

Health Care Revolution at Stanford

Good-bye long waits and arrogant docs - lessons from a cutting-edge clinic

This article appeared in San Francisco Magazine
January 2003

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Little Jack has Sturge-Weber syndrome, a neurological disease. Lucky for him, his parents, Paula and Frank, have found themselves in the middle of a QUIET REVOLUTION IN HEALTH CARE. Where the doctors are compassionate. Patients search the Internet in exam rooms. Nurses say "Come right in" when you call. Will the medical establishment really let a small clinic at Stanford get away with all this?

On the night that his son, Jack, was born in September 2001, Frank Filipanits drove home alone, exhausted, still wearing the green scrubs he'd donned hurriedly in the Stanford hospital delivery room. As he stepped into his house, Luna, his wife Paula's dog, loped out to greet him. Luna took a couple of sniffs, cowered, and bolted under a table with her tail between her legs. "She must have smelled the blood and the fear in my sweat," Frank says. "She thought I'd killed Paula."

Frank, an audio software writer, and Paula Murray, 42, a graphic designer, live in a tidy neighborhood wedged between the Atherton estates and the Redwood City barrio. They met in 1995, when Frank joined Paula's garage band. It was an unlikely pairing. Frank is ten years younger, and with his long blond hair, he looks straight out of Guns N' Roses. But he played bass and she played drums, and as Paula was always saying, a rhythm section had to be in sync. Still, the romance took them by surprise. One of the first things they agreed upon was that they wanted children.

Paula's delivery was perilous. She pushed for several hours, but the baby couldn't squeeze his head through her pelvis. When the obstetrician detected meconium in the amniotic fluid, she performed an emergency cesarean section. Working quickly, she pulled the baby from the womb. Despite some problems breathing, Jack would be fine. Jack did have a prominent birthmark, a patch of reddened skin covering the right side of his face. The obstetrician called it a port wine stain.

That night at home, Frank's nerves kept him awake, so he turned on his computer and plugged "port wine stain" into a search engine. As he sat alone in the dark, disturbing things appeared on the screen. He pieced together that the port wine stain might be more than cosmetic. He learned that it is an indicator for Sturge-Weber syndrome, or SWS, an incurable neurological condition generated by abnormally formed blood vessels, associated with a broad array of problems. Glaucoma is common. The majority of SWS children develop seizures and experience behavioral problems that demand special education. As adults, they have difficulty staying employed or married. Often the seizures can be controlled with drugs, but in severe cases, neurosurgeons remove the affected part of the brain.

Frank didn't know whether to believe what he read on the Internet. So the next morning at the hospital, he didn't tell Paula, who was still weak from the birth and worried about Jack's breathing, what he'd discovered. Frank was relieved when Dr.

Nancy Morioka-Douglas, Paula's family physician of a decade, arrived. Morioka-Douglas said that Jack looked good and yes, the port wine stain raised issues that were worth looking into. She promised they would do so together and offered to find specialists who could help them investigate whether the birthmark was linked to SWS. Dr. Nancy, as Paula and Frank called her, told Paula that in the coming weeks, whenever she felt exhausted or overwhelmed, she should remember that "her body was dripping with hormones." Later, whenever Paula sobbed and thought, "This is too hard; I never should have had children," she was revived by Dr. Nancy's simple mantra: "It's the hormones, not you."

Morioka-Douglas, who is originally from Hawaii, has long black hair, which is beginning to streak with gray, and a preternatural calm. She joined the Stanford Family Practice clinic nine years ago, drawn by its creative approaches to patient care and the opportunity to teach fresh ideas to a new generation. While it looks like the typical blandly decorated doctor's office, the modest clinic is actually a spunky innovator in health care. As one local university health care expert says, the Stanford family clinic "is the only one I know where all of the physicians want to create new and better ways of caring for patients."

The doctor is no demigod at the Stanford clinic. Morioka-Douglas and her colleagues encourage patients to play an active role in their own health care. Along with its sister organization, the Stanford Medical Group, the clinic makes it easy for patients to get appointments when they need them, usually the same day. It also cuts down on unnecessary appointments by encouraging patients to communicate through email. And when office visits are needed, patients can access their own records on terminals in each exam room and explore medical questions on the web.

What's more, Stanford Family Practice physicians spend time talking with patients. "I feel that helping people means connecting with them yourself," says Morioka-Douglas. "If I'm a happy doctor, I'm going to be better able to help people through all kinds of crises. And what makes me happy is to talk to people."

Since early 2001, the Stanford clinic has collaborated with a handful of others around the nation to foster this new patient-centered model of care. The collaborative was conceived and is guided by a Boston-based organization of doctors and health care professionals called the Institute for Healthcare Improvement. IHI contends that health care desperately needs elemental, root-shaking change. Its leaders have confronted the medical establishment with uncomfortable questions such as: Why should patients wait for doctors? Shouldn't people expect to be safe in a hospital? Why are there twice as many bypass operations in one county as in others? In one recent case, a Redding cardiologist is being investigated by the FBI for Medicare fraud after doing 35,000 cardiac procedures-many of them possibly unnecessary-in the past decade.

While attention is currently focused on the daunting cost of health care, several recent high-profile studies have reported vast problems with the quality of care, including hundreds of thousands of unnecessary disabilities and deaths each year. Hospital errors, in fact, cause more avoidable deaths than breast cancer or AIDS. Dr. Daniel Masys, who directs "biomedical informatics" at the University of California, San Diego, calls the high rates of medical errors the "groans of a collapsing paradigm." The groans are also heard in a report by a special committee of the prestigious Institute of Medicine. "In its current form, habits and environment, the

health care system is incapable of giving Americans the health care they want and deserve," it concludes. "The current care systems cannot do the job. Trying harder will not work. Changing systems of care will."

But energized IHI reformers, and Stanford Family Practice in particular, are driving forces for more than the much-needed improvements in day-to-day care. They are striving to overcome the prevalent ethos that a doctor's authority is inviolable. They want to show that just as the networked PC user multiplies the power of computing, the networked patient can be a hub of new energy in health care. That entails not only doctors checking their ego at the door but patients waking up to their own potential to take charge of their health.

Frank and Paula, an intelligent, energetic, and Internet-savvy couple, can be seen as model new patients. In a little over a year, they have gone from feeling helpless about Jack to learning everything they can about his condition. And the Stanford Family Practice clinic has been beside them every step of the way. "The clinic has been absolutely there for us," Frank says. "Dr. Nancy is very open and genuinely concerned that we get good care. She's personally involved. She's willing to take emails. There are no roadblocks to jump over to get information or advice. I always feel if I need her, I can get to her directly."

Of course, paradigms shift ever so slowly in a monolithic industry such as medicine. And the Stanford clinic and the patient-centered movement it represents are fighting against powerful currents of opposition. The outcome will affect the health of patients and much about the future of health care.

Dr. Joseph Hopkins, who heads the Stanford Family Practice clinic, picked up the family medicine bug while a student at Stanford in the 1970s. Family medicine had gained new currency from that decade's cultural upheavals, particularly the women's and alternative health movements, which assailed the medical establishment for its paternalism and indifference to the role of psychosocial factors in health.

Hopkins's student practice took him to Livingston, California, a small town on Highway 99. He lunched at the one popular restaurant in town, where he saw his patients with diabetes eating heaping plates of mashed potatoes and meatloaf or chicken potpie. Occasional office visits with the doctor, he realized, weren't going to change that.

Family medicine's emphasis on the coordinated care of a whole person appealed to him, but so did the idea of creating ways of helping patients beyond the one-on-one office visit. With doctors Hal Holman and Kate Lorig, Hopkins found an opportunity to test these ideas at the community-based clinic Mid-Peninsula Health Service, in Palo Alto. In 1989, the clinic joined forces with the Stanford medical complex, changed its name to Stanford Family Practice, and moved to the university.

Among other experiments, doctors organized discussion groups for patients in similar situations. These ranged from people with diabetes to mothers with newborns. Holman still employs the model through a Stanford program called Health Partners. He says that group visits transform both patients—who draw support and practical advice from peers—and doctors, who learn about their patients in richer ways than through standard office visits.

Morioka-Douglas, who trained at Stanford and did her residency at San Jose Community Hospital, came to Stanford Family Practice because she thought it was a place where she could help redefine primary care. She emphasizes the importance of being present with patients and listening carefully, both to address what's going on with them and to renew herself as a doctor. "You can be very efficient in brokering information," she says. "But it's a very dry life to just be on top of your required reading."

Two years ago, Morioka-Douglas and Hopkins attended IHI's national conference at the San Francisco Hilton. "Every other medical conference I'd gone to in recent years was full of grumpy, unhappy people: 'Oh, managed care! Oh, the government! Oh, the paperwork!'" says Hopkins, a large, avuncular man who begins conversations laconically, then speeds up as his enthusiasm heats. "At each of the IHI sessions, the feeling was that we could transform health care."

A disarmingly charismatic Harvard physician named Donald Berwick leads IHI. At the San Francisco conference, Berwick, a fan of Harry Potter, declared that Harry gains power over the evil one whose name must not be spoken by calling him by name, Voldemort. Doctors and nurses, he said, needed to do the same, to name health care's evils-its Voldemorts-to gain power over them. In a similar spirit, Berwick illustrated the revolutionary nature of patient-centered care by presenting a dialogue between "Dr. Olderway" and "Dr. Newerway." In one Potter-like exchange, the two doctors are talking on the phone to a boy and his mother, who is a witch. The boy, Ron, has fallen off his mother's broom and broken his arm.

Dr. Olderway (to the boy): Broke your arm, Ron? No, I didn't know. How would I know? Do I work in the emergency room? Have your mother make an appointment for the cast to come off next week. I've got Thursday a.m. for cast removals.

Dr. Newerway: Hi, Ron. Oh, sure, I saw the emergency room report. We have the same computerized medical record as you do, remember? The same one you can get to at home.

Olderway (to Newerway, incredulous): The kid reads his own medical record?

Newerway: Not often, but it's his. (To Ron): It'll be time to take the cast off next week. Can your mom join us for a minute now on the other extension? Thanks. Mrs. Weasley, hello. You can bring Ron in anytime next week to have the cast taken off. Just call that morning. You want to do it yourself? You're handy with tools? OK, that's an interesting proposal. Why not try it? Yeah, let me know if you have any questions. In fact, I'll talk you through it on an open phone line while you try, and then we'll post the test on our website afterward.

Olderway: Whoa, whoa, whoa! Did you tell that mom she could take the kid's cast off herself? That's crazy.

Newerway: Maybe, but it sounds interesting to me. Her hobbies are wood carving and weaving. Ron's fracture is routine. Anyway, who do you think is going to be more careful than Mom will be in taking off that cast?

Olderway: Sure, sure, let's have everybody take off her own cast. Let's have everybody take out his own stitches.

Newerway: I want my care to be customized to every patient. Some people can take out their own stitches, some can't, some can and don't want to. Every patient is the only patient.

Clearly, Dr. Newerway is the guiding light of Stanford Family Practice. Take the clinic's same-day appointment schedule. Traditionally, doctors' schedules are highly structured. They might do one or two simple cases in the morning, then a couple of physicals and return visits, then finish up with complex or acute cases. Of course, patients have their own schedules, and diseases do, too. Matching the three is a source of bottlenecks and tension. Schedulers and triage nurses spend hours brokering appointments by assessing how urgently a patient needs to be seen. Getting it wrong is a medical risk.

Before the Stanford clinics changed to the newer way of scheduling in 2001, people waited up to 100 days for nonurgent appointments. Now, most people can be seen the same day they call. The era of patients begging for appointments, what one doctor calls "Mother, may I?" is over. Those who want an appointment get one. Hopkins says the rewards are great. No-shows have plummeted. Triage nurses have a fraction of their former load.

Unlike overworked physicians at doctors' offices, Stanford clinic doctors respond to patients' emails, answering questions about symptoms or offering advice about medications. Stanford Family Practice is also ahead of the game on electronic medical records. With the terminals installed in every exam room, patients can call up their history, lab results, and other information. (Unlike "Ron," patients can't access their records at home.) Hopkins notices that people like sitting next to him looking at results together, as you would with a peer, rather than watching him read a chart in a folder.

Morioka-Douglas uses the terminals to scout out answers to questions that come up during the visit. Stanford stores extensive medical information in databases, including its health library, which can be used by anyone. If Morioka-Douglas doesn't know an answer to a question, she can look it up while in the room with a patient and print it. Other times, her patients point out useful sites or pieces of information they've located.

Patients can also learn to help themselves in Stanford-designed self-management groups, which are guided by a simple philosophy. "If you have a long-term illness, you have no choice but to manage it," says Lorig, the Mid-Peninsula Health Service veteran who runs this program. "You can stay at home and suck your thumb or realize this is the hand you have been dealt and get on with it."

Often, the best advice comes from your fellow sufferers. "I remember asking patients in a self-management course why it was valuable," says Holman, another Mid-Peninsula veteran. One elderly lady with disabling rheumatoid arthritis told him that she previously had trouble walking a straight line. "For years, I stayed at home because I didn't want people to think I was drunk," she said. "But people in this group told me I was a damn fool. And now I stagger all over town."

Studies by the federal government's Agency for Healthcare Research and Quality demonstrate that self-management groups lead to better results at less expense. Which makes perfect sense; after all, the groups are designed to teach people that they can improve their own health. When a patient is parked in a waiting room, sits in an uncomfortable gown watching the doctor read a chart, or can't get hold of a doctor or critical information when he or she needs it, the opposite message is telegraphed: You're not that important, the doctor controls your health, and only what he does matters. In the future, says Hopkins, a doctor's job will be about "helping patients understand and succeed with their own health care."

Or with their child's. Five months after Jack was born, he showed no signs of SWS. But that didn't stop Paula and Frank from worrying. Every time Jack didn't develop according to the baby books, they imagined the worst. Then when Jack did cut his teeth or roll over, the new parents' fears faded and they reveled in the joys of raising their son.

When Paula and Frank couldn't suppress their doubts, though, the Stanford clinic was there to hear them. Morioka-Douglas located a celebrated dermatologist at UCSF to remove Jack's birthmark with laser treatments. She also guided the couple to the Sturge-Weber Foundation website, which Frank and Paula plumbed for the latest information. They even joined its list-serve to learn what they could from other parents. Morioka-Douglas also conferred with Paul Fisher, an accommodating Stanford neurologist. Frank and Paula were pleased to learn that Fisher had treated the syndrome before.

At the end of February 2002, when he was five months old, Jack suffered a bout of vomiting. Paula figured it was the flu. When she changed his diaper the next morning, Jack gave her a big smile, and suddenly listed all the way to the left. On the changing table, his head seemed stuck to the surface, as if the muscles in his neck had stopped working. She called Morioka-Douglas, who told her to bring Jack in immediately.

In the clinic, the baby again listed to the left, and threw up on Morioka-Douglas. Knowing that Jack was in the throes of a seizure, Morioka-Douglas sent parents and baby to the Stanford hospital emergency room. She stayed in touch with them by cell phone. In the emergency room, Paula was terrified. Jack appeared dehydrated and limp from exhaustion. After a tense 45 minutes, paramedics put an IV in Jack's arm, and nurses got the seizure under control with drugs.

It was now clear that Jack had SWS. An MRI confirmed it. During his three-day stay in the hospital, he was seen by an army of specialists, residents, and medical students. Fisher, the neurologist, prescribed liquid phenobarbital to keep Jack's seizures at bay. He told Frank and Paula that Jack would be OK and they should take him home.

The Stanford Family Practice clinic now loomed even larger in Paula's and Frank's lives. At first, when Jack had seizures, Paula would call the Stanford hospital neurology department. Invariably, the hospital declined to see him, telling her that vomiting is not usually associated with seizures and that she should take Jack to the clinic. While Paula and Frank obliged, it soon grew obvious that vomiting was a part of Jack's seizures. The couple then began conducting email consultations with the clinic and the neurology department to determine which should see Jack at a

particular time. They also relied on email to figure out when to adjust Jack's meds. After one email that Paula sent when Jack was seven months old, Fisher suggested they increase his dosage. Paula replied a few days later.

Hello Drs. Morioka-Douglas and Fisher,
After Friday's consultation, we upped Jackson's meds to 12.5 ml. Thursday, he was punkish all day and threw up at 4 p.m. This morning, Friday, he woke up lethargic, weak on his left side and feeling punkish. We aren't sure if the staring spells are seizures or not, since the duration is less than 15 seconds. Any thoughts? Anything you'd like us to do differently?

Fisher replied the same day.

Paula,
The weakness could be seizure-related or in some SWS kids, independent of seizure activity. Phenobarbital, too, can cause irritability. I recommend talking first with Nancy to make sure there's not something non-neurologic at play.

Morioka-Douglas then wrote to Fisher and copied the couple:

Dear Paul,
I think we should start with your seeing Jack. Paula and Frank, if Paul thinks that these episodes are not neurologically based, then I'd like for Jack to be seen at Packard GI [gastro-intestinal] clinic.

Fisher then emailed his scheduling nurse to set up an appointment and copied the group. After examining Jack and adjusting his meds at that visit, Fisher told the couple about a new "kinder and gentler" drug, Tegretol, that Jack could start when he turned one in September.

Drugs are the main therapy for Jack's seizures, but their risks and uncertainties kept Frank and Paula vigilant. They logged onto the Sturge-Weber Foundation list-serve to learn what they could from other parents and were deluged with advice. Following one suggestion, Paula installed an extra mirror in her car to detect Jack's seizures and a clock in the bedroom to time them. (Jack likes the ticking, too.)

As time passed, and Jack "grew like a sprout," says Frank, he and Paula became more active in managing his care. In fact, they gained a greater knowledge of SWS and its treatment than most of the doctors they were seeing. In one instance, Jack had a seizure two weeks prior to a scheduled laser treatment to remove the stain from his face. Paula worried that the treatment might provoke another seizure. So she searched the web and made calls to neurologists herself. It turned out that the treatment wouldn't provoke seizures.

As Paula and Frank took charge of Jack's health themselves, they became more accepting of his condition. "We learned to adjust our expectations," Frank says. "I'm a private pilot, but that's something he'll probably never be able to do. We're all born with a handful of weird things. Instead of dropping dead of a heart attack at 40, he's got Sturge-Weber. Is that so bad?"

Frank and Paula's positive outlook, though, was about to be tested. When Jack was ten months old, Fisher was reassigned. The email tree that had branched between the couple, Fisher, and Morioka-Douglas came crashing down. Frank and Paula found themselves back in the frustrating world of Dr. Olderway.

One morning in July 2002, Paula took Jack to see the new neurologist at Stanford's pediatric neurology department. He was 45 minutes late. When he did arrive, he couldn't find Jack's chart, left for several minutes to locate it, then found nothing in it. He assumed Jack was a new patient, although Paula had just spoken with him on the phone.

Paula told this neurologist that whenever she had questions for Dr. Fisher, she would email him. The neurologist told her to call his nurse instead. Nevertheless, when Jack had a seizure, Paula emailed him with a worried question. He didn't reply.

The next time Jack vomited and had a seizure, Paula did call, but the nurse told her that she'd have to see Morioka-Douglas first, because vomiting isn't associated with seizures. "This is an exercise in stupidity," Paula thought. Still, she took Jack to the clinic, and Morioka-Douglas confirmed what Paula already knew-that Jack's vomiting was likely related to his seizures. She sent Paula and Jack back to the neurologist.

When the neurologist's nurse suggested switching Jack from liquid phenobarbital to pills, the pharmacist alerted Paula that the pill contained about a quarter more phenobarbital than Jack had been taking. Paula didn't give it to him.

Not long afterward, Paula and Frank took Jack to his scheduled appointment in the neurologist's office. Again, the neurologist was 45 minutes late. Paula asked, considering that Jack was now a year old, if she should switch his antiseizure medication to Tegretol, a possibility suggested earlier by Fisher. The neurologist said sure and started doing the arithmetic out loud for converting the dosages. Frank could hear him making math errors, and the couple looked at each other in disbelief. They had wanted an open dialogue-the kind they had been accustomed to with Dr. Nancy-to discuss the switch to Tegretol and its possible side effects.

(When contacted, the neurologist didn't remember Jack's case at first, then expressed surprise. He said he thought the family was pleased with his care. He acknowledged that he might have rounded up the Tegretol to a higher dosage but claimed that the difference was insignificant. He said that he does email patients-although Frank and Paula say he never replied to theirs-and that, yes, he often runs late seeing other patients, but the couple just doesn't understand how a clinic operates.)

Meanwhile, the clinic had been having problems of its own, ones that threatened to halt its progress. In January 2001, the Stanford Medical Center had terminated all of its HMO contracts, claiming they didn't pay enough. The move threatened to throw the clinic into a financial tailspin. "In the worst case, we would have lost 50 percent of our patients," Hopkins says.

The clinic's same-day appointment schedule required keeping 65 percent of its time slots open. But without HMO contracts, doctors' incomes rely on their daily appointments being met. If few patients called or showed up, the clinic took it in the

wallet. When an online consultation replaces an office visit, the doctors take another hit, as insurers pay them for office visits and not for answering email.

Despite some grumbling, clinic doctors decided to keep up with emails and retain same-day appointments. "On days that we're light on patients and everyone wants to change back to the old system, you just have to trust that it will all work out in the wash," says Morioka-Douglas. In one way, it has done just that. Last year, following articles in the San Jose Business Journal and Stanford Report about its innovations, the clinic attracted almost as many new patients as had been lost.

Still, the clinic faces resistance inside Stanford itself. When Judith Swain took over the School of Medicine in 1995, she and the dean soon reorganized the Division of Family Medicine and placed it under another department. Associate dean Neil Gesundheit explains that "Dr. Swain's mission is that each division has strong research, patient care, and education." The Division of Family Medicine, he adds, "had it flipped around." Another reason family medicine got reorganized is that substantial federal and private monies flow to basic research, while little goes to family practice or improved patient care. "We're not unique in this," he says.

The lion's share of funds being devoted to research is a symptom of a deep cultural bias, explains Holman, one of the family clinic's early founders. "The basic view is that the intellectual content of family practice is beneath the dignity of Stanford," he says. "That influences the attitude and morale of people in the clinic. Those who wanted to do new things were effectively turned off by what happened." He says that at least one doctor quit in disgust.

It's the same old story, says Chuck Kilo, the former leader of the IHI's primary care collaborative. When it comes to instigating deep-seated changes in health care, he says, "only 10 percent of the difficulty is actually making the change; 90 percent is cultural resistance." Dr. Peter Rudd, who is working with Hopkins to refine a program for the treatment of diabetes, agrees, though he takes a somewhat softer view. "Some doctors are ready to change; others aren't," he says. "It's easy for a person at an academic center to assume what they're doing is great, they don't need to do anything else."

Holman sees such arrogance as a major stumbling block on the road to better patient care. He calls the landmark Institute of Medicine report, cowritten by Berwick, which spells out detailed changes for quality care, "one of the finest things that's come out in a long, long time. But it's fallen on deaf ears in academia. Nothing has really been done."

At Stanford Family Practice, despite the financial setbacks, Hopkins remains optimistic that the quest for better patient care that he and his colleagues at Mid-Peninsula undertook three decades ago is gaining momentum. He says patient-centered care is becoming respected among Stanford's myriad clinics—two of which have asked Hopkins to help install patient email and same-day appointment schedules. Recently, Hopkins advised doctors and nurses in that bastion of acute care medicine, the surgical operating room, on how to cut down on the amount of time that pre-op patients sit alone waiting for the anesthesiologist. He's confident family medicine will soon gain an academic foothold in the Stanford School of Medicine.

Nationally, the Institute for Healthcare Improvement is winning new converts. Thousands of health care organizations now participate in IHI, 20,000 people subscribe to its newsletter, and nearly 11,000 people will attend an IHI event this year. The institute's "philosophy of putting the patient at the center of care is beginning to take hold in a way that is truly meaningful for patients and their families," says Ruby Hearn of the Robert Wood Johnson Foundation, one of the nation's largest contributors to health care reform.

Many longtime medical-industry observers believe that patients themselves will ultimately form the biggest force for improvement. Already, of course, more and more people do what they can—research or chat on Internet health sites, ask questions of their doctors, and eat or exercise their way to better health. The more complicated task of transforming the barnacled traditions of medicine to forge productive, cooperative, and respectful relationships among patients and doctors is just beginning.

And patients like Frank and Paula, in harmony with doctors like Hopkins and Morioka-Douglas, are leading the way. Jack's condition launched his parents into the daunting maze of the health care system. But they insisted on finding the right path for Jack and themselves.

"Initially, I felt things were far beyond my control," Frank says. "But later it became a situation where Paula and I were the ones who knew the most about what was going on. We would not rely on just giving over his care to anybody." Paula's view of the health care system has also changed. "If you're going in for a Pap smear, you do it and go away," she says. "Now, seeing a number of doctors for Jack requires that I keep straight who's doing what and how they all come together."

This past October, Frank and Paula shared their newfound knowledge and confidence with a worried couple whose child was just diagnosed with SWS. The couple, recently thrown into the labyrinth of clinics and hospitals, wrote Frank and Paula an email and asked, "How do you trust what doctors tell you?" Frank replied: "You don't."

I double- and triple-check everything doctors tell us. They are unlikely to spend the same hours online or reading through research papers to find new or salient information. You, however, have a tremendous vested interest in knowing as much as possible. Find a doctor you are comfortable with and provide them with as much information as you can. In the end, remember that doctors are only people looking at a hopelessly complicated organism and making a best guess as to the right course of action.

Despite problems with their latest neurologist, Frank and Paula have managed to keep their son's seizures under control and enjoy him for who he is—a flirt, according to Paula. "Jack is all about standing up right now," she says. "Some might look at his disorder as intimidating, but he's really an easy baby, so easygoing. He chooses to be happy."

Now Jack has a healthy baby sister, Josie. "I didn't intend to get pregnant again this quickly," Paula says. "We just left the door open. Maybe she's come now to help take care of Jack, to help him back up if he falls on the playground. I ask

myself: Do you really want to put that on a child? Then I think, well, that's a part of being a family."