



## **Denise Scott: A DES Daughter, Her Doctor and Their Story**

*Editor's Note: In the Summer 2020 issue of DES ActionVOICE, we published an excerpted version of this essay. Below is the full version.*

*Denise Scott, a retired Floridian, was born in 1955, at the height of DES prescribing before more research revealed that it did not reduce the risk of miscarriage. It wasn't until she was a teenager that she learned her mother had been given the medication, a discovery that ultimately led her to the office of Dr. Farhad Talebian, an OBGYN in Garden City, New York.*

*Dr. Talebian would soon become an integral part of Denise's life. He never stopped caring for her health or about her as a person, no matter how angry or upset she got about the problems she suffered as a DES Daughter.*

*Denise's story is not a happy one. It's a familiar story of frustration, anger, pain, loss, sorrow, and more anger that many in the DES community can relate to. But if there's a single positive note in her tale, it's that a lifelong patient-doctor relationship with the right physician can make all the difference in pushing through the hardest times and ensuring that you always have an advocate in your corner.*

*Even when Denise felt most alone, or even angry at Dr. Talebian, she also knew he was doing everything he could to ensure she remained alive and as healthy as possible, even in spite of what she wanted. Sometimes he conspired with her mother, but in every action he did, he made it clear he wouldn't give up on Denise.*

When she was 16 years old, Denise's mother read an article in Long Island's newspaper Newsday about the link between in utero DES exposure and a gynecological cancer being discovered in young girls. "My mother knew she took something and it sounded similar," Denise said. Fortunately, her mother had the same OBGYN for all those years. She called him in tears and told him what she read, but he didn't seem too concerned.

"Margie, they don't really know," he told Denise's mother. But through the phone, she could hear him flipping through her medical files. He confirmed that he had given her DES. He seemed to blow off the risk but offered to examine Denise anyway. Denise's mother wasn't ready to tell her daughter why she needed to

see a gynecologist when she was 16 and still a virgin. She lied and said all females must see the gynecologist after turning 16.

The appointment did not go well. The doctor made Denise feel awful, and she refused to see him again. When he unexpectedly died at a medical conference two years later, his staff called while going through his estate. Did Denise's mother want her medical files? Denise didn't hesitate: "Get the file," she told her mom. Denise didn't have any medical problems—yet—but her gut told her the records were important.

Soon after his death, Denise's mother learned about DES Action, still in its early days with just a few DES Mothers running the phones. She called the organization to ask for a doctor recommendation for Denise. They said Dr. Talebian had an excellent bedside manner. Denise still refused to go at first—the first experience had been too awful. But then she got engaged and had been hearing more about miscarriage and ectopic pregnancies in DES Daughters.

"I thought, if I'm going to get married, my future husband and I need to know if I'm going to be able to have kids," Denise said.

The visit with Talebian was the opposite of everything she expected. He was kind and gentle. He explained things in a way that made sense. From that day forward, Talebian became the only doctor Denise would ever really trust.

That doesn't mean their appointments were easygoing. Especially as she began developing DES-related problems, Denise hated going to his office, hated seeing happy, carefree pregnant women in the office around her who didn't have to deal with her issues. She hated sitting for what felt like hours in the waiting room so much that she would eventually leave. Talebian would call her back at 5 or 6pm, after all the patients had left, and cajole her back to the office, staying after hours for her visit. Often Denise didn't want to hear what he had to tell her, and she made that abundantly and colorfully clear—at high volume. But she kept going back.

Several months after her wedding, Denise had what she suspected was a miscarriage. Her husband was in the Air Force, so she saw a doctor at the base, but he couldn't tell if she'd had a miscarriage. He ordered a D&C, which wasn't clinically necessary, and afterward told her she had cancer—and one year to live.

"My husband fell apart. It was very difficult," she said. "We were newly married, and I didn't have my family or friends close by for support."

So she got a copy of her medical records, headed home, and took her file to Talebian. The news wasn't good, but it wasn't cancer either.

"You're a classic DES Daughter—a cervical hood, a vaginal hood, a cervix not in the right place—and he was going to use you as a guinea pig," Talebian said. The Air Force doctor's notes made it clear he was going to order procedures Denise didn't need. She was little more than an experiment to him.

Ultimately, though, Denise would need surgeries. The first was a cold knife conization for early stage cervical cancer. She hemorrhaged a week and a half later, and her mother frantically called Talebian's office. They told her to bring Denise in immediately but that Talebian wouldn't be in for a few days.

“Can I bleed like this and live until Thursday when Talebian comes back?” Denise asked. Other doctors called from the practice and hospital, begging her to come in. She finally did.

The cancer came back after the conization, and Denise had four more procedures over the next two years, including cryosurgery, two laser surgeries and another cold knife conization. “Whatever we were doing wasn’t working,” she recalled. “Whenever I had surgery, the cancer got worse.”

During this time, Denise’s mother regularly called Talebian on the phone begging him to give Denise a hysterectomy. “She’s going to die, she’s going to die, she’s going to die,” Denise recalls overhearing her mother say in every call. “I’m not going to give her a hysterectomy,” Talebian said.

Denise was dead set against losing her uterus. But she was also in pain all the time. During a trip to Europe, her mother told her that she’d been holding herself in her sleep, with her hands over where her ovaries would be. “She thought I was going to die,” Denise said.

After the fifth surgery, Talebian realized he had no choice: a hysterectomy really was the only way to save Denise’s life. But he knew she would never go for it. “It’s going to be up to you and me to convince her,” Talebian told Denise’s mother.

It took three months before he even brought it up at an appointment. After hemming and hawing, he finally told her, “I’m not sleeping at night. You have to have a hysterectomy. I don’t know how high up the cancer goes.”

Denise had severe stenosis, where the passage through the cervix is very narrow or completely closed from the cancer. It was amazing she was even continuing to menstruate.

“I’m not doing that,” Denise told him. “You better come up with another f\*\*\*ing plan.” That would become her refrain the next dozen times it came up. But Talebian wouldn’t give up. He finally persuaded her to talk to another doctor. She met with Dr. Burton Krumholz, who led the DES screening program at Long Island Jewish-Hillside Medical Center.

After Krumholz spent a full day with Talebian, going over her records, he told Denise, “You need a hysterectomy.”

She wanted to know how long she would live if she refused. “To me, having a hysterectomy would be horrible,” she said. “I knew I would never be able to live with that.” Krumholz told her she had anywhere from 18 months to 5 years.

When Denise next saw Talebian, she remained steadfast: she would rather die than leave the world with less of herself than she entered it with. But somehow, during a foggy period Denise cannot recall, she consented to the procedure. July 24, 1986 was the last day Denise had a uterus, and she mourns her loss every year.

Just before the surgery, Denise remembers telling Talebian she changed her mind, that she wanted to call a cab and go home. She demanded a uterus transplant and yelled at Talebian when he said it wasn’t possible. He looked past her to the anesthesiologist and said to put her out.

Talebian wasn’t trying to overrule Denise’s wishes. He was trying to save her life in spite of herself. He told her mother that he wished it were anyone but her. “He knew better than anyone I would never get over this, and I haven’t,” Denise said. “It’s been 34 years and it’s still depressing to me.”

The pathology report showed all four quadrants of her cervix were “packed” with cancer. Denise still cried every night for four years. “I don’t remember making the decision to live at all,” she said.

As sick as Denise was all this time, emotionally, mentally and physically, she never stopped fighting to ensure the public knew what drug companies had done. She was always in pain, but when she was asked to speak on TV and on the radio, she did.

When she was told she couldn’t sue because her conditions were pre-existing—since they developed in utero—she traveled to Albany to lobby legislators. She fought relentlessly with busloads of other DES Daughters, despite her pain. It was while Denise was recovering in the hospital after the hysterectomy that a NYPIRG rep called her about the case. They had won. From that day forward, other DES Daughters would be able to sue as well.

But her nightmare wasn’t over. Four years later she saw blood in the toilet. A sonogram revealed a mass the size of a small orange. Talebian was nervous but told her to come back six weeks later. She did. Now there were more. Even after a CT scan and MRI, it wasn’t clear what they were. Talebian wanted to remove them—he didn’t want to lose Denise, his “star patient,” her mother said—but Denise absolutely would not go under the knife again.

She continued to go for imaging, and it eventually stopped growing. To this day, Denise said, the mass is still there, though smaller, and apparently not killing her.

The contentious but caring relationship continued. When a mass showed up in Denise’s breast, she saw Talebian but refused an aspiration. The lump was gone six months later. Her refusals likely drove Talebian crazy, but he understood and respected her too.

“I don’t think he had ever encountered someone like me who put up a fight about everything,” she said. “He really tolerated a lot. I think he felt bad for all I had to go through. He said he knew me inside and out. He knew how to handle me.”

It’s been a decade since Denise last saw Talebian, who retired three years ago. She said she’s only trusted three men her whole life: her father, her dentist, and Talebian.

The feeling was mutual: When Denise sued for her DES exposure, her attorneys met with Talebian. He refused to meet at first, saying he was too emotionally attached to her. After he finally consented and came in, he broke down in tears as he told the two lawyers about Denise’s medical history.

“DES is a tragedy in my family,” Denise said. She won the lawsuit, but the payout was a pittance and could never address how DES impacted her life.

Denise recalls panic attacks that led her to see a therapist. Anger had kept her anxiety at bay for years, but anxiety had begun to take over. Denise needed medication to manage her mental health for just under a decade.

“I was so f\*\*\*ed up that that barely took the edge off in the beginning,” she said. “Thank God I didn’t have an addiction problem.” She never abused the Ativan she took, and one day, Talebian told her she didn’t need it anymore. And he was right.

To this day, Denise has never forgiven the drug companies for pushing DES. But she thanks God she had a doctor who put up with far more than most are willing to tolerate from their patients.

She remembers once overhearing Talebian talking to his nurse. "She hates me," Denise heard him say. "I don't hate you," Denise told him later in the exam room. "I hate what you did." She knew he had to do it, but she also knew he hated to do it.

Despite all she went through, Denise worries today for DES Sons and the Third Generation. "I have a feeling it's always going to be a learning experience," she said. "As time goes on, they're going to learn more. Who would have thought it would affect the next generation?"

In her case, at least, Denise had a doctor in her corner. She remembers waking briefly late at night after the hysterectomy and feeling someone holding her hand. It was Talebian. He looked devastated. But as soon as he noticed she was awake, his entire expression changed. He smiled. "Everything is great," he told her. "Everything is fine." It wasn't, of course. It never would be. But Talebian would do whatever it took to try to make it okay. And Denise has never forgotten that.