GUEST

Bill aims to minimize treatment delays for N.D. patients

BY EMILY BAKKUM

The first thing that came to people's minds about Shanna was her smile. It was warm, inviting and just the right amount of mischievous.

Her family didn't think much of her fall in September; maybe she missed a step off the deck. She had a headache but nothing so bad that it needed medical treatment.

That changed on September 19 when Shanna was life-flighted from Carrington to Fargo with stroke symptoms. After imaging, a neurosurgeon performed an emergency craniotomy, removing part of a tumor applying pressure to the brain. They saw three more inoperable spots. Initial reports determined it was likely lymphoma, but her care team was optimistic.

She was a healthy 40-year-old mother, and lymphoma is treatable. I finished my own cancer treatment a year prior. It was breast cancer spread to lymph nodes, so not the same certainly, but I became fiercely protective of my cousin. I was ready to be involved however she needed me to be.

We lost my cousin Shanna Barone on February 6, less than five months after the first sign of trouble. It was grueling and heartbreaking and perhaps there was nothing that could have been done to save her life, but dealing with the insurance company's prior authorization requirements certainly cost us time in a process where – aside from cancer – time was perhaps our greatest adversary.

Prior authorization is a practice in which physicians must obtain approval from insurers before prescribing medication or moving forward with treatment for their patients. Insurers use this, in part, to contain costs. Physicians report the process can lead to significant delays in care, contributing to negative outcomes in patients, including abandoned treatment. The process was once used sparingly to determine whether costly medical procedures or medications were needed but now providers often must get approval to prescribe even the most routine medications and procedures.

This is why I have testified in support of North Dakota Senate Bill 2280, which will place limits on the amount of time insurers can take to make prior authorization decisions. Such limits could have curtailed at least some of the delays faced by Shanna.

Her team of oncologists submitted prior authorization requests for aggressive chemotherapy and a PET scan upon admittance. She didn't get approval and receive those services until October 3 – an 11-day wait. The PET scan determined a mass in her abdomen, so a prior authorization request was sent for another chemotherapy regimen that would address that as well. She wasn't approved until October 11 – eight days.

Her oncologists remained vigilant and switched the plan on November 18. They wanted a better response, so they switched to R-ICE, a combination of four chemotherapy drugs given over several days. They would follow with CAR-T cell therapy, a process that usually takes between three and four weeks to complete.

On January 2, Shanna's oncologists submitted the prior authorization request for CAR-T because they knew she would need it sooner than later. Her symptoms increased daily. She lost vision in her left eye, then movement and feeling on that side, then her speech. Her skull skin was so tight around the growing tumor it was shiny.

Radiation began then also to buy time waiting for approval. By January 5, she was admitted to the hospital and would never leave.

On January 10 – two weeks after the initial physician request — Shanna got "soft approval" for CAR-T from the insurance company, but they "couldn't" sign off by the end of the business day and told us to wait until the next week. Formal approval was received on January 14 and the lab processes were completed by January 29.

By then, she had declined, so she had to undergo another surgery to place a shunt in her skull to relieve pressure. We were so encouraged by her response – she was responsive and spoke clearly for the first time in weeks. But two days later she declined again. Additional cancer cells had been allowed to grow during the period she waited for approval.

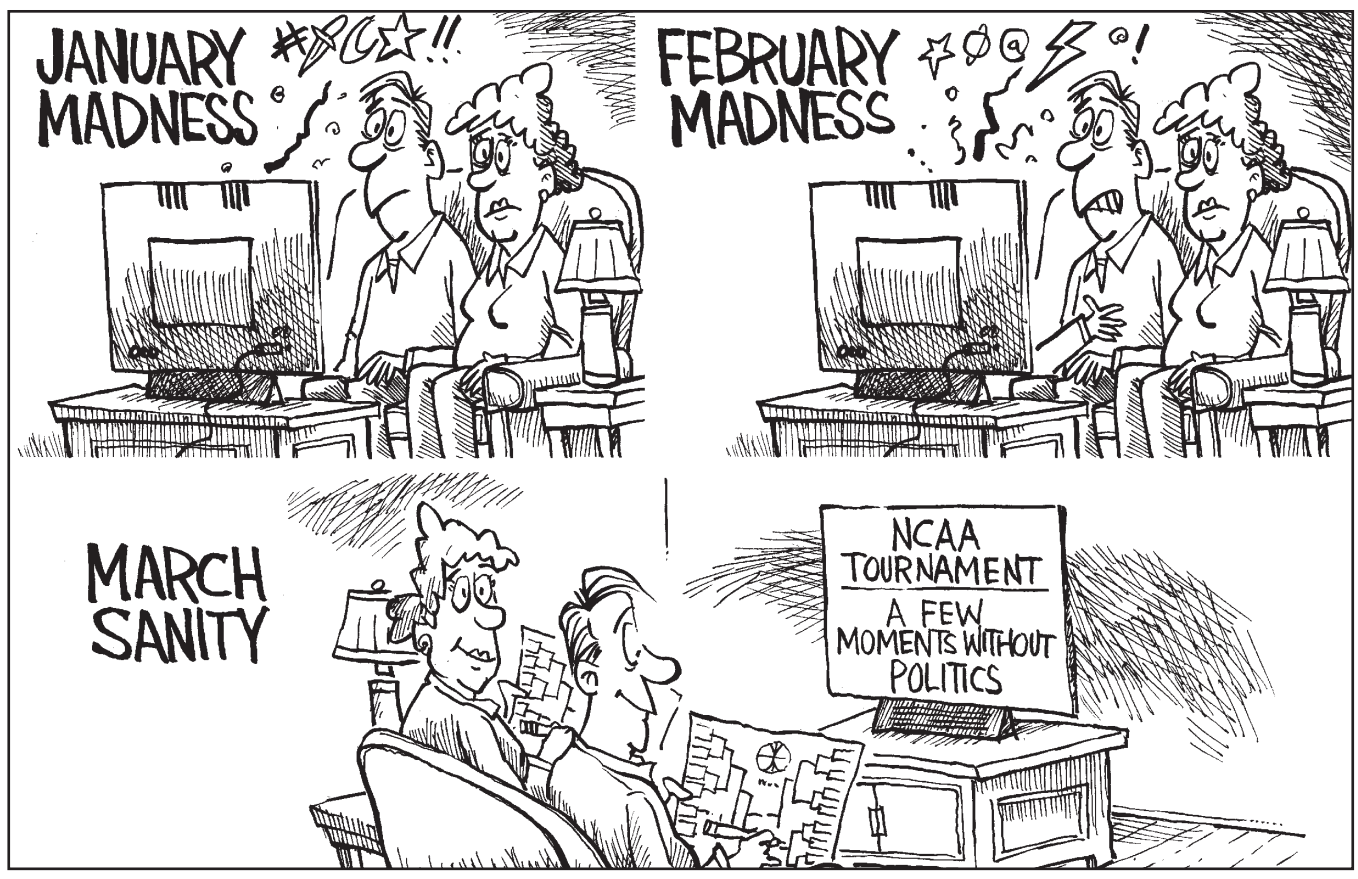
Shanna passed away February 6, 10 days after her 41st birthday.

Shanna knew her battle would be hard, but she went into it with fiery determination, an intelligent, compassionate care team and family support.

Her life depended on decisions she didn't get to make, ones that increased suffering and anxiety in the interim. If a simple set of laws can prevent this situation from happening to another North Dakotan, the decision to pass this bill is an easy one.

This article was originally published on the North Dakota Monitor at https://northdakotamonitor.com/.

Emily Bakkum is a breast cancer survivor and marketing professional based in Fargo. She's passionate about using her experiences to create a gentler pathway through cancer treatment for future patients.



UPSIDE DOWN UNDER

March is National MS month ...

BY MARVIN BAKER

Editor's note: This is the first of a three-part series about multiple sclerosis (MS), an auto-immune disease that attacks the central nervous system. Statistically, North Dakota and Ohio have the second-highest incidence rates in the nation, followed only by New York state. There are numerous possible triggers including a lack of Vitamin D, heritage and radiation.

Because March brings attention to multiple sclerosis in the United States, it seems appropriate to present information about this disease of which there is no cure.

And just to be clear, North Dakota has among the highest rates of MS per 100,000 people. Nationally, the highest rates are northern latitude states with a couple of exceptions.

MS can strike just about anyone at any age, but the highest statistics, by far, are among women age 20-40. MS rates among men in that same age group are two-times less. There is no definitive reason for this, however, several theories. They include Vitamin D deficiency, hereditary and environmental issues such as exposure to unusual amounts of radiation.

Statistically, MS is all over the map. It's very difficult to pin down comparative numbers, although some are available that can shed some light on this mystery.

It's always been believed that the higher the latitude, the greater the chance of contracting MS. And that remains true to a point, in the United States. In Europe, that's not always the case.

According to the National Multiple Sclerosis Society, 2.9 million people in the world suffer from MS, with 1 million living in the United States. The highest rates per country per 100,000 people include Germany 303, the United States 288, Canada 250, Norway 248, Iceland 212 and the United Kingdom 196.

The lowest rates in the world include Panama with 6 people per 100,000 and Russia with 3.8 per 100,000 which certainly defies the latitude argument.

Statewide statistics are very similar. New York has the highest rate per 100,000 at 377 with Syracuse having the highest rate of any city in the nation. North Dakota and Ohio have the second-highest rate at 353, followed by Michigan 348, Minnesota 343 – with Olmstead County, including Rochester and Mayo Clinic with the highest incidence rate of any county in the United States – and Wisconsin 338. The Montana rate is 250 per 100,000.

The lowest rates of MS are in Hawaii and Alaska. Hawaii's rate is 47 per 100,000 and Alaska's rate is even lower at 22 per 100,000, again defying the higher latitude argument.

But because MS incident rates are among the lowest among First Nations people, it could explain the lower rates in Alaska and Russia because of sizable native populations.

In Canada, MS rates are very similar to those in the northern U.S. Alberta has the highest incidence of any province with 358 people per 100,000 contracting MS, followed by Saskatchewan at 315.

Other provinces use different measuring mechanisms so it would be unfair to compare, although Mari-time Canada has similar rate as those in the New England states.

According to the National MS Society, rates have been increasing steadily since 1976 and took a huge jump between 2009 and 2010. But, it's possible part of that increase could be the result of better diagnoses.

In 1976, there were 58 people per 100,000 with the disease. By 1994, it had risen to 85. In 2009, the rate was 209 and it jumped to 309 in just one year. By 2017, the rate had increased again to 362.

It is possible that with an increasing population comes an increased risk. But the increase in cases doesn't seem to match the increase in population levels over the past 50 years.

It has been known that radiation is a cause of MS. In fact, a study of the people who were exposed and survived the Chernobyl explosion in 1986, indicated nearly all of them contracted MS.

However, a stronger belief is in the lack of Vitamin D. Just about every study out there will tell you there is a link between MS and Vitamin D deficiency. It is also assumed that Vitamin D doesn't prevent MS, but adequate use of it can minimize the risk or even control some of its symptoms, according to Mayo Clinic.

Marvin Baker is a news writer for the Kenmare News and formerly Foster County Independent.

GUEST

More children needed

BY TOM PURCELL

It's a growing concern that world leaders, economists and even Pope Francis have warned about: people aren't having enough children.

Across the globe, birth rates are plummeting below the replacement level of 2.1 children per woman, the minimum needed to maintain a stable population.

Countries such as Japan, Italy and even the U.S. are now facing shrinking workforces, aging populations and economic uncertainty as a result.

Pope Francis, too, has urged families to embrace more children, praising the value of big families, which teach children selflessness and sharing – benefits that extend far beyond the home.

And I couldn't agree more.

I was raised as an only boy in a family of six kids, which was at once a blessing and a curse.

When I was 12, the neighborhood bully was constantly picking on me, but I had no brothers to teach me to fight. My sisters taught me. I looked the bully dead in the eye and said, "You are sooooooo immature!"

Despite having no brothers, my father made me wear hand-me-downs. It wasn't too bad most of the year, but Easter Sunday was unpleasant. Do you know how hard it is to outrun the neighborhood bully with your pantyhose bunching up and your bonnet flopping in the wind?

Though my sisters loved and doted on me many times, other times they complained to my parents that I was stinky and gross, which meant I was forever banished to the third seat in the back of the station wagon.

One of my fondest memories was going grocery shopping with my father every Thursday night. We hit the Del Farm grocery store, the beer distributor and the butcher and we arrived home just as "The Waltons" theme song was playing on television.

Like a Red Cross operation, everyone in the house unloaded and packed away our weekly supplies, then we joined for some potato chips and orange and cherry soda pop as we watched John Boy and his many siblings show us what life was like during the Great Depression.

Pope Francis has said that "having brothers and sisters is good for you." He said, "the sons and daughters of a large family are more capable of fraternal communion from early childhood."

He has also said that "each family is the cell of society, but the large family is a richer, more vibrant cell."

I found this to be true.

My parents' house was a wonderful, raucous place, filled with laughter, chaos and lots of love and joy. You had no choice but to interact.

I can't help but wonder how many of today's kids – without siblings and isolated with their smartphones alone in their rooms – are missing out on the childhood I was blessed to have.

According to a 2023 report from the U.S. surgeon general, young people are experiencing record-high levels of loneliness and anxiety.

Being part of a big family would solve that problem. You simply can't isolate yourself with so much commotion going on all around you.

And if you attempted to hide from the rest of the family, one of your siblings would demand you come out of your room or risk the greatest punishment that can happen in a big family.

Someone would threaten to brush their teeth with your toothbrush!

Find Tom Purcell's syndicated column, humor books and funny videos of his dog, Thurber, at TomPurcell.com. Email him at Tom@TomPurcell.com.

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