

DONNA DAVILETTY IMAGES

At a Loss

Medical geneticist Richard Pauli seeks to answer the hardest question that parents ask when their baby is stillborn:
Why?

By Kathleen Bartzen Culver '88, MA'92, PhD'99

ON AN APRIL MORNING IN 2001, JULIA GAYNOR had every expectation that she and her husband would soon greet the round cheeks and heavy eyelids of a newborn. She had enjoyed a healthy pregnancy, her first. She had hit every milestone, and just five weeks short of her due date, she eagerly awaited the arrival of her baby. *But by midnight the following day, her anticipation would turn to numbing grief.*

Admitted to the hospital for monitoring, Gaynor delivered a baby boy, whom the couple named Quinn. Nurses bathed and dressed him and gave him to his mother and father, who held him and took pictures. But they did so with the unbearable pain of knowing that they would not take their son home. Sometime before birth, Quinn had died.

“Honestly, it was hell. It was the worst thing I could imagine,” Gaynor says. “I think I cried an ocean.”

Each year, that ocean swallows thousands of parents for whom the expectant joy of pregnancy is shattered by the delivery of a stillborn baby. Stillbirth — the medical classification for any fetal death that occurs more than twenty weeks into pregnancy — remains such a deeply personal tragedy that few people appreciate how frequently it occurs. In the United States, twenty-five thousand babies — about one of every 115 — are stillborn each year. (Loss of a fetus prior to twenty weeks into pregnancy is considered a miscarriage.) Averaging nearly seventy each day, stillbirths are eight times more common than cases of sudden infant death syndrome (SIDS).

Yet unlike SIDS, which has been well documented in both the scientific and popular press, stillbirth does not garner the media spotlight, research focus, or funding that its pervasiveness might warrant. For decades, many doctors believed that parents who suffered the death of an unborn child didn’t want attention, so deaths were dealt with quietly. As a result, stillbirth became a devastation that many parents suffered in isolation, leaving them with little comfort, and even less information.

Gaynor says that after her son’s still-

birth, she was aching to find reasons for her monumental loss. Then she learned about a unique program at the UW School of Medicine and Public Health, which was run by a doctor who seemed to understand exactly what Gaynor and her husband were going through. Richard Pauli, a professor of pediatrics and medical genetics, knew that they yearned for more than just emotional support. As founder and director of the Wisconsin Stillbirth Service Program (WiSSP), Pauli was willing to help them answer the most painful and crucial question that parents of stillborn babies confront: why?

It is a question Pauli knows all too well.

IN 1979, PAULI WAS THIRTY-TWO

years old and beginning a fellowship in medical genetics at the University of Washington in Seattle. His wife, Mary Lee, was pregnant with their first child, and for seven months, her pregnancy was uneventful. Heading into her thirty-fourth week, however, she noticed that she hadn’t felt the baby move for a while. Mary Lee was evaluated and the couple learned the worst possible news: their son, Zachary Abraham, had died.

The next days came to define not only the couple’s personal grief, but also Pauli’s professional life. In a fruitless search for information, Pauli learned how little stillbirth was studied and how rarely physicians could determine the cause.

“In some ways, I felt sort of lonely back in the early days,” Pauli says. “Nobody was interested, except for the physicians who cared for families who had stillborns.”

After joining the UW faculty in 1980, Pauli began to investigate more deeply, collecting information about the frequency and causes of prenatal death. Three years later, he formed WiSSP to fill what he saw as a critical gap. Too few hospitals had the knowledge or the resources to help parents discover why their babies died, and, as Pauli knew from his own experience, having no answers could leave parents in a fog of confusion and grief. Left with a lingering uncertainty long after Zachary’s death, he was motivated to help other parents find the answers that had eluded him.

But explaining why a fetus dies is no easy task. The known causes of stillbirth lie in three broad areas: birth defects in the baby, placental or umbilical cord problems, and maternal illness or other conditions that affect the pregnancy. Birth defects account for about 25 percent of stillbirths. Pauli says many other cases are blamed on cord and placental problems when no other reason can be found. Identifying the true cause requires medical detective work — a meticulous analysis of any available information about the condition of the baby and the mother. This is where he aims his magnifying glass.

Pauli has worked with pathologists, obstetricians, nurses, and genetics counselors across Wisconsin to create a community-based process for investigating stillbirth cases. At participating hospitals, if parents of stillborns choose to have WiSSP investigate, local hospital staff examine the baby, using a protocol spelled out by Pauli.

After a full array of tests is completed, Pauli receives a robust file that often includes doctors’ examination notes, x-rays, photos, family data, and results of the autopsy and chromosomal tests. He carefully reviews each piece, studying the many clues, forming hypotheses, and winnowing irrelevant information. From this, he tries to reason why a baby died. Pauli emphasizes that the program is not in the business of guessing; he doesn’t report a cause of death unless he can do so with certainty.

He feels certain only half the time. But WiSSP's success rate has improved from 40 percent a decade ago, and with some two thousand cases under his belt, Pauli has refined the ability to home in on a cause. He and Peggy Modaff '93, MS'95, WiSSP's assistant director, expect the success rate to continue to climb as scientists learn more about stillbirth. New research, they hope, will shed light on maternal conditions such as thrombophilia, a tendency toward excessive clotting of the blood that may be of special concern for pregnant women, as clots can cut off a fetus's lifeline of blood from the mother.

Pauli wishes that he could unravel the mystery more often. "He can be very blunt with families when we don't find a cause," says Modaff. "It's not that there wasn't one, but we're just not smart enough to find it yet. It frustrates him to no end that we can't find one."

DOCTORS AND CAREGIVERS

who have worked with Pauli say the program's sensitivity sets it apart. Unlike any other perinatal loss clinic in the country, WiSSP does not require an on-site examination of the baby or the mother, so parents don't have to travel to Madison or arrange transport of their baby's body. When Pauli has studied the case and made his conclusions, the results are returned to the local doctor for review and counseling with the parents.

"It gives you the ability to perform, in essence, a state-of-the-art stillbirth evaluation without having to send the baby to a referral center like Madison," says Michael Schellpfeffer, a Kenosha obstetrician. "That would create a multitude of problems with bringing closure to the family."

Closure for parents is a somewhat new emphasis, indicative of a cultural shift that has taken place during the past few decades. As

recently as thirty years ago, it was common practice for hospital staff to whisk stillborn babies out of delivery rooms, ensuring that parents never saw them.

"They never talked about my baby being born," recalls Sue Stowell, a Madison woman who had a stillborn daughter nearly forty years ago. "They said, 'We took your baby,' and that was kind of it."

Stowell had reached labor in her pregnancy and was full of the same hopes

Julia Gaynor felt before her son died. But when Stowell's doctor failed to hear her daughter's heartbeat, he initiated a protocol much different from Gaynor's experience, but one that was fairly standard at the time. After four days of induced labor, hospital staff gave Stowell a hefty dose of nitrous oxide to put her under, delivered the dead baby girl, and removed her body from the delivery room before her mother could come to.

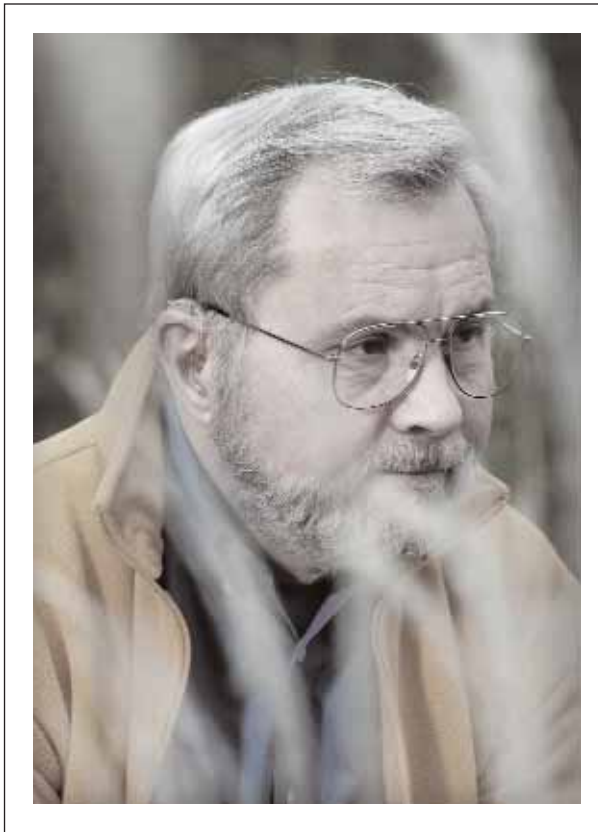
Stowell never saw, touched, held, or named her baby. To this day, she says, she is haunted by how empty her arms felt.

Twelve years later, when the Paulis lost Zachary, attitudes about stillbirth were beginning to change. They were allowed to hold their son, and they did name him. But in retrospect, the Paulis felt robbed of other choices. "We elected not to bury him and had the hospital, as they said, 'dispose of the remains,'" says Pauli. "My wife is forever remorseful that that was a wrong decision because she doesn't have a place to visit."

CAREGIVERS HAVE COME

to understand that well-meaning attempts to ease parents' grief actually exacerbate their feelings of loss and pre-empt healthy grieving. But in the past, both caregivers and parents struggled with how to reconcile the complex feelings of grief. By the time Pauli began to investigate the medical side of stillbirth, a revolution was already taking place surrounding emotional support offered to parents. Pauli's work has helped to drive that change, but also has been shaped by it.

Those who comfort and counsel parents of stillborns now say that much like any grieving mother or father, these parents need to know their child is acknowledged. They crave affirmation that the baby was real and mattered.



Richard Pauli

"In some ways, I felt sort of lonely back in the early days," says stillbirth researcher Richard Pauli, whose own son was stillborn. "Nobody was interested, except for the physicians who cared for families who had stillborns."

"I think it says a lot about our culture's difficulty with death," says Deb Preysz '87, an obstetrical nurse at Madison's Meriter Hospital. "There's no guidepost, no Lamaze class for having a dead baby."

Together with fellow OB nurse Jan Deitte, Preysz now provides formalized bereavement services for parents of stillborns at Meriter. And like Pauli, she does so with a personal drive, forged from the loss of a baby boy twenty-four weeks into her pregnancy. When she lost her child in 1981, Preysz says, Americans were learning to think more about dying and grieving, thanks in part to Elisabeth Kubler-Ross' seminal 1969 book, *On Death and Dying*.

Along with more enlightened studies of grieving came advances in how stillbirth cases were handled; hospitals began to offer services such as those that Preysz and Deitte provide. Today parents are routinely given the chance to hold their babies, as well as take pictures, collect mementos, convene families, hold

baptisms, and arrange funerals.

During sixteen years of practice, Sabine Droste, a UW Health specialist in maternal and fetal medicine, has seen the pendulum swing fully. "Stillborns were not acknowledged and were discarded as hospital trash. That used to happen," she says. "Those days are over."

In Wisconsin, Pauli's program has helped end those days by raising awareness about stillbirths and by sharing information with a broad network of caregivers about the resources available to parents. Deitte and Preysz say the information yielded by Pauli's investigations is a critical complement to organizations such as Resolve through Sharing, an international network that trains caregivers in how to comfort parents who lose babies before birth.

"[Parents] are in a fog, and it's very hard to make decisions, because you can just hardly hold your thoughts together," Preysz says. An essential part of the grief process for parents, she adds, is "the searching and yearning stage,

where they really try to understand why this happened."

UNDERSTANDING WHY IS ALSO essential to the doctors and genetic counselors who want to answer the inevitable question from parents: if we try to have another child, will this happen again?

"When we can find a cause, it alleviates a lot of guilt — probably not anger, but self-doubt that they can have children," says Michael Berman, a New Haven, Connecticut, obstetrician who serves with Pauli as an adviser to the International Stillbirth Alliance. "We want to impart hope on our families. There really is tremendous hope for them to have a baby — not to replace this lost baby, but to have a family."

Overall, parents face about a 0.8 percent chance of having a stillbirth. For those who have had a single stillbirth, the risk of another is about 3 percent. While the odds are overwhelmingly in their

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A FATHER'S GRIEF

When Kevin Thays watched his wife deliver a stillborn boy just as she reached her due date, he was devastated by thoughts of failure. He felt he had let down both his wife and his son.

It was once thought that mothers needed to be protected from the sadness of having a stillbirth. But while people such as UW medical geneticist Richard Pauli have helped turn that notion around and vastly improved care for mothers of stillborns, fathers often face a different, and at times less visible, struggle. While helping their wives or partners through the ordeal, they often have no time to mourn and no one to support them.

"When we lost [our son], I had this feeling that my wife had to go through the physical part," Thays says. "But the father gets left out when people tell you that you have to be there for her. That is so difficult when you're feeling shattered yourself."

Like Thays, many fathers of stillborns feel they have failed as protectors, says Pauli. He recalls one patient who was so distraught that he took a tree limb and began slamming it against his car. Pauli reassured him that his grief was human and necessary.

"It was a normal, healthy response," he says. "He had such overwhelming feelings of anger and inadequacy that he just had to do something."

Doing something can be a way out of the shadows of desperation. Caregivers now counsel parents of stillborns to create a sense of reality around the baby, which data have shown

is a critical step toward healthy grieving. In one WISSP survey of parents who had experienced stillbirth, more than one-third wished they had done more to understand and cope with the loss, while none said they wished they had done less.

"The biggest thing for us is the acknowledgment," Thays says. "We believe we've got this guardian angel, and keeping him part of our lives is so important. It's that feeling of being able to include that child in your life in whatever way works for you."

The difficulty for many parents is that they are not mourning scenes from a life, but dreams of what might have been. UW Health physician Sabine Droste finds this troubling sense plagues many of her patients, from the time they hear the devastating news through the first anniversary of the baby's death — and often years beyond.

"It's a particular problem with stillbirth," she says. "Even with the death of a child and particularly with the death of an adult, you have a history to mourn. You have something to hang your grief on. With a 'potential' child, there are really no memories. All you ever had were your dreams and your hopes for what this child was going to be."

This leaves some parents with an overwhelming need to memorialize their lost children. Pauli's response to his own son's death was to carve a butterfly and add simple drawings, including a gathering of wheat shafts that later became WISSP's logo.

— K.C.

Loss

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favor, many parents who have lived through a fetal death overestimate their risk of suffering another. But even when WiSSP cannot identify a cause of death, its investigations often generate information that can help counselors both rule out factors and assuage parents' concerns.

Margo Grady '89, MS'93, a counselor in Madison, studied with Pauli while earning a master's degree in genetics. She says his training helps him identify subtle clues that would escape many others. Without his program, she says, she could provide her patients with only about a tenth of the answers they can find through Pauli.

"When a stillbirth happens, people have this extreme grief at the loss of their child," Grady says. "They think, 'We have an image of what our family is, but now that dream is destroyed. Can we make a new dream? Can we have children down the line?'"

Julia Gaynor and her husband asked these questions after experiencing stillbirth. She says Pauli and Modaff provided details that helped the couple through a second pregnancy, which resulted in the birth of their son Max.

"Honestly, I don't know if we would have Max right now if we hadn't had the leads they gave us," Gaynor says. "What they provided us helped us through the grief work."

In a small number of cases, Pauli's investigations reveal that the death of a fetus can be attributed to parental behaviors, such as drug or alcohol abuse. In such situations, Pauli tries to help parents focus on what they can do to prevent harm in future pregnancies. "You can't fudge the facts," he says. "I hope they understand that this is supportive, not accusatory."

The cases where no one was at fault far outnumber those where the parents are responsible. Nevertheless, guilt is an overwhelmingly common response. Some parents blame themselves for everything — from exercise to tight clothing — in a desperate quest for answers.

"Most of us would rather deal with guilt than we would with uncertainty," Pauli says. "It's really hard for most of us to live at peace with the idea there is not a reason, it was an irrational act of nature."

Grady sees the results of a WiSSP evaluation as essential to easing that guilt. "It's natural to go through every single day wondering what you did," she says. "People want that answer because then they can say, 'It's not my fault.'"

YET WISSP STILL FACES SOME

significant hurdles in providing those answers. The decision to proceed with an evaluation belongs solely to parents, and some doctors are more encouraging than others. Some, such as Droste, will "forcefully counsel" them to seek as much information as possible. "They don't realize that getting answers and having a thorough investigation will help them process the loss," she says.

But other doctors take a hands-off approach, providing only basic information about the program. As a result, many files are incomplete when Pauli receives them, and many others never reach him at all. Currently, the program reviews only about one-fourth of known stillbirths in Wisconsin, in part because of limited funding and in part because of lack of awareness that the program exists. In addition, Milwaukee-area hospitals review their cases locally.

The program, which operates on only about \$15,000 per year, is in a near-constant battle for funding. It depends on the good will of participating hospitals to cover the costs of autopsies and examinations. With more staff, funding, and outreach, Modaff says WiSSP could dramatically increase its case load and turnaround time.

Progress is also hindered by stillbirth's relatively low profile among researchers and caregivers. More consistent follow-up counseling, as well as a thorough study of clotting disorders and their relationship to stillbirth, are clearly needed, Pauli says. But he understands why more people aren't drawn to the field. "It's frustrating. It's emotionally difficult. It's not very


sexy," he says, adding that research in the area is "historically unfundable," meaning that few government or private organizations offer grant money to investigate stillbirth-related topics.

Berman, of the International Stillbirth Alliance, is hopeful that a groundswell of stillbirth parents will help change this outlook. "What's going to make [Pauli's] work — and all the others who are doing this — more important is that we are going to be in a position in the next ten years to treat all these conditions that cause stillbirths," he says. "That's where our future is going right now, but we have to start at the basics. And the basic is that funding has to go toward understanding stillbirth."

Stillbirth gets more focus in Britain and Canada, and those countries have better success rates in identifying causes, notes UW Health's Droste. Still, she says, it will take substantial education to change the attitude of many doctors that stillbirth is an unexplainable tragedy.

"It would be nice if patients would understand that in a significant proportion of cases, the cause can be identified," says Droste. "They should demand of their physicians to seek a cause."

At sixty years old, Pauli may never get that kind of closure. A geneticist and pediatrician by training, he is able to devote only a sliver of his professional life to stillbirth research. Work on WiSSP cases competes with faculty appointments in two departments, a heavy teaching load, and a clinical practice in which he cares for patients with bone dysplasia and dwarfing disorders. He plans to retire in about three years, and the program's future is punctuated with a question mark.

While Pauli appears wistfully optimistic that emerging national interest in stillbirth will find new solutions, others worry that losing the program would be devastating to a group of people who are already well acquainted with loss. 

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