https://www.breezejmu.org/culture/vibrant-light-after-loss-of-firstborn-local-woman-helps-other/article_6c2952cc-6b7c-11e9-bbc5-039ad51948a8.html

'Vibrant light': After loss of firstborn, local woman helps other mourning parents

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Harlow (right) often holds support meetings at the foundation house in Dayton, Virginia.

Alexis Miller | The Breeze

The wedding gown spreads across a plastic fold-out table like spilled milk. It’s gathered up in sets of hands and torn to shreds.

Rrrrrrrip. Rrrrrrrrip.

It comes apart effortlessly. Ruby Yoder, who specializes in wedding dress alterations, shows a group of three women how it’s done.

One woman in the group traces out patterns with a blue Crayola marker, each designed specifically for a different weight. These can range anywhere from 1.5 pounds — or micro — to 8 pounds for newborns.

What will become of the larger gown rests in a box on the opposite end of the table.

The small gowns are intricate and fragile, just like the bodies they'll adorn, each one silky with elegant beading.

The women deconstructing wedding gowns today don't know who they'll sew the tinier ones for, but some of them know the recipient's pain better than anyone else. A few days from now, these gowns will be boxed up and taken to a hospital 30 minutes down the road.

There, they'll be given to the parents of babies who have died.

The foundation

At The Sadie Rose Foundation House in Dayton, Virginia, paper butterflies wrap the walls in a hug.

At least 100 lay here among the animal-shaped, sponged clouds in the living room. Regina Cyzick Harlow, 41, sits on a floral couch in a brightly patterned maxi skirt. She explains how each butterfly represents a child or infant who's died, with their birthdate and death date. Those that touch either died the same way or were siblings.

Behind her on the fireplace near the window is a light pink one that reads "Sadie H." — Regina's first daughter.

The butterflies on the walls represent only some of the children.

“If we put all the butterflies up,” Regina says, “you couldn’t see the blue sky.”

The butterfly means resurrection and hope. There’s difficulty in the cocoon, and also a transformation people go through when grieving, Regina says. This is what she hopes to help bereaved parents with.

Even though Sadie died years ago, her memory is alive in this house and the foundation’s work. Whenever Regina’s three children, Eli, Elsie and Korana, see butterflies now, they say hello to her, she says.

In the bathrooms, changing tables for those with children are tucked behind shower curtains so mothers who’ve recently experienced loss don’t have to see and be reminded of what happened. A sage green-colored room houses 30-35 wedding dresses — part of the foundation’s newest project.

The Sadie Rose Foundation aims to help families who’ve lost children through support services. It all started when Regina lost her daughter, Sadie Rose.

The diagnosis

Regina joked she’d been “entering spinsterhood” by the time she met her husband.

She grew up in the Old Order Mennonite community, where the expectation to marry and have tons of kids is stressed. Even though she left the church, she says the idea followed her out. Regina married her husband, Lee Harlow, in late 2006, and was pregnant with her first child by early 2007 at 29.

“I never had any reason to think anything would be any different, that we would have a healthy baby and a good pregnancy,” Regina says.

It made sense to name her Sadie Rose. Lee’s grandmother was Sadie, Regina’s middle name is Rose. There was also a book series called “Sadie Rose Adventure Series” by Hilda Stahl, a distant cousin of “Little House on the Prairie.” It was one of Regina’s favorites growing up.

On Mother's Day week in 2007, Regina went into Harrisonburg OBGYN for a 20-week ultrasound. Something wasn't right. The doctors guessed it could be Down syndrome, Lee said, but they weren't exactly sure. At the Prenatal Diagnosis Center at Martha Jefferson Hospital in Charlottesville, experts gave Lee and Regina the results after speculating what it could be: skeletal dysplasia, particularly dwarfism.

"We were scared to death," Lee says of the appointment.

Regina says the doctors' biggest worry was that 30 percent of diagnoses are lethal, potentially fatal. For Sadie, the latter was uncertain. Regina wasn't concerned with the details as long as neither her or Sadie's lives were in danger.

Regina recalls extensive ultrasounds. The couple was offered amniocentesis, which came with risk, and for Regina's bloodwork to be sent to Los Angeles to determine the type of dwarfism Sadie had. They opted out — either way, they wanted to continue the pregnancy.

While Regina and Lee were shocked by the diagnoses, Regina worked with a special needs class in the past and the couple even included the children their wedding. They possessed a benevolence for them and their families, and she and Lee quickly found hope.

"[Sadie] was always this way," Regina says, "and I loved her before I knew about her diagnosis, and so my love didn't change afterward."

After discussion and comparing ultrasounds to textbooks, at Regina's final appointment before she gave birth she left with some solace. She was told she'd most likely have a healthy dwarf.

The sunrise

She didn't initially recognize it as labor.

Regina was familiar with the process. After all, she grew up farming and was a certified artificial insemination technician for cattle. Surely, she thought, she'd know her own body was about to give birth.

She was in pain. Her contractions wouldn't subside and her stomach began to harden. She was only 26 weeks along.

Regina drove to Rockingham Memorial Hospital, then was sent by helicopter to U. Va. Medical Center. Sadie couldn't process the amniotic fluid and Regina's body was filling up, causing her body to register full-term pregnancy. She was subsequently placed on bedrest that Friday.

Then began almost a week of labor. They tried everything to get them to stop, including slanting Regina's bed so her head was tilted down and feet up. Gravity didn't take affect.

"It was terrible and it was a terrible time to be with your wife while she's going through that because you can't do anything but hold her hand," Lee says.

On Wednesday, Sadie was born breech without any pain medication at 27 weeks and was taken to the neonatal intensive care unit. She had dark hair, chubby cheeks and tiny fingers and toes. Doctors told Regina to rest and pump milk — Sadie would need the nourishment.

Regina and Lee occasionally visited the NICU. They didn't insist on holding her because they knew she needed to receive care.

"It's bittersweet," Regina says. "If we had known that all we were gonna get was 17 hours … we would not have left her, but we were hoping for a different outcome and believing for a different outcome."

The doctors came back into Regina's room at around 7 p.m. that night. Sadie wasn't going to make it.

"Everything changes for you," Lee says. "You go from the chronic worry of, 'How are we gonna do this? How are we gonna make it through the months in the hospital?' to now you're thinking about just being with her."

Regina had always believed in God. In that moment, she felt abandoned.

Lee describes Sadie's final moments as quiet and peaceful. They held her until she died. Before Sadie took her final breath, Regina laid her in the bassinet. She passed at around 11 p.m.

"You can't like 'What to Expect When You're Expecting,' these books that prepare you for parenting," Regina says. "You don't get books that prepare you for your baby dying."

Lee and Regina were asked if they wanted to help bathe Sadie once she passed. Lee said no. In that moment, he couldn’t do it. Regina followed his lead — a decision she’d later have to work through. She didn’t know what else to do.

“You’re just not thinking,” Regina says. “You just are not thinking for yourself, you’re not thinking about it in the same way you do when you’re able to process afterward.”

Regina described it as a nightmare she couldn’t wake from. In some dreams, Sadie was alive. She’d wake up, go to Sadie’s nursery and “lose her all over again.”

When asked how she’d imagined Sadie’s future, she said she pictured a “vibrant light.”

She lets out a huff of air.

“That just hits me right now because it’s like she is a vibrant light — even now,” she said, her voice cracking. “But I imagined it in a different way. I imagined her being this, you know, big personality in this little body that was just full of life and somebody who would touch a lot of people.”

It’s an epiphany for her.

“I don’t think anybody, in all these years, has asked me that.”

‘Sadie’s second birth’

In the hospital, the mothers on bedrest in the labor and delivery unit passed around a journal where they’d write stories and words of encouragement.

During the entirety of her experience, Regina was never by herself. Others in the unit didn’t have the same experience. One woman wrote in the book that she’d been on bedrest for 30 days and had yet to receive a visitor or phone call.

“People do this alone, and that should never have to happen,” Regina says.

During a weekly cleaning at home following Sadie’s death, Regina scrubbed her hardwood floor and cried. Then, a name came to mind — The Sadie Rose Foundation.

Sadie was going to keep living on. Regina called it “Sadie’s second birth.”

Regina’s foundation has been alive since 2008 and helping families ever since. Burial gowns are only one of the newest parts of its initiative — the nonprofit also does support groups and funeral services.

For years, people reached out to Regina and asked if the foundation would take their wedding dresses and use them to make gowns. At the time, she didn’t have the resources or time to do it on top of the support she was providing.

One of these phone calls late last summer changed her mind. Reminded of her Mennonite connections, Regina phoned a friend in the community who’d also experienced a loss, asking her if she’d think about doing it if she brought her a few gowns. She agreed.

Her friend was looking for a way to help grieving families quietly and found this was the perfect means. She practiced, and the foundation officially announced it would start taking gowns in late August. The post was shared 326 times and gowns came pouring in.

“I couldn’t keep up,” Regina says.

In mid-September, the foundation announced it would stop taking gowns until it could get caught up. Eager donors won’t listen.

“I’ve come and there’ve been wedding gowns hanging on the front door. I’ve come and there’ve been wedding gowns on our back porch,” Regina says. “Like, so even though they’re working on them and we’re not actively accepting gowns, people are still dropping them off.”

When Regina's friend became sick and could no longer work on the project, Yoder came in. Regina called it a "God moment."

Yoder began making burial gowns because her cousin did for an organization in Nebraska. When she found out about the foundation, she reached out to Regina.

Gown makers include Yoder and three Old Order Mennonite women, with other women waiting in the wings. Regina has held dressmaking workshops at the house where the women will take patterns home and come back with gowns and their sewing machines.

Though she's in charge, Regina doesn't do any of the sewing. Her explanation is simple: she's not a seamstress.

"For years, I've bargained mowing the yard and cooking supper to get out of making my own homemade dresses," she says.

Regina explains the significance of the gown is to have something beautiful to bury one's child or baby in. While there are plenty of outfits one can buy, most aren't formal. The idea of something formal, Regina says, is about honor, dignity and respect.

After Sadie's death, the hospital gave Lee and Regina a white cotton bonnet and dress along with Sadie's things — a blood pressure cuff, a thermometer, a measuring tape with her length marked. Regina didn't register it as a burial gown at the time, but she still has it to this day.

For Regina, the gowns are about resources.

The initiative began with gowns but has blossomed into sets as donations came in forms of small knitted hats and blankets. The foundation now packages them up together. Regina says that while the service is mostly catered to newborns, they also have seamstresses on call to make gowns of any size for any family who needs them for their child.

"It's not always the case, but most of the time, the last thing you're prepared to do is go shop for something to bury your child in, or your baby," Regina says. "If one of these sets can provide comfort to the family, support to the family … you're just bombarded with decision making at a time of loss, and if it can just eliminate the need for that part of decision making, in any way that it helps them, that's wonderful."

Yoder can make a burial gown in about an hour, but there's work to do before it hits the sewing machine. First, the maker has to disassemble the gown. Layers that are ripped or soiled can't be used.

At the workshop, three wedding gowns hung off the back of one of the dining room's French doors. One was a heavy, size six gown with layers of fabric, tulle and topped off with beading. This one, Yoder said, will make about 20-30 gowns with the usable material.

Gowns need to be taken apart, then one takes the material and traces it out using a pattern. Once the patterns are traced, the parts are ready to be put together.

The drop off

Regina's brown cowboy boots click across a snow melted parking lot. Today, she's making her first gown drop off at Augusta Health in Fishersville, Virginia.

At the Sadie Rose House, she slaps a size sticker on some of the gowns before putting them in a square cardboard box with a lid. There are 21 there — six unpackaged, the rest in clear plastic bags with a blanket and knitted hat.

As she drives her white Kia Sedona, she talks with her mother. They usually speak almost every day but hadn't spoken in close to a week. Regina's just been busy.

She enters the hospital and the concierge directs her to the third floor. They lead her through the labor and delivery unit's two sets of double doors. The space has tan and mauve walls and a group of giggling nurses. Regina asks for a woman named Claire, then Roxanne Harris, director of women's health and pediatrics, who she's spoken to once.

Harris arrives and Regina explains logistics. She insists they do with the gowns what feels best.

As she goes to leave, she tells them to "let me know if you need anything."

"Absolutely. Unfortunately, it is part of what happens," Harris says to her. "It's the part that nobody talks about."

It's conflicting for the foundation to be excited about something sad, Regina says. Yet, the sensation's still there. For her, it's an ongoing thing, and she's happy to provide support.

"Well, the thing about it, it's gonna happen whether we talk about it and whether we do anything to prepare for it," Harris says. "It's gonna happen, and the thing about it is then moms have something to hold on to and to know that they're not alone."

Down the hall, an infant cries out.

"And nobody expects for a bad outcome," Harris continues. "Never. And it happens, and they're in shellshock."

Regina knows, she responds. She's been that mom.

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Tags Regina Gown Sadie Rose Clothing Medicine Anatomy Tailoring Fashion

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