37,000 shot keeps Waynesboro girl with rare juvenile arthritis alive

Rebecca Bussey has Systemic Juvenile Idiopathic Arthritis. This is not your grandmother's arthritis.

By Monique Calello, Staunton News Leader

https://www.newsleader.com/story/news/2019/04/03/shot-keeps-waynesboro-girl-rare-disease-alive-rheumatoid-systemic-juvenile-idiopathic-arthritis-va/3280511002/

LADD – On a warm, breezy Friday night in the middle of March, four kids are playing in their backyard overlooking a cornfield. Squinting from the sun beginning to set, mom and dad stand by and watch their joy.

The youngest of the four is 3-year-old Rebecca. She is wearing a superhero cape and running through the field giggling. Her sister and brothers chase and twirl her around before they all plop down on the grass laughing and taking turns to hug her.

This is the Bussey family – Julia, Carter, Wyatt, Rebecca and parents Amy and Brent. Amy teaches English and theater and directs the theater program at Stuarts Draft High School, and Brent manages the local Sprint store on Main Street.

You would never know by looking at Rebecca that there is anything wrong, that her family is thankful she is alive. For them, every day they have with her is a celebration.

“Right now, she’s doing great,” says Amy. “We’ll fight for her.”

Rebecca has a rare disease, Systemic Juvenile Idiopathic Arthritis. SJIA is not your grandmother’s arthritis. Known as Still's disease in adults, about 300,000 U.S. kids under the age of 16 have JIA. Ten to 20 percent of them have the systemic form, which means the disease not only affects the joints but also other parts of the body, including the liver, lungs and heart. Idiopathic means the cause is unknown.

“She’s a trooper, and tries to be happy no matter what,” says Amy. “And I am trying to be positive, too, but I hate this disease.”

Brent picks up Rebecca and looks at her tiny hand as she grasps her cape. He’s quiet and contemplative. Amy is hopeful, but you can see she is scared. Loving parents, both of them are humbled by circumstance, with a sadness behind their eyes.

“I feel like I’m waiting for the other shoe to drop,” says Brent. “I’m constantly in a state of alert waiting for something to happen.”

Amy wonders, could it have been the chemicals used in the cornfield? That’s what parents do when their children are diagnosed with something unknown. In the uncertainty, parents search for answers. They wonder, did we do something wrong? Was it this place? My age? Something I took while I was pregnant? Could it be the water? Could the answer be hidden in the cornfields?

“There is so much anxiety and fear at the unknown diagnosis,” says Amy.

It's an incurable disease with information so new and uncertain that their doctor made them promise to resist the temptation of researching it on the internet. Medications are expensive. What's next is unknown.

She became very sick and almost died, but that could be when the condition ends, a one-time problem. She could remain in remission for years. Or she could be on a lifelong roller coaster of hopeful ups and terrifying downs. The third possibility is more ominous: Rebecca getting sicker and sicker from a potentially fatal disease.

“That’s our fear,” says Amy. “Lung complications are a thing that a lot of people deal with, with SJIA. We are hoping and praying that this does not turn into interstitial lung disease like a lot of kids with this get.”

An autoimmune and auto-inflammatory disease, it has resulted in multiple ear infections, strep, flu, pneumonia three times and a pleural effusion that required chest tubes and surgery. Any inflammation confuses her immune system to ramp up and attack itself.

“Her condition makes her more susceptible, and it also makes her body’s reaction to things more extreme,” says Amy. “When her immune system gets turned on, it goes off the charts.”

“It doesn’t differentiate between the good and the bad,” adds Brent.

Because her form of the condition is systemic, she can experience a condition called MAS – macrophage activation syndrome – a life-threatening complication that can occur in systemic rheumatic diseases.

“The systemic feature is what is the most difficult,” says Amy. “That’s the part that’s scary because it can cause organ inflammation, inflammation of the brain, inflammation anywhere in the body. There’s a little girl – the inflammation is in her brain, and she’s had 10 surgeries.”

SJIA and MAS are so rare, each member of Rebecca’s family carries an awareness card to hand to emergency physicians should Rebecca wind up in the hospital. Since they joined an online support group, five of the group's children have died, and only four pediatric rheumatologists in Virginia are qualified to treat Rebecca.

They're lucky, Brent says. She has one of the best doctors. He’s in such demand and so dedicated that it is not unusual for him to answer phone calls from frightened parents in the middle of the night while on vacation. Brent knows because he’s one of them.

“Absent having a working crystal ball, we don’t know what the future will be,” says Brent. “What will be the new ‘normal’ for our lives and hers? We have a long road ahead of us.”

‘Little Bit’

After playing outside, the family sits down in the living room. The kids are on the floor by Rebecca’s dollhouse. Big sister Julia, now a sophomore in college, sits by the coffee table. Mom and dad are on the couch and talk about what started happening when Rebecca was a year old.

In the fall of 2016, Rebecca started to get sick and wasn't getting better. She got an ear infection, then strep, a cold, strep again, the flu, pneumonia, another ear infection.

A really good sleeper, as an infant Rebecca was the only one who slept in her own bed all night. But she had trouble gaining weight, so they couldn't let her sleep through the night. It was Thanksgiving when she started to get sick and would climb into her parent's bed unable to sleep unless it was with them.

She started to have a high fever, and they couldn't figure out what was causing it. She wasn't testing positive for anything.

"She'd be OK in the morning, and then every night she'd have a fever," says Amy. "Every day, right about 3:30, the fever would go up."

The fever would last four months, reaching 103.5 degrees.

"That's one of the hallmarks of the diagnosis," says Amy. "A fever that spikes at the same time of the day, every day."

Rebecca was in severe pain, with hot, swollen joints and was lethargic at night. All she could do was sit on her daddy's lap. She suffered from diarrhea and vomiting along with respiratory and ear, nose and throat infections.

Brent took her to the pediatrician four days in a row. After 16 consecutive days of a high fever, the doctors told him to take her to the emergency room at University of Virginia Health System University Hospital. They went in that night, and Amy stayed at the hospital with Rebecca for more than a week.

"It was Saturday morning that they came to us," Brent remembers. The hospital called pediatric rheumatologist Dr. Aarat Patel while he was at a conference in Baltimore. Patel told them to try naproxen to see what would happen.

"The first dose of naproxen, the fever went down. It was almost magical."

Brent reached out to family and friends online to update them.

"'Little Bit' has been home from the hospital for almost two weeks now. She hasn't had any fever to speak of for well over a week now. But she's still a sick little girl."

A diagnosis of exclusion was the key. Once Patel ruled out leukemia and lymphoma, he told them he was certain it was SJIA based on how well she responded to anti-inflammatory medication, along with the hallmark sign of an everyday fever for a month.

"Those days when we thought Rebecca might have cancer were among the worst of my life," says Brent. "Then, there was the relief of hearing that she definitely doesn't have cancer, followed by the earth shatteringly painful realization that this diagnosis isn't a whole lot better."

"I gotta bring you back down to Earth," Amy remembers Rebecca's doctor saying. "This is not necessarily good."

After the fevers went down, they discovered Rebecca was in considerable pain. Amy’s grandfather had passed away; while attending his funeral in Tennessee, her mom, who is a physician, said, “Amy, she’s in pain.”

“She was waking up in the middle of the night screaming in pain,” says Brent. “Every night.”

“She was really, really hurting,” says Amy. “We thought we were losing her. We thought she was dying. It is terrifying.”

“We went through that twice in the space of one year,” says Julia. “Where she got really sick, and we didn’t know if she was going to make it to the next hour.”

“The second time she was hospitalized,” says Amy, “I thought, I’m losing my baby.”

“That was during the lag time between him writing the prescription for the Ilaris and the approval,” says Brent. “Three months. The initial prescription for Ilaris was written on Oct. 11, 2017. Her first dose was administered on Jan. 11, 2018.”

A $37,000 cure

A car pulls into the gravel driveway and the conversation comes to a stop.

The home health care nurse has arrived to give Rebecca a monthly dose of the biologic medication, Novartis’s Ilaris. The small vial costs anywhere from $16,000 to $37,000 per dose depending on insurance coverage. It was those three months waiting for approval that almost killed Rebecca and resulted in a $300,000 hospital surgery bill, while the family waited for their daughter's medication.

“The straw that finally broke that camel’s back was the rheumatologist calling them and saying, ‘I want to know why you’re denying it. I want to talk to your medical evaluation board, and I want to know there’s a pediatric rheumatologist sitting on it.’ They said, there’s an adult rheumatologist. He said, ‘No. They don’t get it. I want a pediatric rheumatologist on it.’”

While their health care insurance company Aetna approved the medication, the family still has to pay a portion of the cost negotiated by their prescription benefits company, which owns the specialty pharmacy that provides the biologic.

“Our prescription benefits through Aetna are through Express Scripts who own Accredo,” says Brent.

Since the biologic is as rare as the disease it treats, there are only three specialty pharmacies in the country that provide it. SJIA specialty pharmacy advocates help parents get the medication shipped overnight since this isn't a treatment where someone can miss a day.

The insurance coverage and cost negotiations vary so drastically that none of the families with SJIA kids can get a straight answer on price. Brent has given up trying to find the answer after calling the pharmaceutical company, insurance provider, prescription benefits manager, specialty pharmacy and asking other SJIA parents.

“I’ve never been able to get a straight answer from Accredo regarding cost without insurance,” says Brent. “They simply won’t answer the question. We were initially told $25,000 per dose by the rheumatologist. One of the parents at a conference in Cincinnati last summer said it had risen to $37,000, and there was a Novartis rep there who didn’t confirm or dispute that figure.”

'We have to take a third of this and just throw it away'

Now on his 16th visit with the Bussey family, there is a comfort level as nurse Dan Wyatt enters through the back door and into the kitchen. They all fall into rhythm together as they begin to distract and soothe Rebecca while Wyatt fills up the syringe with the medication.

Rebecca sits on the kitchen island while Julia plays patty cake and touches nose to nose, as mom and dad slowly gather round her.

When Wyatt is ready to give her the shot, the three help to hold her down because shots are scary for little kids. After he is done, they put a kid’s Band-aid on Rebecca’s arm while making sure she knows what a brave warrior princess she is until the fear and tears are replaced with happy laughter.

They started Rebecca on 50mg of Ilaris, then increased it to 75 and then 100. Each time, the family has to go through an approval process with their insurance. The vial comes in set milligram increments, so any remaining medication inside the vial must be thrown away.

“The most painful part is this is a 150mg vial,” explains Brent. “She gets 100mg injected, but after oxygen is introduced, when he draws it out with the syringe, it has to be thrown away. So we have to take a third of this and just throw it away.”

Before starting the biologic, she was on steroids daily, naproxen twice a day and methotrexate, a chemotherapy medication. Because of her compromised immune system, being off the steroids has resulted in a major improvement in her overall health. Now she’s on naproxen only as needed.

Little Bit is no longer too little or underweight. She had fallen physically behind, but she’s made up all of that, says Amy, and intellectually, says Brent, they don’t see anything wrong.

“What a difference one year (and some great doctors and magical medications) can make,” says Brent. “Rebecca still struggles. She probably always will. But she’s strong, and she’s tougher than anyone I know. She’s a warrior.”

Last summer, the family traveled to Ohio to participate in a study at Cincinnati Children’s Hospital, the first of its kind for kids with SJIA. About 40 families attended, which helped the family grow their support net while living in the unknown and trying to find answers. But it also gave them a close-up view of what those three roads look like ahead.

Amy and Brent know Rebecca isn’t yet on the first paved road of remission, but while the Bussey family walk down that second bumpy road of ups and downs with their Little Bit warrior princess, they hope they will never find themselves going uphill on that last road.

“What are we looking at?” Brent asked Patel during one visit. “Just please level with me,” he pleaded. “And the doctor said, ‘I will not stop until this child develops and has a normal childhood. I will not stop. I will not give up.’”

And neither will Rebecca’s family. They will hold her hand in the grass, the cornfields, the kitchen, hospital, and on any road, hill or mountain because this is the Bussey family, and whether you can see it or not, they are all wearing superhero capes.

One downhill bike ride and Dr. Robert Kyler knew he would never walk again

When Jim Vance ran to help his friend in the ditch, Kyler was already trying to diagnose himself.

By Monique Calello, Staunton News Leader

https://www.newsleader.com/story/news/2019/04/29/spinal-cord-injuries-dr-kyler-knew-he-would-never-walk-again-cycling-virginia/3466065002/

STAUNTON – It was over in a second before Jim Vance could process it. They were riding downhill fast on their bikes. It was their typical "go-to quick two-hour ride," said Vance.

On a paved road in sparsely populated farmland on an early July morning, his friend Rob Kyler was out front descending on a long, steep hill. Next door neighbors during the summer in upstate New York, the two rode bikes together all over the world.

Kyler liked to go down hills quickly, and when Vance looked up he saw his friend's bike veer to the right into the gravel on the side of the road and flip over into a ditch.

Vance came to a sudden stop and ran to the ditch to find Kyler lying on his back on top of his bike. Conscious and moaning, he asked Vance to move his leg for him. Vance straightened Kyler's arm out, took his helmet off and gave him water, but wouldn't move his leg. He was worried he might cause further damage.

"He was already trying to diagnose himself."

Dr. Kyler led a healthy lifestyle

Radiation oncology medical director in private practice at Augusta Health’s Cancer Center, at 58 years old Dr. Robert Kyler led a healthy lifestyle.

Physically active his entire life, he was in good shape and enjoyed exercising, being outside and working up a sweat. Athletic, his vacations were tailor-made for cyclists. And he reaped the benefits in total health. His face had a rosy glow, he was muscular and full of energy.

He was the physician; not the patient.

The dichotomy of shifting from one identity to another didn’t surface until later. At the moment, lying by the side of the road in excruciating pain, he knew when he couldn’t feel his legs that he'd suffered a spinal cord injury.

“I never bike by myself because it’s just not safe,” said Kyler as he looked back on that July morning from his living room at home. There is subtle irony in his voice as he talks about how he followed safety rules for cyclists — the guy who always had the high-intensity LED blinking lights.

Sitting in his wheelchair, his primary chair, he calls out to Fritz, his dog. His rosy glow gone, he is pale and slightly dehydrated. Wearing a bright green t-shirt from rehab and sweatpants, his muscles below the waist have atrophied.

He is still building strength in his upper body while working through constant neuropathic pain and pain from the damage developing in his shoulders.

With a body type that is tall, long and lean, it is essential he build muscle in his chest and shoulders. He keeps an electrical stimulation (e-stim) bike in another room to keep the muscles in his legs from further atrophy, which helps to reduce swelling.

Now his life isn't about working up a sweat and using up all that good energy from exercise. Now his life revolves around utilizing the best methods to conserve energy.

Making sense of the accident

Trying to make sense of the accident is impossible. The irony spills out everywhere. While he may have been a risk taker on the bike from time to time, he wasn't doing anything risky on what was supposed to be an uneventful ride; a ritual before he and Vance headed to a late morning workshop they liked to attend during summer.

Vance said Kyler was riding maybe 35 mph, tops. That's fast, but not crazy fast according to other cyclists. In bike speak, they were cruising.

It was an accident for no reason, plain and simple. He grapples with this brutal truth as he attempts to accept he will never find the reason why it happened.

“As I was going down the hill, I just lost control of the bike and don’t know how because I’ve been down that hill multiple times.”

Kyler said he hit something on the road and was thrown from his bike. He landed in the ditch, his feet pointing uphill.

“As soon as I landed, I realized that I had done something pretty bad. I couldn’t feel my legs, couldn’t feel my waist. Really from the mid-chest down.”

Vance called 911 and sat there with him until the ambulance arrived, which took him to a landing zone a few miles down the road. A helicopter was waiting to airlift Kyler to a hospital with a trauma center in Erie, Pennsylvania.

Learning new normal: Paralyzed, rehab and painkillers

Even before he saw the scans from the ER doctor, Kyler knew he was paralyzed.

“It’s weird. There’s this dichotomy. As a physician, you’re taught to be very objective and look at the facts and analyze things. That’s what I was doing initially because that becomes second nature to you. There was that intellectual part of me that said, you’ve severed your cord, you are never going to walk again.”

After seven hours of surgery to stabilize his spine, followed by surgery on his neck, he remained in ICU for a week before he went to the Shepherd Center in Atlanta, a facility specializing in spinal cord injuries. Kyler spent seven weeks there as an inpatient, followed by six weeks of outpatient rehab.

Much of that time was spent in a drug-induced haze from painkillers, which also helped to shield him from the full emotional impact of what had happened.

It was at the Shepherd Center he realized his life would never be the same.

“You can’t even roll around in bed. When you don’t have any trunk strength, the lower two-thirds of your body is dead weight. It doesn’t help you.”

His center of gravity off, Kyler had to learn a new way of moving. He realized that being paralyzed was much more than not being able to move his legs. He had to learn how to do everything again.

And he was so tired. Given the limitations imposed by his health insurance provider, the Shepherd Center had to do as much as they could within the coverage time period.

He was in exhausting therapy every day, all day.

Come evening when he was lying in bed, he'd binge on "Game of Thrones."

"I used that as a way to distract myself from facing or thinking too much about what I was going through."

Teacher becomes the student: 'Pain is inevitable, suffering is optional'

For years, people suffering from chronic pain that medicine alone could not alleviate had come to Kyler for advice.

Now the teacher of the meditation- and yoga-based program would have to become the student.

He had a list of principles, mantras and sayings that he'd mentioned hundreds of times.

"Pain is inevitable; suffering is optional. Pain times resistance equals suffering. You're not ever going to get through life without some pain or unpleasant circumstances, but it's the degree to which you resist and push it away, that causes the suffering."

It would be different being the one who needed to listen and apply them.

"I still suffered. I didn't want to be there. I didn't want to be going through any of this," he said. "But I realized, I can't go back in time and change this. The more I resist, the more I try and wish it away and complain and feel sorry for myself, the worse it's going to be."

"The transfers are a huge part of what you learn," he said. "It was so hard at first because you're weak and your balance is off, and again, you have all this dead weight that isn't helping. You learn how to use it."

Having to learn how to do simple things he used to do with little effort were now tremendous challenges—and when he accomplished them, significant milestones. Learning how to sit himself up in bed. How to get himself to the edge of the bed. And the "transfers"—transferring himself into a wheelchair, out of a wheelchair, into a car.

"Stuff you take for granted. When you think about spinal cord injuries, most people think, oh, you can't walk anymore. If it were just that it wouldn't be so bad. But what people don't see is that there's no bowel or bladder control, and it's a whole new way of learning how to regulate that," he said as he rolls himself out of his bathroom after explaining the devices and items he needs to urinate, empty his bowels and bathe.

"And get dressed. How long does it take you to get dressed?"

It used to take him five minutes in the morning.

At the start of his rehabilitation, it took him over an hour to put on underwear, pull on pants and socks, get his shirt on. Now he can do it in 15 minutes.

“It was so frustrating to all of a sudden be at the very beginning.”

Building up his endurance and strength were concrete tasks that he could do that weren’t challenging psychologically.

Kyler learned the basics to function at home almost independently, though he still needs some help. Wilson Workforce and Rehabilitation Center provided a home assessment to fine-tune everyday living to help cultivate this independence.

When he goes to WWRC for physical and occupational therapies, he calls it finishing school. His occupational therapist is helping him with the way he’s transferring from his primary chair to his car. She will observe him and offer more efficient methods to get himself, and his wheelchair, in and out in a way that won’t wear him out.

His therapists are helping him prepare for a trip. Experiences that usually meant packing a suitcase and grabbing his bike gear now require careful examination and a vastly different itinerary.

From buying the right mobile toilet seat to getting back into a pool ahead of time, he needs to deconstruct the trip in advance and conduct a trial run. Since the trip involves going into the water, he wants to go into the water first with a therapist's help. He must regulate his bowels and said he is like a baby who poops in the pool. Feeling infantilized, he cracks jokes about bodily functions to ease the discomfort that might be felt by others.

It's this discomfort that creates a disconnect between the person sitting in the wheelchair and the chair.

Kyler is matter of fact with an incredible sense of humor and wit given his circumstance. He just bought a Tesla, and he wants to make it work even though it isn't wheelchair friendly. But will it ultimately be the right car for him? It is up to him to determine where he wants to expend his energy, even if now that energy is essential. It is a balancing act between fighting the disability and living with the disability and deciding what quality of life is best for him. And that's his decision to figure out.

He's going to work with a company that makes equipment to lift his chair into the trunk so he doesn't have to take it apart and bring it into the passenger seat, then put it back together in order to transfer in and out of his car. It's expensive, but he can afford it financially.

Whether or not he can afford it physically and then mentally remains to be seen. He isn't hiding from the pros and cons and his occupational therapist gives him options. They work out the transfer in the Tesla, and then they try out a wheelchair accessible van. It's up to him. And it should be. He isn't helpless in this respect.

Physical therapists help him manage pain. Now that he is in a wheelchair, strength and flexibility in his shoulders are critical, and injuries sustained from the wear and tear of adapting to the wheelchair will require shoulder surgery. Any smart drive device for his wheelchair won't be approved by insurance for a one-year time period following the date of his accident, and until he can provide evidence of shoulder damage.

He cracks an offhand remark that insurance companies are waiting to see who lives a year after their accidents.

"Attrition rate," he jests.

It helps to ease the tension most of us feel regarding insurance coverage rules. This particular rule surrounds a device that will reduce shoulder damage, alleviate pain and improve quality of life. Waiting for the damage to happen requires an offhand remark, and Kyler has the wit to deal it.

According to his physical therapist at WWRC, almost all "outside the home" devices, including any to make his vehicle handicap-accessible, are not covered by health care insurance providers.

Kyler paid out of pocket for a $15,000 stair lift at home, something he came to discover he can't use safely or independently to get to the second floor of his house

He wanted it to work so that he didn't have to depend on his wife so much. But it didn't work, and as a result, he moved his bedroom and bathroom to the ground floor into what used to be his home office.

It has a makeshift feel. It wasn't meant to be a bedroom and there's a "I'm still figuring this out" feel about it.

"Nancy has had her life changed as dramatically as mine. She has been on this journey with me every step of the way. My hope and goal throughout the rehab process was that I would be able to become as independent as possible so that she could go back to becoming my spouse rather than my caregiver, but the fact remains that I still need her for so many things and would not be where I am now without her."

Reactions from others spur blog to write about his experiences

After Kyler's accident, his daughter started a blog on Post Hope, a support website normally used by patients to journal their experiences, as a means to update people on her father's progress. While at Shepherd, when Kyler was finished with therapy and alone at night, he began to post. He remembers thinking it could be more than a "how's Rob doing."

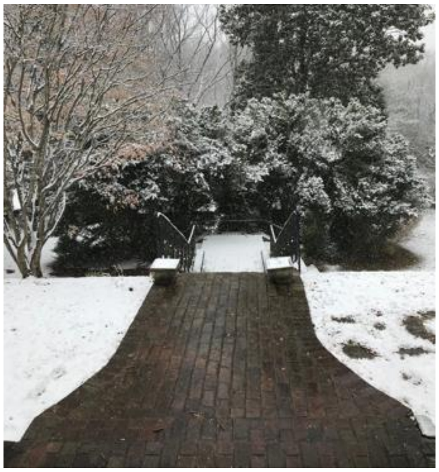
"I realized this is more than going to the hospital, having an operation, going home and recovering. This is about learning a whole new way of living, and I never knew anyone who had ever been through this. Statistics would say that most people haven't."

Most people don't want to ask a person what happened when they see a person in a wheelchair. All you see is the wheelchair, Kyler says.

"I never did," he said.

There is an overwhelming sense of helplessness, and in this feeling it is easier to stare at the chair than the human being sitting in it because we cannot imagine what this must feel like. It is frightening, and in this fear we become silent. A chasm forms that dehumanizes the individual with the disability.

"I think for many people it makes them uncomfortable, and they are scared to ask what happened. What is it like? What are your issues?"



His home in Staunton is a house of steps. Multiple sets of steep brick steps leading up to his front door and a staircase as soon as you enter. Although changes have been made to his home so it is wheelchair accessible, the steps are a reminder of what he can't do. He will never walk up those steps again. Extraordinarily beautiful landscaping of a house on a hill that now feels extraordinarily brutal.

One of those scary questions might be: Does it bother you?

This gut reaction is one of those thoughts you keep to yourself. A question that lingers. Our minds begin to fill in the blanks quietly while he sits in the room alone.

Thoughts flood in... questions we are afraid to ask ourselves.

It must be so hard.

How do you stay positive? How do you stay strong? Are you depressed?

I don't think I could do it.

What is the hardest thing for you? Do you feel alone? Do people treat you differently?

As human beings, another person's experience is a mirror. The questions feel too personal. We haven't figured out how we feel yet about what we are seeing, but we yearn to know so we can understand.

Kyler saw the blog as an opportunity for those who may be interested in learning the process of recovering from a spinal cord injury. What’s life going to be like? How has it changed? To give people a chance to ask him questions and express their feelings.

Perhaps this shared understanding will help more people see the human being instead of the wheelchair.

It is also giving him a chance to say what he is feeling at every step of his rehab.

For Kyler, the blog became a form of therapy. He had to solidify thoughts surrounding his experience and write them down, which helped him come to terms with what happened and the journey ahead.

“What was I thinking at this point? How was it? What were the difficult things for me? That’s what it became,” he said.

Physician-patient bond

Less than four months after the accident, Kyler returned to work.

First a couple half days a week; gradually more. In retrospect, he thinks he may have started back earlier than he should have, but he had to do something outside of just being at home. He wanted to feel useful again.

It wasn't long before he was back at work full-time.

Kyler's life was about taking care of himself while helping others. Although the accident happened at 58 and the average person who suffers from a spinal cord injury is about 20 years younger, he believes because he was in good shape and took care of himself, it helped his recovery.

He says work is going great. If anything, he finds it more gratifying than ever. After the accident, he wasn't sure he would ever be able to go back to work. He also had time to reflect on his career and realized how much he loved and missed his work.

And he’s learning to adapt. He has a power assist chair that helps him get around the clinic and alleviate stress on his shoulders.

“It’s not all happiness. I have chronic pain. I’ve got chronic neuropathic pain that’s there all the time.”

The pain gradually gets worse as the day goes by, and he has to deal with ongoing pain that never goes away. It waxes and wanes. It's been bearable, he says, but it's a constant presence in his life.

"Again, it's ironic because the class that I taught was for people with chronic pain that had reached the limits of what medicine can provide. And that's kind of where I am now. All these medications don't help with this kind of pain. So I'm just learning. I've had to really put into practice what I taught people, which is acknowledge the pain, be present with it, don't push it away, notice it, and watch it come and go and accept that it's there."

Acceptance is different from resignation, he says.

Sometimes Kyler is in resignation rather than acceptance, he admits. It has taught him a deeper empathy and genuine connection with his patients. Almost every one of his patients has an issue he connects with now. He knows chronic pain. He knows what it's like to take a handful of meds. He knows what it's like to deal with constipation, incontinence, depression and having to go back to work with all of this happening.

Of all the doctors Virginia Lloyd-Davies has seen, Kyler is the most compassionate, she said. When she heard about his accident, she burst into tears. Diagnosed with anal cancer, she said she is part of the NED club now—no evidence of disease.

"Having been through absolutely agonizing cancer treatment two years ago, I'm extremely grateful to be in good health. Rob Kyler is a large part of the cause of how I'm doing now."

Never in her wildest dreams did she think Kyler would be able to return to work.

"He had been through the fires of hell, just as I have, just as so many of his cancer patients go through this incredibly difficult situation. He is the same person—deeper, richer, if possible, more compassionate because of his own vulnerability. The pain he had been through and continues to go through makes him understand pain and trial in other people."

Lloyd-Davies mentions that even under dire circumstances, he managed to keep his sense of humor. She begins to laugh and says he cracks her up. He wrote in a blog post that he always felt doctors should go through some kind of health issue to improve their compassion, but what he had in the mind was a bad case of hemorrhoids.

He is not only their physician now, but a patient right alongside them. They are going through it together. And for Lloyd-Davies, she too has learned to put mindfulness into practice. Her experience was so painful and terrifying, all she could do is say, “I’m alright at this particular moment.”

Kyler hopes to teach meditation again someday, but said he needs to strengthen his own practice first.

He thinks his patients sense he understands them. For him, this understanding is therapeutic. A shared experience he didn’t expect. A bond he hopes will make him a better doctor.

“When all of sudden you’ve been told you have cancer, it’s probably not all that different from what it’s like realizing you’re never going to walk again,” Kyler said. “Your life changes dramatically, and it’s never going to go back to the way it was. And yet somehow, you keep moving forward, and you keep living your life.”

Night shift in an emergency room is a different world

'You choose to do it because you love it.'

By Monique Calello, Staunton News Leader

https://www.newsleader.com/story/news/2019/01/17/night-shift-emergency-room-emergency-medicine-emergency-department-hospital-augusta-health/2542207002/

FISHERSVILLE – There's a monitor that's always beeping. There's a mix of sounds including people swearing, moaning, crying. There's silence. There's a space, somewhere in there, where that sound changes from a mix to individual sounds of people being treated in rooms. A nurse or doctor is asking a patient questions. You lie in bed, look at the closed curtain and wonder if you're next.

Dr. Glen Michael remembers a person that came into the emergency room after their heart stopped beating. Often, he says, these patients are pronounced dead in the field, but the ones that come through emergency means there's a chance his team can reverse this.

They revive and resuscitate the patient and then admit this person to the hospital.

“You don't really know what happens to them.”

“I saw the same person back a few months afterwards,” says Michael. “They were in the ER, and they don't remember me because they were dead. And I don't recognize their face because they look a lot different when they're super, super ill as opposed to this time they're coming in with something minor and were relatively healthy.”

It isn't until he looks at the chart when he remembers that he saved this person's life.

“They don't remember you, and you don't remember them.”

That's life in emergency medicine, but working the night shift is a different world.

The night shift

As the overnight supervising emergency physician at Augusta Health’s Emergency Department, Michael’s the doctor patients will see when a health crisis occurs in the middle of the night.

Wearing the same pair of gray mocs he’s been buying for 10 years because they are comfortable and somewhat professional, before starting his shift at 10 p.m., he stops at his locker to change into a set of gray scrubs monogrammed ED (patients think that's his name), throws on his stethoscope, grabs a few pens he uses to sign off on countless EKGs and walks into the emergency department.

“Then you’re out there seeing whichever patient has been waiting for you,” says Michael. “We're constantly moving. There are many nights where there’s no time to pee. We definitely don’t do a lunch break. My dinner is often graham crackers with peanut butter when I have time or think to do that.”

But Michael’s not alone. Physician assistant Candice Bronez has been working since 7 p.m., and the two have been a team for over a year and a half. Bronez prefers sneakers and always has a jacket on hand for the middle of the night when she begins to get cold.

“It’s not normal to be up all night,” she says. “My body thinks it should be asleep and starts to shut down and shiver at night.”

Michael's been at the hospital about eight years, Bronez for three. They both chose the night shift so they could be home for their families. Michael has three young children, and Bronez started working nights after her son was born.

"I always get to be there for bedtime with my kids and dinner with my family," says Michael. "It's challenging in its own way because there's night shift sleep disorder and all those kinds of things that go along with it, but at least you're there for those key hours with your family."

Bronez and Michael think of each other as friends even though they only get a minute or two if they're lucky to talk about anything outside of work. When they do come up for air, their go-to topics are kids and real estate.

Thick skin and compassion

The overnight shift together is a unique relationship, says Bronez. "At some point in the night, it's only going to be the two of you no matter how busy it gets."

It's unpredictable who and how many patients are going to come through the door. They arrive by ambulance, car, sometimes dropped off at the front door. They arrive with sore throats. They arrive in labor. They arrive with gunshot wounds. They arrive having a massive heart attack.

"It's got its own unique, special flavor," says Michael. "We see anyone that comes through the door, and we try to be compassionate and do our best for all of them, no matter who you are."

In the span of one evening, Michael might go from a room taking care of a homeless patient who has a special set of needs and then the next patient he sees is the CEO of a multimillion-dollar corporation.

The skills of an ER physician are called upon in vastly different situations. Michael can be in a high-intensity room handling a life-threatening issue one minute and then a simple toe stub the next. He has to be adaptable enough to treat both situations equally even if the patient with the stubbed toe is angry and doesn't understand why he had to wait.

"Because you were doing everything you could to save someone's life," says Michael. "You can't say that is what you were just doing. This is one of the hard aspects of the job."

Michael can't think of many jobs where he can count on being cursed out or spat at or threatened to be sued.

“People are not always appreciative, and people are downright rude or assault you some nights. That's hard. We all go into the job because we want to take care of people.”

Michael believes this is one of the key drivers of burnout in emergency medicine.

“Frustrations run high, and we see a lot of people who are struggling with drug addiction or intoxicated or have mental health or personality disorders that make it difficult to help them as much as we want.”

No one wants to be in the emergency department, he says. A patient is in some sort of great need if they are there.

“You have to have a thick skin, but at the same time try to preserve the compassion that drove you to the job in the first place.”

Michael loves emergency medicine and the camaraderie of his team. After the nurses triage patients, it is Bronez’s role to keep the ED moving while Michael is taking care of critical patients. Some nights that's all he is doing. While Michael is tied up, sometimes for hours, Bronez will see less critical patients to make sure they are not falling hours behind.

“To them, they’re having an emergency,” says Bronez. “But to us, it’s not the most critical thing that can be walking through the door.”

Bronez realizes patients are hurting and scared, but it is her job to prioritize based on need. Doing this while treating all patients the same when she walks into their treatment rooms is important to her.

Trust between physician and physician assistant is essential. Bronez will determine if Michael needs to step in and take over based on the situation. On occasion, they team up when a patient is complex.

“I think as much as we try to match patient volumes with how many of us are there, it can happen where 15 people check in at 3 a.m., and you have to decide who needs to be seen first, and by whom, and get everything moving as quickly as you can.”

Augusta Health is not immune from the nursing shortage happening nationwide, and sometimes it is especially palpable, says Micheal. The few nurses they have overnight do their best to triage patients.

“I think it’s a little bit different at night when your nursing staff is short,” says Bronez. “It’s definitely a you’re-in-the-trenches-together feeling at night because there are fewer of us.”

They don’t know what’s going to come in, and they can’t staff for what could happen, so they staff for what’s most likely to happen.

“It’s not always easy to triage on that rush of 15 patients that check in at one time,” adds Michael.

The human being and being human

All of them play a brief but profound role in the life of a stranger.

“Whether it’s a baby that’s not breathing or someone’s that’s been shot or someone near death, you exert all your energy and focus on that patient for an hour to try to save them,” says Michael. “Most of the time we do, and sometimes we don't. Then you walk out of that room.”

In most jobs, a person will celebrate when he accomplishes something significant. If someone dies, he might take some time off to grieve, says Michael. But emergency medicine doesn't allow time for reflection. Michael saves a life and then immediately walks into the next room to take care of another patient.

“I think that's one of the hard things about medicine, and adverse medicine specifically, is preserving that compassion and the reason you went into medicine in the first place. Not letting it overwhelm your emotional well-being. It’s hard.”

Michael doesn't want to bring the weight of those experiences home with him, and he doesn't want to feel like “a heartless person that doesn't care.”

When the team experiences a patient death, they gather together and pause.

“You take 45 seconds for everyone to bow their heads and reflect on it. It helps you reflect and recognize the gravity and significance of what just happened.”

Michael learned “the pause” from Jonathan Bartels, a palliative nurse at University of Virginia Medical Center, during his residency in their emergency department. Right after Michael pronounces the death – “calls it”– and with the team still gathered around the body, he asks everyone to take a moment to pause and honor the person.

> ### The Pause
>
> *“This was someone who was alive and now has passed away. They were someone who loved and was loved. They were someone’s friend and family member. In our own way and in silence let us stand and take a moment to honor both this person in the bed and all the valiant efforts that were made on their behalf.”*

The emotional impact is tough for all of them. While Michael manages to “leave it at work” most of the time, occasionally he says there will be an especially tough case like a little child being abused or the death of a young parent with small children, and those stick with him. Sometimes he talks with his wife about those tough cases, but more often he processes those emotions by talking with his colleagues who are going through the experiences with him.

“Fortunately, the law of averages seems to work out such that for every tough case there is another case where there is a great save or career-affirming human interaction. Emergency medicine is an immensely challenging and at the same time uniquely rewarding career – there are ups and downs, but I can't imagine a better job.”

'Emergency medicine is its own special'

After 27 years of school, including medical school, a four-year residency and a fellowship, Michael chose to concentrate on emergency medicine.

“Emergency medicine is its own special. You choose to do it because you love it.”

But Michael says it doesn’t have the same level of respect as other specialties, and people assume he is going to specialize in something else. When they ask him, they react with confusion when they learn he already did specialize in something.

“It is its own board-certified specialty with its own unique skills and drawbacks, and that’s what I’m going to do forever,” he says.

Though he may not do the night shift forever.

“It definitely takes a toll on your body. My diet sucks when I'm working nights, and I don't feel as healthy. I don't exercise as much and feel less healthy in general when I'm doing nights.”

While he likes to go hiking and spend time outdoors playing with his kids, and swim a couple times a week when he can, Michael says it's difficult to stay healthy when so much of eating healthy and exercising involves maintaining a routine — a routine that is near impossible when he is flipping between nights and days.

He says he's fortunate. His spouse eats a very healthy diet and that rubs off on him when he's home for dinner, but admits his typical post-night shift diet of breakfast burritos or egg and cheese biscuits right before going to bed in the morning isn't exactly healthy.

Daytime

Michael and Bronez also have other professional responsibilities.

Michael is the medical director for the hospital’s transportation agency, and he works as medical team manager on an urban search and rescue federal disaster response team.

“You want to help people in their greatest need. I actually thought it was a volunteer job when I joined.”

National deployments can take a week at a time, so trying to jive that with his night schedule is challenging, he says. He doesn’t go on minor deployments because it seems wrong to him to ask a physician who is already working full time to then step up and cover his shift when he’s gone for a week.

During the day Bronez manages the schedule for the group of advance practice practitioners working at the hospital.

Getting subpoenaed is another thing that adds to the challenges of working nights. Both have to go to court from time to time to testify that someone got injured or assaulted in some way.

Camaraderie

Given the bond between them, the night shift team also has a special way of handling things that may be a little embarrassing for their supervising physician.

Although Michael has been a doctor for 12 years, he still looks very young, and he hears this from patients at least twice a night, he says, with half of them making a joke about his age or asking if he finished high school and can they see a diploma.

“They used to call me Doogie Howser, but I’m old enough now where that doesn’t happen as much.”

Before he walks in, the nurses will get that elephant out of the room and warn patients that your doctor looks like he is 15 years old, but he isn’t.

“They make my life easier by making that joke for the patient before I come in the room and making it less awkward and embarrassing for me.”

When he first started out it was upsetting to him. It made him feel like he wasn’t really a doctor, but now he says he will feel bad when people stop saying it. Between night shifts and kids, he’s starting to feel his 38 years.

At the end of the night

“At the end of the night you came together and did the best you could for people,” says Bronez. “When you talk about nurses being short-staffed, they don't have to do some of the things that they're doing. I feel like everyone keeps going as hard as they can.”

What gets Bronez through are the patients who express gratitude. Because they leave right after treatment, it doesn't happen that often but sometimes if they come back, they'll remember her. They spot her in the hallway and thank her for relieving their pain and helping them – for being their angel.

“It doesn't take much,” says Bronez. “That one little thing can keep you going for a few shifts. You are making a difference.”

None of them get to know their patients like a family doctor. There is no follow-up or smile shared when someone is feeling better.

“You are getting these strangers, and they each have their own life story,” says Michael. “And you get to be a part of that in a small, but significant way.”