Two parents whose love for their son knows no bounds are about to take the most dangerous of chances with him: an operation — brain surgery no less — which they can’t get in the U.S.

“I WOULDN’T TRADE him for 10 other children,” says Lisa Soebys. “He just has such a heart of gold and he seems to have a knowledge of just of life and how to bounce back that’s beyond his age.”

Jon Soebys says, “He’s happy, he’s carefree and he views the world as a nearly perfect place. He hasn’t been dented, well, much yet.”

“I want to be able to say, ‘You can be anything you want to be,’ but I can’t say that right now to him,” says Lisa.

“We’ll figure it out,” says Jon.

Two parents whose love for their son knows no bounds are about to take the most dangerous of chances with him: an operation — brain surgery no less — which they can’t get in the U.S.

Are the Soebys afraid at all that their son will wake up after surgery a different boy?

“I’ve asked that and I said, will I get CJ back?” says Lisa. “I can’t lose that little boy. He’s the best thing we’ve got.”

What is it about this little boy that’s so different? What is it that makes his devoted parents so worried?

It’s a mystery that began literally at birth.

Carlton, “CJ,” Soebys — child of an Air Force couple — was born with military precision right on his due date: July 10th, 1997, on a base in Turkey where Jon Soebys was stationed.

But in the delivery room, just after Jon cut the umbilical cord, his wife Lisa says baby CJ startled everyone.

“He actually started to make this grunting noise, and the doctor at the time said, ‘What do you know, I never had one trying to talk this early,’” says Lisa. “So he didn’t assume there was anything bad, just something he noticed. But we both kind of looked it each other and went, you know in this situation, probably unusual things are not good things.”

But when these grunting noises continued for three days, the worried parents brought CJ to the doctor on duty in the hospital’s emergency room.

“And he said, ‘He is fine, you’re first time parents,’” says Lisa. “He gave us the pat on the back and said he’s just got colic.”

He thought they were being over anxious parents?

“Absolutely,” says Lisa.

Jon says, “You know, we heard it the first time and we wanted to believe it.”

But the doctors diagnosis of colic, abdominal discomfort common to many infants, just didn’t sit right with the Soebys — particularly when it finally dawned on them that CJ’s round-the-clock spells were happening with bizarre precision. In fact, Jon and Lisa could predict just when their son would grunt and fuss — right down to the second.

WORRYING SYMPTOMS

“I looked at my watch and I said he’s going to have one in about 15 seconds, 4,3,2,1 right on cue, CJ performed,” says Jon.

When Jon captured the disturbing pattern on video, the doctor finally saw what the Soebys saw. And for the first time there was talk that CJ’s episodes were not in his tummy, but in his brain and were in fact epileptic seizures — electrical disturbances in the central nervous system which were then being felt throughout his tiny body. But why was he having them?

The family immediately flew from Turkey to a medical center in Germany for more sophisticated testing. There, a doctor grimly presented the Soebys with an MRI of CJ’s brain, and with some devastating news. They’d found what appeared to be a brain tumor.

“He said, ‘See that big lump right there in the middle of his brain, that shouldn’t be there. And by the way, the chaplain’s out in the hall, if you’d like to talk to him, he’d like to talk to you,’” says Lisa.

What did this mean?
“I thought he was a goner,” says Lisa. “I thought, it’s cancer. It’s three months and he’s gone. I just spent the night grieving, thinking I had lost him.”

The Soebys were rushed onto an Air Force plane back to the United States to the military’s premiere hospital — Walter Reed. There doctors would open up CJ’s brain, and see what they found. The night before the dangerous exploratory procedure, three month old CJ was baptized.

“That was something that I felt had to be done and I would have done it at his bedside with a glass of water if I had to,” says Lisa.

Because there was a real chance they felt that he would die? “Oh yes, absolutely,” says Lisa.

It was a trying seven hours, but CJ thankfully came out OK, and 13 days later, his frazzled parents finally got a definitive diagnosis for what was causing his epileptic seizures — a condition called hypothalamic hamartoma.

“The good news is it’s not cancer,” says Lisa. “And that, you know, was a gift from God. No chemo, no radiation, it doesn’t spread throughout the body. The bad news is you can’t do anything about the seizures.”

Seizures — electrical activity caused by that tumor in CJ’s brain — would be a way of life for him. That was one of the few things known about his rare condition which is not inherited, but happens as a terrible accident of nature. Jon and Lisa were even more horrified to learn that over time, the seizures would become more severe and damaging to the brain. This can send a child into early puberty. Bouts of rage become commonplace.

And even more ominous is that mental abilities inevitably decline. CJ, the Soebys were told, might never lead an independent life.

“By the time they are 9 or 10 or 11, they’ve gone from being an average or above average intelligence to an IQ around 70 or 80,” says Jon.

Wasn’t there anything to be done about a brain tumor like CJ’s? Not as far as the Soebys could tell.

“What we learned was people have tried to remove it surgically and results were spotty at best and sometimes disastrous,” says Jon. “So the wisdom was, you don’t take these things out, you live with them.”

That proved almost unbearable for Lisa, who watched helplessly as CJ seized throughout the days and nights as many as 300 times in a 24 hour period. And now she watched knowing a terrible truth, his seizures were stealing CJ’s chance to be a normal boy with a hopeful future.

“It was much more difficult for me as I think it is for any mother,” says Lisa. “I think you just have that bond. Every time CJ had a seizure, I had a seizure. I felt every single one of them.”

Jon says, “She took all of CJ’s pain and she took it inside of her as a mother.”

“But you want to,” says Lisa. “You want to say let me have the seizures. Don’t let him have them.”

Jon got what’s called a “compassionate care” transfer to a military base in Phoenix, so the Soebys could raise their infant son near a first class medical institution. Still, real help was elusive. Over the next couple of years they tried as many as ten different anti-seizure medications for CJ, but found the drugs had only limited, if any effect, and were sometimes counterproductive.

“He didn’t walk till one and a half because he was so drugged up,” says Lisa. “He would lay down on the floor face down into the carpet and just his arms and legs like he was trying to swim, and that’s when I said, we’re done, we’re done with drugs, and at two years we stopped.”

Did that mean giving up without a fight?

“Oh, absolutely not,” says Lisa.

INCORPORATING SEIZURES

As CJ Soebys grew older, the character of his seizure activity changed dramatically. His parents would capture them on videotape for doctors and then for “Dateline.”

It is painful to watch, but the Soebys say CJ doesn’t feel any physical pain and what may seem like a laugh or a cry is neither. It is part of the seizure.
Electrical impulses pounding his brain trigger involuntary muscle contractions and leave him virtually locked.

“When he was about two, when he would have a seizure, afterwards he’d say, Mom, the monkeys are chasing me and biting me,” says Lisa. “And then he got a little bit older, about six months later, it was monsters. And that was a scary thing to him.”

Imagine your child told you how frightened he was and you felt powerless to do anything about it — and exhausted besides.

“I’m on alert, 24 hours a day,” says Lisa. “I hear every seizure and I hear it from start to finish.”

Mothers always do, don’t they?

“Oh, that ear,” says Lisa. “You just do.”

On top of that Lisa says Jon, who became a commercial pilot, was often away sometimes as much as half of every month, so it was up to her to hold it all together.

“You know, being the mom and being the caretaker, and the one who has to deal with it day to day to make it better, sometimes I would look at him and say, do you have a heart of stone?” says Lisa. “Don’t you see, I mean this child is suffering. He’s not going to have a normal life.”

INFORMATION FROM ABROAD

Jon and Lisa scoured the internet for anything they could find on hypothalamic hamartoma and how to deal with it. And in the fall of 1999, the couple stumbled upon a small worldwide support group still in its infancy of parents with children afflicted with the same rare disorder as CJ.

It was a connection inconceivable before today. Parents from countries around the world, arming each other electronically with information and support.

“It was a God-send,” says Jon. “It was, finally there was somebody out there that understood what we were going through.”

The Soebys had no idea then how important this connection would be. Meantime, in spite of his recurrent seizures, their sweet tempered boy was on track intellectually.

“He tested out a year or so ahead of his peers,” says Jon.

CJ’s progress encouraged Jon and Lisa to do all they could to make CJ’s life as normal as possible.

“He has played basketball and done quite well,” says Lisa. “He got a nice little trophy. But he has also had seizures in the middle of the game and he’s fallen down in the middle of the court. And I take him off and I take him home. And I guess I’ve just gotten used to the fact that that the way life would be.”

We got a sense of just how fleeting normal life can be for the Soebys last November in the first hour that “Dateline” met them.

They were all having a good time when in the blink of an eye, 4-year-old CJ’s world was turned upside down as a seizure erupted.

The “spark” as CJ calls it, lasts less than a minute and leaves CJ physically spent. And his mom says it often makes him feel ashamed and shy about being close to other children.

“Kids will say why are you doing that?” says Lisa. “Stop doing that. What’s that noise? Everybody kind of looks — what’s that kid doing?”

We watch at CJ’s pre-school as he played apart from the others. Lisa said he does this because he’s already anticipating his next seizure.

“He’s self-conscious about it so he doesn’t want it to happen in front of another kid,” she says.

And sure enough, when CJ did have an attack during lunch, he quickly folded into his mother’s arms.

“I was just wallowing,” she says. “And what do I do? What do I do? Every night, I would go to bed and say, what do I do? I’ve got to fix this. I cannot go on. It’s my job. I’m his mom. I’ve got to fix it and I couldn’t.”

A NEW APPROACH

But maybe she could. In 1999, the Soebys learned about a girl — 10-year-old Rebecca Faulkner — who also suffered from CJ’s rare epileptic condition.
Through their internet support group, the Soeby's heard that Rebecca had a landmark surgery in Australia that seemed to fix her. Rebecca’s parents wrote in an e-mail: “Still no seizures 70 days after surgery.”

Lisa says that was their first real ray of hope for CJ. Their internet connection reported that the Australian team scored one apparent success after another, taking a different pathway into the brain than the one usually tried by surgeons in the U.S. for CJ’s kind of tumor. They were going at it from above while in this country surgeons have typically gone at it from underneath the brain. But when the Soeby’s explained all of this to an American neurosurgeon, hoping he’d consider the Australian approach for CJ, they say he rejected it.

“We heard quite a few of the negative aspects of the approach in through the top of the brain and why that wasn’t an approach that they embrace there in Phoenix,” says Jon.

The Soeby’s talked to the top guy in Phoenix.

“I think we talked to one of the top guys in the United States, if not one of the top guys in the world,” says Jon.

They’re referring to surgeon Dr. Robert Spetzler, Director of the renowned Barrow Neurological Institute in Phoenix.

“I said I would prefer the approach from going below,” says Dr. Spetzler.

He was willing to operate on CJ, he says, but not how the Soeby’s wanted him to. The Australian approach, he told “Dateline,” has not proven itself in this country yet.

“It is not a matter that it can’t be performed,” says Dr. Spetzler. “It’s a matter that it hasn’t been performed routinely for this particular tumor.”

Nothing this little group on the internet was telling these people would necessarily in and of itself be persuasive to the doctor?

“The internet can give you guidance, but it’s certainly not the proof of whether something works or not,” says Dr. Spetzler.

While they carefully weighed Dr. Spetzler’s concerns, the Soeby’s were still intrigued by what they were hearing about the Australian team’s successes. They also figured the longer they could hold off surgery however tantalizing, the more practice the Australians would have on other patients with CJ’s condition.

But suddenly time ran out.

“His head goes down, his hands come up and it’s just a jerk,” says Jon.

CJ’s seizures began to be much more violent. The Soeby’s knew what that meant. They’d been dreading this moment for four years — the moment when the seizures could produce lasting brain damage and plummeting IQ. Now it was here.

Jon asks CJ, “What do you think the doctors in Australia are going to do for you?”

“Fix me,” says the boy.

“They’re going to get rid of those sparks?” asks Jon.

“Yep,” says CJ.

“That’s what we’d like,” says Jon. “And we’re going to say thank you if they can and thank you even if they can’t, because they’re going to try their hardest.”

The seizures caused by CJ Soeby’s brain tumor were getting worse, so they finally dared to do what no American medical team they could find would support — they scheduled brain surgery for their 4-year-old son halfway around the world with doctors in Melbourne, Australia.

Even though their doctors in America regard what they do as an extremely dangerous surgery with mixed results?

“I think, yes,” says Jon.

They’d spend six weeks down under and spend $25,000 for CJ’s brain surgery — far less, they say, an operation would cost in the states. But they’d still need help from insurance, which considered it experimental. But finally after repeated appeals, the money came through.

“We’re ecstatic, and it’s such a load off,” says Jon.
But if Jon and Lisa were hoping to find enthusiasm for their decision at a last minute visit to one of CJ’s doctors, they were wrong.

What did they think about what the Soebys were doing?

“It’s scary,” they say. “It’s gutsy. If I was CJ’s parents, I don’t know what I’d do if I was in their place.”

What’s the worst that could happen?

“He could die,” says the doctor. “You’re talking about neurosurgery.”

Lisa says, “Risky is scary. I mean, this is my child’s life. I am making a decision for him that will affect the rest of his life. And it may be in a good way and won’t that be great. But it might be in a bad way, and that’s something that we’ll have to live with. And we don’t take that responsibility lightly. But it’s a heavy burden.”

**TAKing A RISK**

In February 2002, after 17 hours in flight, the Soebys arrive in Australia for a visit to one of the world’s best medical centers.

Many know this country as “the land down under.” But some hopeful families from abroad who are drawn here by the promise of revolutionary surgery have taken to calling Australia something else — the land of Oz. And they’ve dubbed two of its doctors “the wizards.”

“Well, it’s quite an honor to be held in such high regard,” says Dr. Simon Harvey, a neurologist at the Royal Children’s Hospital in Melbourne, Australia.

His associate, Professor Jeffrey Rosenfeld, Doctor of Neurosurgery says, “We are considered the wizards of Oz because these children have often had previous surgery, have had every treatment under the sun, all sorts of drugs, sometimes they’ve had parts of their brain removed, but they still got the epilepsy. What they are hearing is that we are able to, in many cases stop, the epilepsy.”

At the Royal Children’s Hospital, the Australian team quickly gets to the business at hand. This will be the first opportunity they have to actually monitor the seizures over a 24 hour period.

Strange, and for the first time, there’s a kind of comfort for Lisa in witnessing her son’s spasms. They’re in full view of a medical team who’s intent on attacking the problem.

The team is coming at this from a very unconventional direction. In fact, no other medical team anywhere approaches it like they do.

“They haven’t done it up till now,” says Dr. Rosenfeld.

Remember, in most of the world, including the United States, surgeons typically approach a tumor like CJ’s by coming at it from underneath the brain. The tumor is entrenched near the bottom so that is the shortest path to it, and theoretically safer. But these doctors say there’s a catch.

“You cannot technically remove these lesions completely through that route as I found out myself when I did my first case,” says Dr. Rosenfeld. “I found I could get there safely, but I couldn’t remove the lesion.”

That’s when Professor Rosenfeld decided to try another approach, coming all the way from the top of the skull down through the two halves of the brain to the tumor lodged below.

He takes the longest path. Yet these doctors say the route that’s potentially the most dangerous has also yielded the most impressive results.

“At the endpoint, 70 percent of our patients are free of seizures,” says Dr. Harvey.

Keep in mind the total number of patients is very small. Only 25 children have undergone the brain surgery pioneered by the medical team here. Now, CJ is scheduled to be patient number 26.

“You have to be prepared,” says Dr. Rosenfeld. “I can’t predict the future. I don’t know for sure that we’ll get a perfect result.”

Four days before surgery, Professor Rosenfeld goes over the specifics of the operation, as well as some of the more frightening possible side effects, including one of the more likely ones — short term memory loss.

Short term memory is the ability to remember new things. It’s the way we learn.

“If it’s at his worst, he won’t remember what he’s taught in school,” says Dr. Rosenfeld. “You know you could say things over and over to him again: one plus one equals two and these are the reasons why. And he won’t take it in.”
CJs parents are frightened.
“lt have to be honest, it’s brain surgery,” says Lisa.
There is a list of risks — death, stroke, brain damage, blindness, coma, diabetes, hormone problems, behavior changes, short term memory loss that’s possibly permanent. Have the doctors spelled all those things out?
Over and over say the Soebys.
But they’ve also been told they must balance all of the possible dangers against CJ’s near-certain deterioration if they do nothing.
They are hopeful for the best and you’re prepared for the worst.
“Tonight we have to go to bed and just know that it’s out of our hands,” says Lisa.
How do CJ’s parents feel just 12 hours away from surgery?
“I’m going to spend the night with him and just hold him, and talk to him and tell him that it’s going to be OK,” says Lisa. “And that’s how we’ll spend our night and I want to be the last face he sees before they go into surgery and tomorrow morning. I want to be the first one to wake him up and say, ‘Good morning, son, it’s going to be a great day.’”

CJ goes into surgery and his parents wait through the longest hours of their lives

On February 12 2002, 4-year-old CJ Soebby is beginning the most important day of his life — one which may determine whether his parents hopes for the future will ever come true.
“I dream for him of a life with no boundaries that have been imposed by this disorder,” says Jon. “If he wants to live an independent life, he’s going to have no problem doing that. He’s going to fly an airplane if he wants to fly an airplane.”
Lisa says, “My wishes are even more short term than that, I guess. I want to see him go through a day and a week and a month and not have any seizures and be able to play and not get jabbed.”
He’s come from Phoenix, Arizona to the farthest corner of the earth for a controversial brain surgery not offered in the U.S. — one which the Soebys desperately hope will correct CJ’s worsening epileptic disorder.
Lisa tells CJ, “You know what? You have a mission to do, too. You have a mission to go into the surgery and help Professor Rosenfeld get rid of those sparks, OK? That’s your mission, little rescue hero.”
CJ says, “I’m a big boy rescue hero.”
It seems incredible that CJ is perhaps the calmest person in the hospital today. While he surely doesn’t understand the fine details of what he’s about to undergo, he does know that he is going to have his head opened up, and that this could make his terrible sparks go away. What a brave boy and how much trust he must have in his parents.
Dr. Rosenfeld cuts down through CJ’s brain through its most vital regions.
“The precision is that fine that I can’t move one millimeter out of alignment or else I can produce devastating complications or death,” he says.
Dr. Rosenfeld slowly proceeds down to the hypothalamus — a sort of command center which controls memory, emotion, appetite, hormonal balance — all the things that in essence make us human. That is where the tumor lies.
“It’s quite big,” he says.
After thousands of seizures, drugs that didn’t work, countless sleepless nights, and an agonizing decision to come here, it has all come down to this.
“This is all the abnormal lump that I’m removing,” he says. “See the white tissue — that’s normal brain. We’ve got to spare that.”
Nearly three hours into surgery Dr. Harvey puts in a call to the Soebys, who are waiting in CJ’s hospital room four floors up.
“No details, but everything is going exactly as planned,” says Jon. “That’s the first milestone. Can you hang out for 20 more minutes?”
Lisa says, “We’ve waited four years for this. I think I can wait 20 more minutes.”
But Jon can’t wait that long to relay the news to the other parents in their internet support group, who themselves are standing by in a kind of global waiting room. Like the Soebys, families around the world have a stake in what happens here.

“Things are going smoothly,” Jon writes in his e-mail. And in a second one a few minutes later he adds, “Thanks for all the prayers.”

“Things went well,” Dr. Harvey tells them when he comes in.
“There’s a smile on your face, so that’s a good sign,” says Jon.
“It went well,” he says. “Professor Rosenfeld is closing up now. No problems with bleeding. It does appear to be all out, but we don’t know that until the MRI scan. Whether it fixes his condition, that’s a few months down the line.”

Yet even as the Soebys and Lisa’s parents rejoice, the family still has no idea what the actual outcome is for the still unconscious CJ. Have his seizures finally been eliminated? Have any of his vital brain regions been hurt? Even the ever confident Dr. Rosenfeld isn’t willing to promise anything at this moment.

“I don’t know whether he’s going to wake up,” says Dr. Rosenfeld. “He might be a vegetable for all I know. I might have damaged his brain stem. I might have interfered with the blood supply in the most delicate part of his brain. He might end up with a stroke. But I’ve done everything in my power to prevent that.”

In the immediate aftermath of CJ Soeby’s tense 3 1/2 hour brain surgery, the hospital staff tries to rouse him. Wakefulness is a vital first milestone — the all-important sign that surgery to remove his brain tumor has not left the four-year-old in a vegetative state.

CJ is not budging, at least not yet. Now Jon and Lisa, who’ve invested all their hopes and dreams in this day, anxiously hurry in to see their only child. Professor Rosenfeld, hopeful that he hasn’t hurt CJ, steps in, also eager to see any signs of movement.

“He’s moving,” says Dr. Rosenfeld. “He’s moving his right arm. How about his left arm?”
Then with movement and a cry comes the first huge wave of relief.
CJ is able to squeeze his hand.

“That’s all very encouraging, what he’s doing now,” says Dr. Rosenfeld. “It’s still very early.”
Just hours after surgery, Lisa is once again intently watching over her son, who briefly wakes up from time to time, and most important, who lies for the longest time, and for the first time, apparently free of seizures. Yet there are some uneasy moments.

“Did you see? He had a jerk,” says Lisa.
It’s almost imperceptible. But Lisa wonders if the tiny movement of CJ’s hand that she’s just seen is the glimmer of a seizure.

“Just now, that’s the first one I’ve seen,” she says. “And the fact that he jerked and woke up, who knows?”
There is no answer. For the moment, every little movement will be analyzed and will be suspect.

But in the few short days following surgery, it seems that CJ is recovering nicely. On day one he speaks his first words.

“I’m thirsty,” he says. “My head hurts.”
On day two he’s up and even out of bed.
It’s momentous enough for Jon to get it on camera so he can relay it back to the internet support group.

“This is a big thing for me getting him off that bed,” says Lisa. “He’s back to being a little boy.”

His remarkable progress has done a lot to buoy the spirits of other parents the world over contemplating the same surgery for their children.

Jon reads e-mail from south Africa. “Jon and Lisa, sounds as if CJ has won the gold. Keeping you all in our thoughts and prayers.”

For Jon and Lisa it’s incredibly exciting, but nerve-wracking, too. Is it all going too well, she worries?

“You almost think, this can’t be real,” says Lisa. “I don’t want to jump for joy too soon. And I don’t want to start planning for his first bike ride around the block, because there still may be some clouds.”
And even if CJ is seizure free, has it come at too high a price? The Soebys are about to confront some of their darkest fears about the side effects of his brain surgery. Although the doctors told them not to rush things, they want to know whether CJ’s short term memory is in tact.

Lisa tells CJ, “I’m going to put your rescue hero behind the curtain for a minute. So don’t let me forget that I put it over here, OK?

It’s not scientific, of course, but maybe this test — placing one of his toys out of sight — will give them a clue.

After letting a few minutes go by, mom and dad ask CJ to remind them of the toy’s location. CJ stares blankly.

“You looked over there,” says Lisa. “Is that where he is? Point for Dad so he can get him.”

“Is this Billy?” Jon asks CJ.

“Yes! That’s it,” says Lisa. “His first reaction was to look where I had put it. I’m not worried. I’m not worried about short term memory.”

Just four days after surgery, he is well enough to leave the hospital. His doctors will continue to assess him, however, so the Soebys intend to remain in Australia another five weeks.

While he’s here, there’s a kind of family reunion — not with actual relatives, but with children and their parents from the Soeby’s close knit internet support group.

For the first time, CJ meets Rebecca Faulkner — the girl from Australia whom the Soebys excitedly read about in her parents’ e-mails, the girl whose successful brain surgery gave them hope. Since her operation, Rebecca has been seizure free for nearly three years.

And now it is CJ’s turn to be a source of inspiration. Arriving from Oregon is 14-year-old Lindsie Christy, who will be patient number 27 for the Australian team.

“What has happened is that their internet support group and the trust they put in us has led to improvement in medical care,” says Dr. Harvey.

“Because they’ve had initial success, they have received enough patients so that they can make advances based on experience,” says Dr. Spetzler. “And that’s how medicine advances.”

Even Dr. Robert Spetzler, the eminent neurosurgeon who declined to use the Australian approach on CJ then, now says he believes it will one day be proven to be the treatment of choice in the U.S.

In late March, after seven weeks in Australia, CJ and his parents return home. He’s still seemingly seizure free, except for what his folks say are some occasional twitches.

When Dateline visited CJ and his family several months after his brain surgery, it was clear the Soebys have gotten their boy back — only better.

“We definitely have a new boy,” says Lisa. “It’s kind of hard to tie him down some days. He’s out actually swimming, running, and riding a bike. I’m having to learn what it’s like to chase down an almost 5-year-old. It’s incredible. I’ve never had to do that before and it’s a wonderful, wonderful feeling.”

Life, she says, is no longer a constant crisis. No need to be worried about what sharp objects CJ holds in his hand. No longer is he embarrassed to play with other children, or forced to sleep the day away in seizure induced exhaustion. CJ is growing, and learning. His mind, mostly free of sparks as he calls them, is doing just fine.

“Typically once a day he will get an uncomfortable feeling that he’s going to have a regular seizure, and then it just stops, so it doesn’t go on to be anything,” says Lisa.

Lisa says the doctors believe even this will fade with time — an incredible victory for the remarkable parents who went as far as they could go to make this life possible for their son.

“Now I know CJ can be anything he wants to be,” says Lisa.

“We kind of had our head down for a long time. It’s nice to be able to look up at the sun again and just be really excited about life.”

The Soebys tell “Dateline” that CJ started kindergarten right on schedule this fall, and that, with no sign of the seizures, he’s thriving. The Australian surgeons, Dr. Harvey and Dr. Rosenfeld, are looking for a hospital in United States where they can teach American doctors how to perform their operation.