



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

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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.



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

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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.”



A day with Temple Grandin on Polyface Farms

Grandin shares her expertise in animal psychology and profound wisdom as a person with autism.

By Monique Calello, Staunton News Leader

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SWOOPE – About 10 years ago, Dr. Temple Grandin gave Sarah Shafer two big pieces of advice for her twin sons with autism.

Only allow them a small amount of time to live in their worlds.

Get them involved in volunteering to help them socialize and identify skill sets and working tools they can build upon as they get older.

Now 16, brothers Dedrik and Tre Shafer run their own coffee shop in Harpers Ferry, West Virginia. They handle the day to day operations, make sandwiches and espresso based drinks and interact with the customers. Shafer and her spouse Dan Jimenl own the business.



The family drove out to Polyface Farms on an early Wednesday morning to see Grandin again.

“I just wanted her to meet them,” says Shafer. “They’re extremely successful now. We wanted to learn everything today, but also be able to show that we are appreciative of the advice she gave when they were so much younger.”

They weren't the only ones who came a long way to see her.

You didn't need directions to find your way to Polyface Farms that morning. You just followed the other cars. More than 300 people living across the country as far as Washington, Idaho and Texas came to spend the day with two people who are their mentors and inspiration.

What many called a once in a lifetime opportunity — a chance to meet Temple Grandin.

Animal scientist and author, Grandin is a public figure in high demand for her expertise in animal psychology and profound wisdom as a person with autism. One of the first individuals to publicly share her experience of autism, she has been featured in an HBO movie and has written numerous books to share her inner narrative; how thinking visually allows her to see the world through “a cow's eye view.”

A view she believes should be a healthy and happy one. A view people want to be able to see and understand because it makes for a more humane life.

For Joel Salatin, it's a chance to have one his first teachers come and see all he's learned from her. Forty years ago, when Salatin first learned of Grandin's work focusing on the humane treatment of animals, he redesigned the farm according to her guidelines.

“It's how we honor and respect the least of these that creates an ethical framework around which we honor and respect the greatest of these,” says Salatin who puts into practice what he preaches at Polyface Farms. A way of life and philosophy Grandin's teaching principles helped him to realize.

When Salatin stood next to Grandin that morning, he burst in tears. He wasn't the only one.

“She's the goddess of humans and animals,” says Peppy, from Austin, Texas, sitting on the front lawn beside Pat Schneider from Luray, Virginia.

“I got to shake her hand inside, and I realized after I walked out that that was bucket list stuff,” says Schneider. “She’s somebody I’ve been in awe of my entire life.” Fanatical about the humane handling of animals, Schneider wanted a chance to meet the person she’s learned from over the years.

“I just want to give her a hug and invite her to come ride horses with me in Texas,” says Peppy, who credits Grandin as the milestone of what is possible in developing relationships with animals.

On animals and autism

The day would be split in two. Touring the farm with Grandin and Salatin in the morning followed by an afternoon talking with Grandin about autism. Those who needed to, hopped on one of the wagons for the tour. Hundreds of people walked together as we made our way through Polyface Farms with both of them.

Eleven-year-old Lily Lind from Middleway, West Virginia, got an educational leave so she could come with her mom to listen to Grandin, who inspires her because she did a lot of work to get where she is today, she says. Lily and her mom Mary Lind watched the movie about Grandin and when Mary found out she was coming to Swoope, Lily got very excited, so she went ahead and got the tickets.

Friends Tracey Wolfe and Mari-Peyton Kouchinsky, both from Staunton, are big fans of Grandin and Polyface Farms.

“Her relationship with animal psychology and autism is very fascinating to me,” says Kouchinsky, who studied psychology in college.

Wolfe just wanted to be in Grandin’s presence.

“Just the opportunity to be in the presence of her and glean whatever knowledge she’s ready to share is a once in a lifetime opportunity for us,” says Wolfe. “It’s amazing that she’s come here.”

Wolfe laughs and says, typical fan stuff.

From Richmond, retired nurse Nancy Potter identifies with Grandin’s childhood. When she heard that Grandin had a choice between spending two weeks or the entire summer on a farm but either way, she was going, Potter thought, that’s just like my childhood.

Katie Millhorn is a raw dairy farmer in Worley, Idaho, and Ann Accetta-Scott runs a sustainable homestead in Seattle, Washington. Friends, they both made the trip out together to see Grandin and Salatin in action at Polyface Farms.

For Millhorn, any way she can learn to be a better livestock farmer is important. She sees this as a chance for Grandin to teach her how animals communicate and learn.

“We forget that animals are sensory,” says Millhorn. “They don’t communicate the way we do, and when you’re running things as a business and you’re go-go-go, you tend to forget.”

Accetta-Scott, who has taught at sustainable farming conferences with Salatin and Grandin, loves how Grandin relates to the animals.

“It’s definitely a trip of a lifetime,” she says.

For half a century, Grandin has challenged the orthodox. Challenged the paradigm, says Salatin.



“In a world dominated by men in that genre,” he emphasizes. “And to carve out the place of respect and move the needle like she’s moved it in animal welfare, in slaughterhouses and handling facilities in ranches... she’s an icon.”

Salatin’s animal handling facilities on Polyface Farms were designed after he read her work in Farm Journal.

“For me, she simply takes the Polyface message and amps it up. You get X with me. With Temple, you get XXX.”

The tour began outside of the entrance to the farm. When Grandin first started working with cattle, she looked at what cattle were seeing when they went through the chute. A visual thinker, when she began working on a farm, she assumed everyone else was a visual thinker, too. It was obvious to Grandin what was scaring the cows.

“New things are both scary and attractive,” says Grandin about animals. “They are attractive when the animal can voluntarily approach. And they’re scary when you shove it in their face.”

Offering a dual perspective as scientist and a person with autism, she developed working systems to improve the treatment of livestock. One third of cattle and hogs in the country are now handled in facilities designed by Grandin.

“They are a prey species, ever wary and watchful for signs of danger,” she explains in her book “Thinking in Pictures.”



“Similarly, some people with autism are like fearful animals in a world full of dangerous predators. ... Fear is a universal emotion in the animal kingdom, because it provides an intense motivation to avoid predators. Fear is also a dominant emotion in autism.”

Grandin says she started her business one small project at a time, and then she'd write about it. As the tour made stops at locations on the farm to discuss how Polyface is run, Grandin kept emphasizing the importance of farmers, of any group doing innovative things, to get outside of their “bubbles” and “silos” and write about it.

If they do write about what they are doing, they only write for their own silos, she says. “The farmers write to their silo. The autism people write to their silo. The tech people write to their silo.”

Throughout the tour, Grandin offered insight and advice on everything from what scares a cow and making sure a bull knows he's a bull to raising animal guard dogs that don't bite people and a direct answer to Salatin on knowing how to balance the ecosystem with problems that surface in farming.

“How do you know whether we've got too many coyotes or we need to work on the ecosystem?” Salatin asks her at the eggmobile stop on the tour.

“When they start killing the chickens!” she quips to Salatin.

It's a simple answer for Grandin. Sometimes it's as easy as six pieces of duct tape to cover holes in a stun box. A problem encountered by a beef plant in Ireland that Grandin spotted when she visited the facility. The cattle could see movement happening inside and it frightened them, so they wouldn't go into the stun box. Flying there by helicopter, she gets out of the helicopter, listens to the dilemma, walks around the stun box and sees the problem.

Forthright, Grandin reminds everyone during the afternoon that this goes for the autism community, too. “You've got to get out of this bubble.”

“You need to get out beyond that,” she says. “I was with big Ag yesterday working on guidelines. I was at Apple last week in the mothership. Then I was doing an autism meeting. I make a point in my talks, and I'm doing it deliberately, of jumping from bubble to bubble.”

She advises the farmers who came to learn from her to start at the local level, one project at a time, and write about it. Where you made mistakes. What things you did to make it work.

Grandin is also concerned that people have forgotten about the real world. And the real world is a world of opportunity for anyone with autism.

Shortages in high-end trade skilled jobs; careers that could be fulfilling for a person on the autism spectrum — plumbing, heating and air conditioning, metal welding, auto mechanic. Stuff, she says, that's not going to get replaced by computers.

“There's a huge shortage. Good jobs, full health benefits. The other thing we got to look at is somebody happy.”

Grandin says she wants to see people be everything they can be. She thinks people are using too many labels, and these labels are getting in the way of a person's potential.

“I see a kid who is probably 16 years old that looks like he ought to go work for Google, and his mother's never had him go shopping by himself. This is where mom's too tied up in the handicapped mindset, and they just can't let go. They get stuck in that.”

She goes on to advise families and educators on the importance of education as a pathway to doing something you love and gets angry when education prohibits a person from moving on to vocational school if he can't pass sixth grade algebra.

As far as Grandin is concerned, if a kid has a seventh grade reading level, he can be a CEO. She says she knows because she's met them.

What Grandin was emphasizing to a parent concerned about what she could do to help her son was, don't let his reading level define him. Don't get stuck in that. She was showing the mom what is possible and making everyone laugh at the same time.

Grandin believes too many people let the label define them. Again, it's a simple answer for her:

Find out what a person with autism is good at and help them bring those skill sets into the real world.

The jobs are waiting for them.

They just need the opportunity to discover them.

Work that will lead to a fulfilling life and ultimately benefit society.

Polyface Farms sits on 650 acres of pristine, forested land. The mist drifting down from the mountains seems to embody the hush of a remote and pure landscape; the civilized world disappears. Polyface means many faces and this refers to Salatin's belief that we should “provide a habitat that allows animals to express their physiological distinctiveness. Respecting and honoring the pigness of the pig...”