New Mutter Museum exhibit grants final wish for woman who turned to bone

by Marie McCullough, Updated: February 28, 2019- 10:13 AM

Long before her death, Carol Orzel told friends and caregivers that she wanted to donate her body to the Mutter Museum of the College of Physicians of Philadelphia.

Orzel didn’t have a written will. Nor did she know what a challenge her bequest would be for the famed museum of anatomical anomalies and its collaborators, including the Oklahoma company charged with preparing her skeleton for exhibit.

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All she knew is that in death, she wanted to continue what she had done in life: Serve as a testament to human resilience and teach others about fibrodysplasia ossificans progressiva (FOP).

FOP cripples and immobilizes by turning connective tissue — muscles, tendons, ligaments — into bone. Any attempt to surgically remove the extra bone triggers explosive new growth.

Orzel, who was born in South Philadelphia and died a year ago at age 58, got her final wish on Thursday. Her 4-foot-7 skeleton went on exhibit, paired with that of Harry Eastlack, the only other completely preserved example of FOP in North America.

Orzel’s installation comes at a crucial time for the ultra-rare disorder, known to afflict a few thousand people worldwide. When Eastlack died at age 39 in 1973, FOP research was nonexistent. Now, it has spawned an industry. Several potential therapies are in clinical trials, and dozens of companies are racing to exploit new insights that could transform the treatment not only of FOP, but of head trauma, fractures, bone malformations, osteoporosis, joint replacements, and much more.

The turning point came in 2006, when a University of Pennsylvania team discovered the genetic mutation that causes FOP. The team was led by Frederick Kaplan, 67, a Penn professor of orthopedic molecular medicine.

His rise to become a preeminent FOP researcher began with Orzel.

"Although I had read about FOP, I had never seen anyone with it until I met Carol in 1984," Kaplan said Thursday at the unveiling. "From the moment I met her, she was unforgettable – witty, charming, and in charge.

That spirit is on display at the Mutter, too. Near Orzel's skeleton is some of her costume jewelry, per the wishes of the self-described "Queen of Bling."

Overwhelming joy in life

Snapshots of Orzel, an only child, show a girl with red hair and a megawatt grin, cutting birthday cakes, celebrating her First Communion, holding her pet dog, wearing a T-shirt featuring Fonzie from TV's Happy Days.

The photos also show the toll of FOP.

By 1982, at age 23, she couldn't stand without a cane. She needed help with eating and dressing because she couldn't bend her elbows. She had lost both parents by then, so an aunt helped her move to the sprawling Belmont Avenue campus of Inglis House, a nursing care facility for people with severe physical disabilities.

GALLERY

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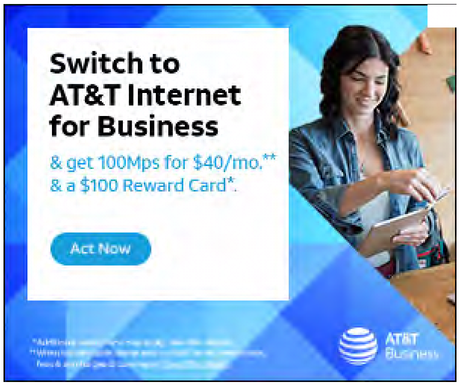
FROM CAROL ORZEL'S PERSONAL COLLECTION
An only child, Carol Orzel grew up in South Philadelphia.

Kaplan, then a young orthopedic surgeon, met Orzel two years later when Inglis' medical director sought advice to manage her pain.

FOP progresses through mysterious flare-ups that can occur without warning, or after an injury. Even a minor bump or bruise can trigger a painful, swollen nodule that turns into misplaced bone. Sometimes, the bone is ragged or jutting. So far, there is no treatment to prevent or stop FOP. Corticosteroids, anti-inflammatory painkillers, and muscle relaxants are used to relieve symptoms.



“I could see the marked effects of FOP in her body and on her X-rays,” Kaplan recalled. “But her spirit and her joy in life were overwhelming.”

Orzel loved fashion, and had an extensive wardrobe that an Inglis House seamstress modified for easier donning with Velcro and zippers. Orzel was strong-willed, once organizing a wheelchair brigade on Belmont Avenue to protest a state health regulation. She was an early adopter of computers and email, and was paid by Inglis to do data entry.

Going online was her gateway to romance. That’s how she met her longtime boyfriend, who moved from California to be with her.

“He died about a year before her, but he adored her,” said adaptive technology expert Dawn Waller, who recently retired from Inglis. “Carol always had boyfriends.”

Orzel's best friend, Mary Hitner, recalled marathon clothes shopping trips to the former Gallery in Center City and rushing in their motorized wheelchairs to catch SEPTA buses. At Orzel's instigation, the two women went blond in the early 1990s.

"If I had to pick one word to describe Carol," Hitner said this week, "it's 'sexy.'"

FROM CAROL ORZELÂ€™S PERSONAL COLLECTION
Carol Orzel in the early 1990s with Mary Hitner, her best friend at Inglis House.

Orzel was an artist, too. Using a stick-like device and prism eyeglasses that compensated for her immobile elbows, wrists, fingers and neck, Orzel painted striking landscapes and made greeting cards. The stick also enabled her to put on makeup — a feat that a CNN TV crew once filmed as part of a story on Orzel.

FROM CAROL ORZELÂ€™S PERSONAL COLLECTION
Carol was an accomplished artist. She used a paintbrush attached to an adaptive stick because she couldnâ€™t bend her elbows.

Every year for decades, Orzel gave a talk to Penn's incoming medical school students to help them better understand people with disabilities. She was also active in the International FOP Association, founded by affected families.

It was at the 1995 IFOPA conference that Orzel got the idea to donate her body. Kaplan had convinced the Mutter Museum to bring Harry Eastlack's skeleton to the conference, held at a Philadelphia hotel. Everyone who knew Kaplan knew that he cherished the skeleton, sometimes visiting it to formulate or confirm hunches about the disease process.

"Carol saw the skeleton and told me then that when her time comes, she wanted to be with Harry at the Mutter, to be an inspiration for students, scientists and doctors for ages to come," Kaplan said Thursday. "As long as her jewelry could be displayed with her skeleton."

Project management problems

FOP is not by itself fatal, but it sets patients up for many life-threatening complications, including respiratory infections as they become bedridden and breathing becomes difficult.

Orzel outlived the normal FOP lifespan by a decade, but she died of such complications in February 2018 at the Hospital of the University of Pennsylvania. Kaplan and Inglis' executives soon contacted the museum.

Mutter curator Anna Dhody says she feels pride — and relief — as she looks back on what turned out to be an arduous, gray hairs."

JESSICA GRIFFIN / STAFF PHOTOGRAPHER
Carol Orzel's skeleton in a new exhibit at the Mutter Museum. She was a victim of fibrodysplasia ossificans progressiva.

It also cost the College of Physicians “tens and tens of thousands of dollars,” even though collaborators on the project donated or deeply discounted their work, she said.

From the start, Dhody knew who she would enlist to prepare the skeleton: Skulls Unlimited in Oklahoma City, the world’s leading supplier of osteological specimens.

Still, there were quandaries. Dead bodies are usually embalmed to meet state burial and transport requirements. But Skulls’ owners, Jay Villemarette and his son, Jay Jr., ruled embalming out. The preservative would be poisonous to the flesh-eating dermestid beetles that they use to remove soft tissue from skeletons without damaging bone.

By serendipity, Dhody had recently met funeral director Dustin Baker. He had the solution: Orzel’s unembalmed body was flown in a galvanized steel, hermetically-sealed container called a Ziegler case.

“It was a little nerve-wracking because we took a lot of time and effort to make sure Carol got there in one piece,” said Baker, owner of Myers-Harner Funeral Service in Camp Hill. “She had zero body fat and very little muscle tissue.”

Indeed, by the time she died, Orzel was a wisp. Her bones were devastated not only by FOP but by postmenopausal osteoporosis and arthritis. After processing, her entire skeleton weighed about five pounds —equivalent to two healthy thigh bones.

“Parts of her skeleton were extremely lightweight — like a cheese puff,” said the younger Villemarette.

That created a problem for the ladybug-size dermestid beetles because they couldn’t distinguish some of Orzel’s bones from her soft tissue. A technician had to carefully watch over the bug colony, brushing them away and applying a temporary protective glue when needed. Ultimately, the 10-week process had to be finished by technicians with tweezers.

When at last the skeleton was finished, the specialists cradled it with six types of foam rubber in a specially ordered crate and had a technician drive it to the Mutter Museum rather than risk air transport.

“We are a science-based company. Our market is scientists,” said Villemarette Sr. “So we were proud to have been part of the project.”

Thursday’s debut of the exhibit does not mark the end of the project. Dhody, the curator, has plans for an online complement with Orzel’s X-rays and photos, FOP patient videos and blogs, and links to educational information.

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