4) Help a family caregiver decorate their home for the holidays or envelopes for their holiday cards.
- 5) Offer comic relief! Give a family caregiver your favorite funny movie to view, or provide them with a book on tape.
- 6) Find 12 different photos of the caregiver's family and friends. Have a copy center create a 2015 calendar that the caregiver can use to keep track of appointments and events.
- 7) Offer to prepare Thanksgiving dinner for a caregiving family in your community.
- 8) Take a few minutes to write a letter. Encourage your faith community to ask for prayers not only for those who are ill, but also those who care for them.
- 9) Encourage family caregivers to become a part of the [JNF Online Support Community](#). It's a great place to not only share but connect with others in like situations.
- 10) Share the [JNF Road to Recovery Handbook](#) with them to help guide them through the recovery process.



offer to address

# WHAT TO LOOK FOR IN YOUR DOCTOR

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



In medicine, as in any profession, there is quite a wide range of physician's skills, knowledge, interests and personalities. All of these factors can play a role in the success they have in caring for patients. These issues are of particular importance when caring for someone diagnosed with a brain aneurysm. As a patient, your outcome may very much depend on who is taking care of you in addition to the severity of your disease. There are many variables to consider when you are evaluating your physician. But there is one quality I would like to elaborate on in this column. That quality is patience.

People are in such a rush these days. Many new businesses are being formed now with the sole purpose of helping us do things faster and more efficient. It's hard not to get caught up with this popular trend, and not let this desire for efficiency get carried away.

With widespread adoption of electronic medical records, an emphasis on medical decisions based on clinical evidence and greater amounts of data available for each patient, there is also a tendency to seek ways to achieve efficiency in the practice of medicine today. Getting caught up in this wave of ever-improving efficiency stifles the opportunity for physicians to practice the type of medicine our patients often times truly need.

When it comes to brain aneurysms, we are confronting something delicate, complex, and potentially life-threatening or at least neurologically disabling. Part of what appeals to me about being a doctor is the necessity of really slowing things down when I care for my patients. There are many opportunities to slow down. When we are in the office reviewing the symptoms, medical history and imaging, I like to take my time and not miss any potentially important details. In our neurovascular conferences where we discuss our management approaches to challenging cases, I like to dwell a little on each case, to make sure we are considering as many perspectives as possible. Even in the procedure room, I carefully review safety checklists, and try to smoothly and methodically complete the case. It is easier to think clearly, to act precisely and to react appropriately when we know when to slow down and really focus in on the patient.

I hope you can recognize this quality in the physician who will be caring for you. After several years in practice, I understand more than ever the value of patience when practicing medicine.

## THE FAMILIAL LINK RISK FACTOR

You might consider having a brain scan if an immediate family member has been diagnosed with a cerebral aneurysm. Ongoing clinical studies have established a link for this condition among close relatives.

Among first-degree relatives, if one person has a cerebral aneurysm, it is suggested to have the rest of the family, children or siblings scanned.

A first-degree relative who has had a cerebral aneurysm may increase your chances. Studies suggest the link may vary between 10 and 20 percent, which only increases if you or your family members have other risk factors for cerebral aneurysms as well.

There are several steps you can take and lifestyle changes that may be beneficial in preventing an aneurysm and staying healthy:

- Don't smoke or use tobacco (cigarettes, cigars, pipes and chewing tobacco are all included)
- Exercise regularly
- Eat a balanced, low-fat diet
- Get help for alcohol and/or drug abuse
- Control your high blood pressure and diabetes

**NEW GROUPS HAVE BEGUN!!!**

[Click here](#) for a complete list of all JNF Support Group Locations



Joe Niekro  
Nov. 7th, 1944 - Oct. 27th, 2006

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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 aiding in the research and treatment of brain aneurysms, AVMs and hemorrhagic strokes. Our goal is to raise awareness about the risk factors, causes and treatments of these conditions while helping support the advancement of neurological research. We provide patient education and advocacy, support for patients and families, and develop awareness programs and educational materials for hospitals, clinics and other institutions nationwide.

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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