

Nancy and Andy Sando spend their days in wheelchairs customized to fit their rigid bodies. Only their fingers are completely unaffected by the disease

ultimately starved to death after their jaws froze shut.

"FOP is a catastrophic sabotage of the skeletal system," says Frederick S. Kaplan, M.D., an orthopedic surgeon and professor of molecular orthopedics at the University of Pennsylvania Medical Center, in Philadelphia, and a leading authority on the condition. "FOP bone is normal in every way but one—it shouldn't be there."

Kaplan and other researchers are working furiously to find the cause of FOP and then a cure. Although much about the disease remains elusive, they do know that it is usually the result of a genetic mutation, as it was for both Nancy and Andy Sando, though it can also be hereditary. Aided by a team of molecular biologists, Kaplan is hunting for the genetic switch that orders the body to manufacture the unnecessary bone. "When an embryo is forming, genetic instructions tell it where, when and how to make bones, and when to stop making them," he explains. "But the FOP body fails to turn the program off."

### Everyday courage

What is it like to live with FOP? The Sandos, devout Christians, waste no time feeling sorry for themselves. "We have a choice in how we react to FOP," says Andy. "We can be angry. Or we can learn how to manage each limitation."

The couple spend their days in powered wheelchairs. Andy can walk with a metal crutch, but Nancy, who is slightly bent at the waist, can manage only a few steps with assistance. Both their necks are firmly locked, so they must angle their chairs to see each other. Nancy's jaw is fused shut; Andy's is in the process of fusing. Because Nancy can't open her mouth, she talks through clenched teeth. Neither she nor Andy can chew solid food.

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# Turning to Stone

**I**n many ways, Nancy and Andy Sando have a typical marriage. Nancy, thirty-nine, runs the household and designs her church newsletter while Andy, forty, pursues an M.B.A. Like any couple, they have their routines: They watch *Jeopardy* in the evenings; on Sundays, they attend Bible study. In their spare time they go to the movies.

But the Sandos themselves are anything but typical. Nancy and Andy are the only husband and wife in the world with fibrodysplasia ossificans progressiva (FOP), a mysterious disease that relentlessly attacks the body, essentially causing it to make an entire second skeleton. The condition is rare, affecting just 2,500 people around the world. Beginning in childhood, sufferers' muscles, tendons and ligaments are turned to bone, which often retains the shape of the connective tissue it replaced. As the disease advances, patients become frozen permanently in one position—standing up, sitting

A mysterious bone disease has left this couple prisoners in their own bodies

By Cynthia Hanson

down or twisted to one side. They are trapped in a cage, their limbs the bars that never bend.

FOP begins with a "flare-up"—a minor injury to muscles or connective tissue, such as a bump or a bruise—that causes a painful, doughy mass to form under the skin, with redness and swelling on the surface. Within weeks or months, this leads to the formation of new bone at the site of the injury.

There is no cure, no prevention and no treatment for FOP. Surgery to remove the extra bone only accelerates the condition. And while the disease itself does not cause premature death, complications can be fatal: A cold can turn into pneumonia, and a few patients have

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one small measure of freedom: Although their elbows are locked at right angles, their fingers are unaffected. That could change, but for now, Nancy and Andy can type on angled computer keyboards, handle utensils and use cordless phones that are attached to two-foot sticks.

Aside from FOP, Nancy is in good health, though she takes an anti-inflammatory drug every day to quell joint pain, and a blood thinner to prevent clotting that could result from her inability to move her body. Unfortunately, Andy also has asthma, and earlier this year a respiratory infection nearly killed him.

The couple live in Petoskey, Michigan, in a house that has been modified to meet their needs. The floor is tiled to withstand the weight of their motorized chairs and the jumbo-sized bathroom includes a hot tub with an electric hoist to lower them into the tub.

Six caregivers—one licensed practical nurse and five certified nurses' aides—provide round-the-clock assistance. This at-home care costs \$10,000 a month, and is funded by the settlement of a lawsuit Nancy filed in the 1980s when she was badly injured in a bus accident. Social Security is their only income now that Andy has given up his telemarketing and computer graphics businesses to study. (After he earns his degree, he hopes to teach part-time at a community college.) Medicare covers their medical expenses.

Each day, the Sandos' caregivers help them in and out of bed, and to bathe and dress. The aides also cook, clean and chauffeur the couple to the grocery store, shopping mall and movie theater.

Not surprisingly, the Sandos live by a strict schedule. "We have no spontaneity and no privacy," Nancy says matter-of-factly. Getting ready for the day is a three-hour process.

Meals are equally orchestrated events. Because their food must be whipped in a food processor so they can eat it, they rely on sauces,

gravies and marinades to smooth the textures of hamburger, fish and chicken. Their favorite take-out entrées are chicken chow mein and seafood enchiladas, which they whip at home.

FOP has robbed Nancy and Andy of activities that most married couples take for granted—hugging, kissing and making love. "People might say, 'That's not much of a marriage,'" Nancy concedes. "But we're thankful we can hold hands in bed. A relationship goes much deeper than just the physical level."

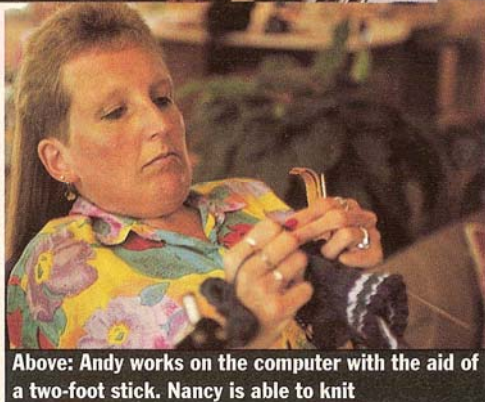
One of the most striking things about this couple is their acceptance of their limitations. "People expect us to be angry, but we're not," insists Nancy. "They may see us and think, That's a horrible thing to live with. But we don't consider FOP horrible. We've grown up with it."

### Soul mates

In fact, Nancy was just five years old when her mother discovered a grapefruit-sized red lump on the back of her neck. She was misdiagnosed with a fast-growing cancer. "The doctors gave her months to live," recalls Nancy's father, John Whitmore, a retired aerospace engineer. "But the lump disappeared."

Once the cancer scare was over, Nancy's doctor referred her parents to specialists in New York City. There, the doctors took one look at Nancy's malformed big toes—a hallmark of FOP—and made a correct diagnosis. The physicians assured the Whitmores that Nancy wasn't in immediate danger of dying, but they never explained how debilitating the disease would become.

Nancy learned about the condition as it inflicted its cruelty. Her neck fused when she was in kindergarten; by age eight, sheets of bone covered her shoulders and spine like



Above: Andy works on the computer with the aid of a two-foot stick. Nancy is able to knit

a carapace. She soon lost mobility in her waist; then her elbows locked when she was thirteen. Classmates taunted her because she walked with a limp and couldn't move her head to look them in the eye. "Being a wallflower was my coping mechanism," Nancy recalls.

With her movement impaired, Nancy relied on her mother and older sister Sharon for personal care. Her father encouraged her to find creative ways to do things. She even paddled a kayak on family outings. "Nancy never wanted special concessions," John says.

Still, she grieved in silence for her losses. "I'd say good-bye to something I could no longer do," Nancy explains quietly. "In the eighth grade, when I felt my left arm getting stiff, I knew it was only a matter of time before I wouldn't be able to reach down to pull my socks up. I'd say to myself, 'I'm pulling up my socks again, and I don't know how long it will last.'"

Nancy's parents divorced during her senior year in high school, and she moved in with Sharon. After graduation, Nancy took business courses at a local college and worked as a bookkeeper. Her right hip locked when she bumped it on (continued)

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a car door in 1979, and within six weeks, her knee and ankle were immobile. Nine months later, a flare-up in her left leg made it impossible for her to continue working.

Determined to support herself, Nancy studied computer programming and became an independent contractor. Occasionally she commuted to clients' offices on a public bus equipped with a wheelchair lift.

Nancy was returning from a job on April 12, 1985, when the bus driver pulled into her driveway. She rolled her chair onto the horizontal platform waiting to be lowered to the ground, but the driver pushed the wrong button, hurling Nancy backward. Her head and shoulders slammed into the side of the bus. "I heard a crunch, and my neck moved," Nancy recalls. "My head was dangling."

To this day, just thinking about the accident brings Nancy to tears. Her painful recuperation at home lasted two years, as new bone developed across her shoulders, above her knees and over her ankles. Even sitting became difficult.

New FOP bone formed in Nancy's neck, and continued upward. In 1987, her jaw froze shut. "The last time I ate real food was that Mother's Day," she says, softly. "I had steak and lobster." Nancy blinks back a tear. "Losing my jaw was my biggest loss. It's the most difficult part of living with FOP."

The accident also cost her a fulfilling and lucrative career. As a result, she sued the bus company and the manufacturer of the wheelchair lift and received a substantial settlement (she won't say how much).

Later that year, Nancy traveled to the Mary Free Bed Rehabilitation Hospital, in Grand Rapids, to get a new wheelchair. Hoping to recruit members for an organization called the International FOP Association

(IFOPA) she was helping to start, she asked the staff to pass her name and address on to other FOP patients who came for treatment.

In April 1988, Andy Sando went to the rehab center from his home in St. Joseph, Michigan. The staff gave him Nancy's phone number. But Andy wasn't interested. "I led a full life," he says. "And I had plenty of male and female friends. I didn't think meeting Nancy would make a big difference."

Like Nancy, Andy's FOP was diagnosed in childhood. At age four, while he was being treated for a fractured neck, doctors noticed his malformed big toes and told his parents he had FOP. "They said he'd

Andy blurted out a marriage proposal. A startled Nancy accepted. They were married in December.

As the minister pronounced them husband and wife, Andy's brother and a friend picked Andy up and turned him sideways so he could kiss Nancy. "Our guests giggled and clapped," Nancy says.

Including Nancy's father (her mother has since died). "For two people with FOP to meet, fall in love and marry, that's the real miracle," John Whitmore says.

## A new beginning

"As a child, I didn't have a preconceived vision of my future," says Nancy. "I didn't want to get my hopes up and then be disappointed. So I rarely daydreamed about marriage. When our love blossomed, it just felt right. Andy has made my life fuller beyond compare."

Nancy and Andy's marriage has also shifted their family dynamic. For thirty years, Minnie Sando and her ex-husband, Elmer, had been their son's primary caregivers. Since the late 1970s, Sharon had been Nancy's sole provider.

But after their marriage, the couple hired a staff so they could establish their independence. "It's important to have your own identity," Nancy explains. "Now, our family members are in our lives because we want them to be, not because we need them to be."

As they approach their tenth wedding anniversary, Nancy and Andy are optimistic about the future. They don't worry about the next turn FOP will take. Nor do they dwell on whether a cure or treatment will be discovered soon. "We believe God will meet our needs; to worry too much about tomorrow is counterproductive," says Nancy. "We're happy taking life one day at a time." ●

*Cynthia Hanson is a contributing editor for Chicago Magazine.*



"People expect us to be angry, but we're not," says Nancy (here, with Andy taking Mopsey for a walk). "We've grown up with FOP"

be bedridden long before he reached adulthood, but that he'd live until old age," recalls Minnie Sando, Andy's mother. "My fear was that he would end up in an institution."

In 1988, Andy was starting his last year at community college when he received a letter from Nancy, inviting him to join the IFOPA. This time he decided to call her.

They became pen pals, and in October, they met. It was the first time either Nancy or Andy had ever seen another FOP patient face-to-face. "It was wonderful to meet somebody who understood everything I'd gone through," Andy recalls.

In November, Andy and his mother were shopping in Grand Rapids, when he persuaded her to drive him 180 miles to Petoskey to see Nancy. The next day, as he was preparing to say good-bye,