

A Chance For Shawna



"The doctor got the big seizures out!" says a happy and healthier Shawna, who goes to school regularly now.

By CHERYL KICK. "I thought they'd put Wayne on some sort of medicine to control the seizures, and that would be the end of it," my new friend told me, recalling the day, over two years ago, when she first learned her young son had epilepsy. "But the medication didn't work. Wayne's seizures just kept getting worse. Every moment with him was like an hour, waiting for the next convulsion."

I met Melody Horn and her son, Wayne, at St. Louis Children's Hospital in October 1979 while in my defiant pursuit of a highly controversial surgical procedure that might help stop my daughter Shawna's epileptic seizures. Over lunch in the coffee shop, we shared our experiences as mothers of children with epilepsy.

"Wayne would often hurt himself during the seizures," Melody said, "teeth through the lips, split chin, bruises all over his body. Our doctor kept trying all types of drugs, but nothing stopped those exhausting seizures."

I recognized the utter frustration in Melody's tone, and understood her anguish only too well. My daughter Shawna, like four-year-old Wayne, was among the 400,000 children and adults in this country whose seizures rage on in spite of the numerous drugs available for the treatment of epilepsy today. As I listened to Melody's familiar account, I couldn't

help but contemplate the cruel irony of our two situations. Most of the country's more than 2 million epileptics can substantially or totally control their seizures by taking daily medication.

But, unfortunately Wayne and my daughter, Shawna, were among the 20 percent of epileptics who couldn't be treated by drug therapy, the backbone of epilepsy treatment. Drug which usually prevent convulsions, even when pushed to toxic doses, provided little, if any, relief for Shawna and Wayne. For them, and other victims of uncontrollable seizures, fear and apprehension become a way of life. And, due to compounding health problems, progressive deterioration in their condition—even to the point of institutionalization or death looms as an ever-present threat for sufferers and their families.

Because of this threat, both Melody Horn and I had traveled to St. Louis Children's Hospital over a year ago, she from a small town in Texas, and I from Los Angeles, in hopes that our seizure-plagued children could be helped by the surgery that we couldn't obtain in our home states.

My daughter Shawna, at five years old, had been having seizures for three years. My husband Keith and I had watched helplessly as our only child, once healthy and vibrant, gradually became thin, weak, and partially paralyzed over the right side

of her body from the constant seizures that were virtually impossible to control. In addition, the six anti-convulsant drugs she had to take made her drowsy and unalert-side effects as debilitating as the disease itself.

After the labors of eight pediatric neurologists over the three years had proven unsuccessful, Keith and I were faced with the agonizing conclusion that nothing more could be done for our daughter that hadn't already been done, and that the doctors were probably justified in recommending we place her in the state hospital, where her constant medical needs could be met. We found ourselves torn between an uncompromising determination to keep our child at home with us, and the aching reality that she was not getting any better, or any easier to care for.

It was in this eleventh hour that by sheer chance I came upon a reference book about epilepsy, written expressly for doctors. Amidst all the cryptic medical terminology, I read about a surgical procedure called "removal of seizure focus." I wondered why I had not heard about this operation before.

It seemed that in a scant few university medical centers in the country, specially skilled neurosurgeons were screening epileptics, whose seizures couldn't be drug-controlled, for an extremely sophisticated surgical technique, in which the brain tissue causing the seizures is strategically removed. The procedure, long past the experimental stage, was considered to be both safe and effective-when performed by capable surgeons - according to a 1977 report compiled by the U.S. Commission for the Control of Epilepsy. Up to 50% of selected patients having the surgery gained complete freedom from the uncontrollable seizures, and an additional 15 to 20% obtained substantial relief not possible on medication alone.

"I immediately picked up the phone to call Shawna's doctors. "It's just too radical," was their unanimous reply. "It's not considered the accepted method of treatment."

"Accepted method!" I retorted angrily. "What is more unacceptable than putting your child in an institution without trying everything else first?" Radical or not, Keith and I were determined to look into the treatment. Outraged that our doctors had not offered us this option long ago, we decided to pursue it on our own. We encountered one unnerving obstacle right from the start - the surgery was not available anywhere in California. Despite all the favorable statistics I had read, this surgery was conspicuously unheralded, unsought, and veiled in a curtain of controversy by the doctors specializing in the treatment of epilepsy.

Still determined, but uncertain where to turn next, I telephoned a New York neurologist whom I remembered had seen Shawna the year before when he was visiting Los Angeles. Bracing myself for another dead end, I reacquainted him with Shawna's history, and timidly explained what we were trying to do.

"I remember your daughter," he replied to my amazement.

"And yes, I think she might well be a good candidate for the surgery." So it was due to his confident guidance that Shawna and I boarded a plane to St. Louis three days later. This special technique was being performed on a regular basis at St. Louis Children's Hospital, under the auspices of Missouri's Washington University.

It wasn't until we were halfway there that all the determination and grit I started out with began giving way to a fainthearted fear. I was without the support and approval of the doctors on whom I had depended and trusted for three years. All I had was an overstuffed envelope of photocopied medical records attesting to their blighted efforts.

But hours later, as I pushed Shawna's wheelchair down the halls of the century-old hospital, my confidence slowly returned. The time-worn antiquity of the building, bearing witness to generations of service, seemed to soothe my senses, dispelling some of my apprehension about this sudden juncture in our lives.

When I met Melody in the neurology ward that first day, Wayne was already three days into his recovery from the surgery. Having suffered about thirty seizures a day before the surgery, he had had only one seizure since. Seeing the elation twinkling in Melody's eyes revived my hopes for Shawna once more.

The next morning I met Dr. Sydney Goldring, the Chief of Neurosurgery at Washington University. He was the doctor who had operated on Wayne, and would now be evaluating Shawna. A kind-faced, yet strikingly intense looking man, he

Faced With The Decision Of Institutionalizing Their Daughter Or Having A Dangerous Brain Operation That Could Leave Shawna Partially Paralyzed-The Kicks Risked Surgery

entered Shawna's room flanked by a half dozen-white-coated attendants. After asking me a few questions, he soberly explained the elaborate evaluation process that would determine if Shawna was a candidate for the surgery. I was anxious to know what results we could expect from the surgery, but Dr. Goldring gently advised me to take one step at a time-the first being the evaluation process.

This surgery could not help every type of epilepsy, he cautioned. It was only considered when the affected brain tissue was confined to an area that could be safely removed without causing significant functional damage. This criteria, he forewarned, ruled out a number of candidates during the evaluation process. Shawna could be turned away at any point.

But according to what I had read, at least 800,000 persons in the United States, or 40% of all epileptics, have this type of seizure disorder, called focal epilepsy, and 360,000 of them are uncontrollable. Although the evaluation would be an arduous process, it would be worth it to see if Shawna might be among the ones who could be helped.

Only when the results of the preliminary tests were within

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"The surgical treatment of uncontrollable epilepsy hangs in limbo. Many physicians are reluctant to consider surgery, even when a patient is faced with institutionalization or possible death. So, while time sits in judgment, many live in despair, unaware that the operation exists."

MY WILDERNESS WEAVING
continued from page 53

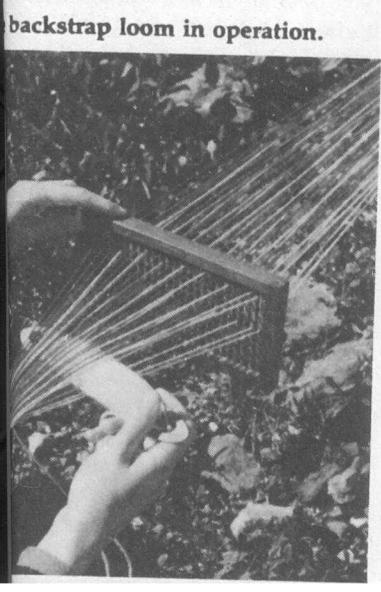
order to draw customers for its own ds. The last option would be an ordi- consignment arrangement in which proprietor of the store would expect a ater profit.

ways keep a project on the loom. en you finish one project, string up ther immediately, even if you don't

to weave just then. That way you'll ositioned to make use of odd inter- during the day-what I call "low ity time"-to relax and produce a or two of cloth.

keep accurate records of your ine and also of every single expense can be attributed to your weaving

ess, right down to phone calls, ge stamps and checking-account es. Your records will be important orne tax time.



backstrap loom in operation.

tips For Experienced Weavers
nds are warp-predominant, so nly need to consider the warp s when designing patterns. I aldiagramed each pattern on graph as a guide both in preparing the nd in stringing up the loom.

ce the weft shows only at the I generally chose its color to the outer warp threads.

making up my warps, I used a 'pegs in the wall, spaced accorde length of the item to be woven. t-foot warp will yield one stane-foot band. (Loom waste could and productivity increased, by the warp long enough to yield ds on a single string-up.)

ways warped around a pair of one end, in order to form the Cross-a neat weaver's trick

ps the threads in proper se- see 1981

quence. Sometimes I would tie the cross with a piece of cord, remove the warp from the pegs, chain it up, and store it away for weaving later. At other times I would transfer the threads directly from the pegs to the loom and begin weaving.

And finally, share your skill with other people. There is no reason why an interested teenager or senior citizen couldn't produce beautiful bands and earn ample spending money by weaving in their spare time. _

Manya Wik and her family make their per- manent home in Ambler, Alaska,

A CHANCE FOR SHAWNA continued from page 17

the qualifying range, would the final, most discriminating step in the evaluation be performed - the implantation of electrode monitors onto the surface of the brain.

A major surgical procedure in itself, it was the first stage of the two-part operation. Once the implant was in place on Shawna's brain, the electrical impulses it received would be recorded on video tape. If the tapes indicated a single dominant seizure focus in the brain, this area would be removed at the second stage of the surgery, in order to try to .reduce or even totally eliminate the seizures.

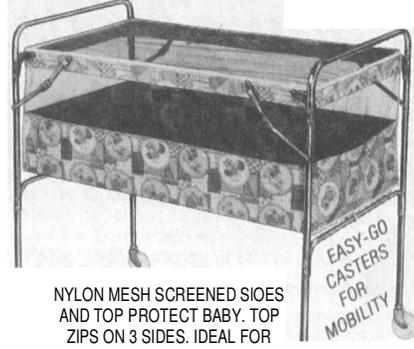
If on the other hand, no clear trouble area was evident, and the problem appeared to be generalized over the entire brain, the implant would be removed and the evaluation discontinued.

Shawna's preliminary testing went smoothly, and in a few days Dr. Goldring was ready to perform the implant surgery. Keith joined us in St. Louis. We both tried not to get our hopes up, but others could sense the emotion straining beneath our calm facades. We had never been this close to a solution to Shawna's problems.

In the early dawn hours of November 6, 1979, Shawna was wheeled to surgery, where Dr. Goldring and a team of over twenty assistants were preparing for the implant. As Keith and I walked alongside the stretcher toward the surgical suite, we were careful not to let our eyes meet. We knew if they did we would be faced with each other's fears, and neither of us could bear that just then.

By nightfall Shawna had been transferred back to the neurology unit, into intensive care. When we were permitted to see her, we found her lying silent and

LITTLE SLEEPER by WOJf(;



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