

The girl

in the mirror | When Brenna Johnston's face is revealed, her parents and doctors will search for signs that its new form matches its functions. Brenna will search for signs of herself.

The shape of things to come

THE THIRD OF 3 PARTS

BY JULIA SOMMERFELD
Seattle times staff reporter

Robyn Johnston tries to snap herself awake.

They want her to sign what?

She's half-asleep after a fitful night on the vinyl foldout couch in her daughter's room at Seattle's Children's Hospital. In the raised hospital bed nearby, Brenna slides in and out of sleep, hard-core antibiotics flushing through her small body.

Robyn has slept in hospital rooms dozens of times. But last night rest eluded her, interrupted by Brenna's nightmares – and her own.

She hasn't had her coffee yet, and still feels groggy when two documents are thrust at her: consent forms from Brenna's craniofacial surgeon, Dr. Richard Hopper.

The first is for the removal of the infected screw. One of the 10 screws securing the titanium halo to Brenna's skull has formed an abscess. The wound seeps with a dangerous drug-resistant staph infection.

OK, she expected the doctor might do that.

The other form is for the immediate removal of the RED, the halo and scaffold braced to Brenna's face. The RED, or Rigid External Distraction system, has pulled Brenna's sunken face forward over the last several weeks, and now holds it in place as her new bones set.

Robyn is suddenly alert, boiling with questions. This is the first she's heard of this.

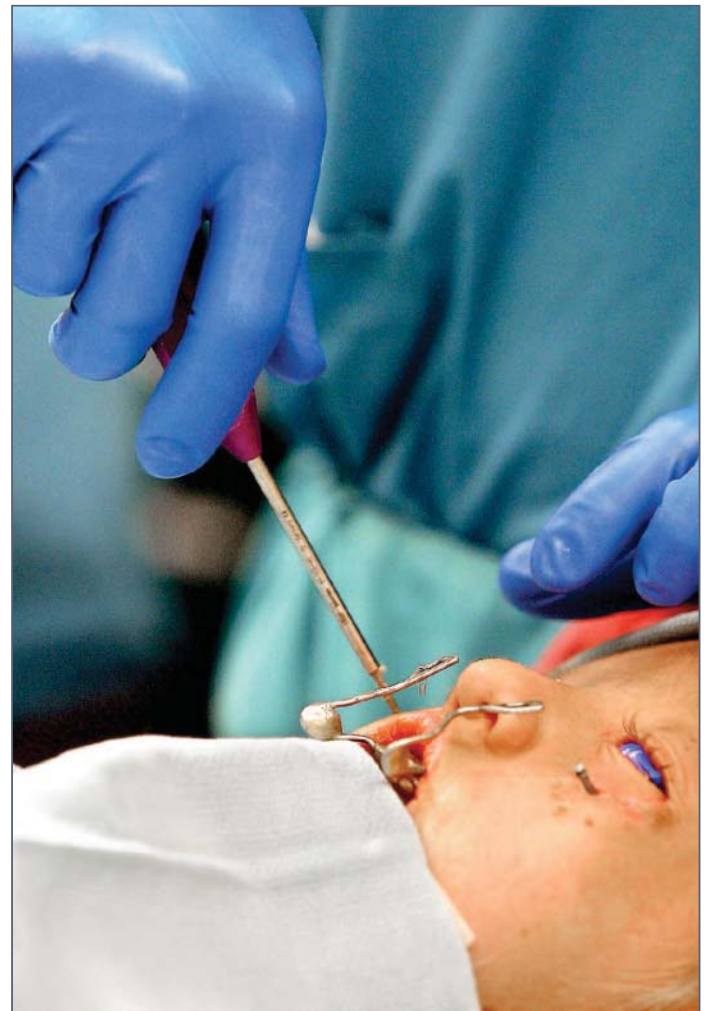
The RED has been on just six weeks – not the prescribed eight. Could removing it now put the entire procedure at risk? Would Brenna's face sink back to the quarter-moon shape she was born with, the result of Crouzon Syndrome? Could she lose the expanded airway that allows her to breathe easily through her nose for the first time in her life?

Would they have to start over?

In a nine-hour surgery in June, Hopper had peeled off Brenna's face, sawed through her facial bones and wrenched them from her skull. He then bolted her bones to the RED, a high-tech yet medieval-looking contraption that caged her for the summer as it forged her new face.

Robyn can't imagine putting her 8-year-old daughter – or the rest of the family – through this again: Flying to Seattle from their home in Veneta, Ore., each week for checkups; twisting the screws on the RED to crank Brenna's face forward a millimeter a day; hiring a nanny to care for the boys so she could care for Brenna.

No, they're too close.



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THE TIME COMES for Dr. Richard Hopper to dismantle the titanium halo that has been bolted to Brenna Johnston's face for weeks. Blue plastic shields protect Brenna's eyes as Hopper removes the screws and wires that have pulled her underdeveloped bones forward – giving her a new, and functional, face.

Robyn won't sign anything until she talks to Dr. Hopper. "I'm not about to give up that easily," she says.

Facing Brenna

As Robyn frets, Hopper operates on a little boy, expanding

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his skull so his brain can grow. Brenna has had the same surgery three times already.

Hopper hands off to a neurosurgeon so he can take a break. He strips off his mask and gloves and heads to the Giraffe wing of Children's Hospital.

He dreads facing Brenna.

Last night, he decided that if her infection hasn't abated, if she's still the broken, weepy rag doll of yesterday, he'll remove the RED. He's never taken it off this soon, but the risk of infection spreading to her brain or bloodstream outweighs the benefits of her new and functional profile.

Hopper pulls on a fresh smock and gloves before he enters Brenna's room. Her infection means special contact precautions are in place.

But when he opens the door, Brenna is sitting up in bed, eating and watching a cartoon on TV. The red blotches are gone from her skin. Her eyes are clear.

And before Robyn can start her argument to keep the RED on, Brenna's chirpy "Hi, Hopper!" makes the case for her.

The antibiotics had kicked in overnight.

"Kids have this little aura around them," Hopper says. "They wear how they are feeling on their sleeves. You can just tell. She didn't look systemically ill; she had the aura of a child that was going to be OK."

So he will leave the RED on, for now.

Instead, he'll remove the infected screw from Brenna's skull, and another suspicious one from the other side.

"We're going to do everything short of duct tape to keep this thing on for as long as we can," he says.

Brenna's timeout

Brenna is less than pleased. She wants the cage off her face, and she wants to go home.

But the infection confines her to her hospital room. She throws a tantrum when a hospital aide brings her a puzzle instead of an art project from the playroom. She kicks out another who dares to enter her room.

Robyn orders a timeout. Brenna huffs and crosses her arms at the unfairness of it all. She doesn't quite catch on that timeout, which consists of sitting in her hospital bed, is pretty much what she's been doing anyway.

"I can't really blame her," Robyn says. "If it were me with that thing on my face, I would have had a meltdown weeks ago."

The summer in the RED is the culmination of more than eight years and 30

surgeries to correct the deformities of Crouzon Syndrome, a genetic typo that left Brenna with a too-tight skull, shrunk-en facial bones and an endless list of medical complications, from blocked tear ducts to sleep apnea.

The RED procedure – essentially a two-month-long surgery – should be the last operation of her childhood. But with only two weeks to go, Brenna is spent.

She has exhausted the hospital's arts-and-crafts options. Her table is littered with fairies, sticker books, finger-paint portraits and painted horses. She's Jackson Pollock with the glitter glue, slapping it on so thick her construction-paper creation still isn't dry when she and Robyn go home, four days later.

The favor

Back at the Johnstons' home overlooking Fern Ridge Reservoir in Veneta, Brenna plays computer games. She cranes her neck, then angles her eyes, trying to look around the bars of the RED to see the monitor.

Her dad, Erin Johnston, is the first to notice. Why is Brenna twisting her neck so much? Has that beam always blocked her line of sight?

Over the next few hours, the top of the scaffold sags down to Brenna's nose. By morning, the wires connecting her cheekbones to the beam have slipped down. The mouth-piece dangles off her teeth.

Robyn tries to tighten the RED but Brenna howls. Robyn



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ONCE BRENNA IS RELEASED from the titanium cage, she spends a lot of time looking at the girl in the mirror. She studies her, makes funny faces at her, wrinkles her nose and traces her cheeks. She even kisses her image in a hospital mirror, earning a scolding from Mom: "Brenna, I'm so glad you love yourself, but that's just gross," says Robyn, wiping off the lip imprint. On the night before she starts third grade, Brenna and her dad take another long look at the new face she will wear to school.

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calls Dr. Hopper, then books an emergency flight to Seattle with Angel Flight, a group of volunteer pilots who shuttle patients to medical care.

Driving up from the airport, Brenna is pensive.

“Mom, do you think God made my RED slip off?” she asks.

“Uh, maybe,” says Robyn. “Maybe he’s letting us know it’s time for it to come off.”

“That God,” Brenna says, shaking her head.

Back in an exam room at Children’s Hospital, Hopper debates returning to surgery to reattach the RED. He presses his thumbs on Brenna’s cheeks and upper jaw; the bones feel solid.

Hopper ventures the device has come loose because its work is done. Once the bones are set, there’s no longer enough tension to hold the RED in place, he says.

An extra week in the RED would provide a last measure of security. But Hopper decides it’s not worth it; Brenna has had enough.

He schedules the removal surgery for the next day.

As they leave the exam room, Robyn pulls a small jewelry box out of her purse and hands it to Hopper.

“I have a favor to ask,” she says.

He opens the box. Tiny gold turtle earrings nest inside.

“Sure,” he laughs. “She deserves it.”

What’s in a face

A face is unlike any other part of the body. It feels somehow like the person herself, not just a part of her. It’s what you link to someone’s name in your mental Rolodex.

It’s more than a first impression – it’s the lasting imprint. It’s too primal to be merely superficial; even infants know to look into someone’s face.

“When you miss someone, you picture their face,” Hopper says. “When you love someone, you imagine their face.”

Beyond the halo, around the wires and through the scaffolding, Brenna’s parents have spent the summer watching the face she was born with transform into the face she will



Dr. Hopper’s before-and-after photos document that Brenna’s profile has grown by almost an inch.

grow old with.

“As she changes, you change with her,” Erin says. “Like losing your hair, you slowly but surely change, but you don’t notice from day to day.”

But sometimes, when he’s not expecting it, he’ll catch his daughter’s profile a certain way and there are Brenna’s eyes – peering out through someone else’s face.

Robyn and Erin can’t help themselves. They sneak glances at Brenna when she is busy coloring or watching TV. But they don’t make a fuss over her changing face.

“We’ve never been hung up on looks and we won’t be now,” Robyn says.

Nor do they talk much about the not-so-far-off future, about things like high school and dating. About the choices that will later face Brenna who, as a carrier of Crouzon, has a 50 percent chance of passing the gene on to her own children.

“We really haven’t gone down that road yet,” Robyn says. “Right now it’s about getting her healthy and building her self-esteem so that nothing holds her back.”

Erin takes comfort in the fact that Brenna’s new face reminds him of his late grandmother’s. She finally looks like someone in the family.

“It’s a sad and happy kind of thing,” he says. “She doesn’t have the face she had as a baby anymore; she’s not my little button anymore. But this face will be just as lovable.

“How can I not love the face that’s allowing her to breathe?”

A matter of identity

The face isn’t just how you identify someone else; it’s how you see yourself.

Dr. Michael Cunningham, Brenna’s craniofacial pediatrician at Children’s Hospital, recalls an experiment where people were shown photographs of their body parts – their hands, feet, ears and face – and asked to identify them. They’d answer, predictably, “That’s my hands. My feet. My ears.”

But when they came to the photos of their face, they said simply, “That’s me.”

“That’s because our faces are our identities,” Cunningham says.

Most cosmetic surgeries manipulate the skin or one feature of the face but leave patients looking like modified versions of themselves. But Brenna’s surgery has changed the gestalt of her face. Two centimeters – nearly an inch – make a big change in the close quarters of a face. It’s enough to create an entirely new one.

Brenna knows she looks different because she keeps catching her parents and grandparents staring. She can’t quite make out her new face in the mirror. It’s obscured by the scaffold and pins. But she can see she now has cheeks.

“Do you like my cheekbones?” she asks, striking a model’s pose. “I think they’re my best feature.”

But her excitement is tinged with anxiety. She begins

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third grade in a few weeks and is bracing, once again, for the stares – and more.

“I’m worried that I’ll look different and then they’ll probably stare.”

“I hope they like me still.”

“Will Lainey like my face?”

“What if they don’t recognize me? I’ll have a new face. Plus, I’ll have my ears pierced.”

“If they stare, I’ll smile and then maybe they’ll recognize my smile and I’ll just tell them, ‘I’m Brenna.’”

Removing the cage

The removal surgery is minor compared to the operation Hopper performed on Brenna exactly seven weeks ago. He removes the halo screws in minutes and reveals a very different profile than the one he last studied on the operating table.

He reaches inside Brenna’s mouth to snip the wires that wrap around her cheekbones and pry off the acrylic retainer.

He makes small incisions in her cheeks to remove the plates and pins. He shaves down the bumpy ridges that have formed on her new cheekbones and leaves a smooth contour.

“A perfectionist has to be careful in this situation,” he says. “You could keep chipping away until you think it looks perfect, but that’s not what this is about.”

The profile on his table is hardly perfect. Even with the middle of her face where it’s supposed to be, strangers will likely still look twice at Brenna. Some will still notice that her wide-set eyes tilt down at the corners.

But the looks won’t come as often, or last as long.

Hopper knows there’s more work to be done. In a few



BRENNA KNOWS MOST OF THE KIDS in her third-grade class at Willamette Christian School in Eugene, Ore. Most of them had long ago stopped staring at her misshapen face. But now, after surgery, she looks different – again – and she takes refuge behind Mom on open-house night. “People looking all the time has taken a toll,” Robyn says. “So that even when they aren’t looking, she assumes they are.”



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BEST FRIEND LAINEY BLANCHER has always seen past Brenna’s looks. “When I saw her with the RED thing on, I told myself I’m not going to be scared. I’ll still love her no matter what she looks like. Now that it’s off, I think she looks really beautiful. But it is weird – she does look very different than she used to.”

years, Brenna will need orthodontia. And when she’s done growing, at about 16, he will operate again to align her jaws.

There’s a list of minor improvements she can have done as a teenager, if she chooses. She can have the corners of her eyes hoisted up. Her nose can be tweaked. Her cheeks can be rounded out. Some kids, Hopper says, get this far and want the fine-tuning. Others never want to go through surgery again.

But for now, Hopper is satisfied that the form of Brenna’s face fulfills its functions. She can breathe through her nose, bite into a hamburger and close her eyelids all the way. A wayward soccer ball would now hit a cheekbone or eye socket rather than her eyeball. What could be more beautiful than that?

Hopper pauses a moment and studies Brenna’s tiny ears. He then surveys the operating room, eyeing the nurses’ ears for direction. With a felt-tip pen, he marks dots in the center of each of Brenna’s earlobes, then stands back to make sure they’re symmetrical.

“This is the most nerve-wracking part of the surgery,” he jokes.

As he picks up the needle, he calls to the nurses, “Speak now or forever hold your peace.”

The post-surgery CT scans show a profile with two more centimeters of solid bone – and the outlines of two tiny turtles.

The first impression

As Brenna struggles her way up from anesthesia in the recovery room, Robyn drinks in her daughter’s new face.

“It looks different, it really does look different,” she says.

“But I’m a mom. You’d have to do a lot more than change her face for me not to know my Brenna girl.”

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Brenna comes to, her throat sore and raspy after surgery.

“Is it off?”

“Mmm-huh.”

“Can I see?”

Robyn hands Brenna her Mary Kay pocketbook, its flap turned to reveal a small rectangular mirror.

Brenna stares at the girl in the mirror. She moves the mirror around, taking in her face a quadrant at a time. Her eyes follow the new angles, the youthful overbite in place of a sunken underbite, the protruding nose, the sockets cradling her eyes and definite cheekbones. She traces her features with her fingers to confirm what she sees.

Identity isn't a word in her vocabulary, but there's a layer between the girl she sees in her mind and the girl she sees in the mirror.

She returns to the mirror over and over, searching, as if by looking hard enough she just might find herself.

“Do you like my new face?” she finally asks her mom.

“Of course, I love it.”

“Is it beautiful?”

“Yes, it's beautiful. But it always was beautiful.”

Later that night, back at the hotel, Brenna again plants herself in front of a mirror. This time, it's a full-sized and starkly lit bathroom mirror. Whatever her thoughts, she doesn't share them. She just continues her search.

Then she smiles. It's a new and different smile, but it's Brenna.

Postscript

Brenna stalls in the hallway of Willamette Christian School in Eugene. It's the first day of third grade and her stomach flutters.

She eyes herself in the glass door.



BRENNA JOINS THIRD-GRADE CLASSMATES Hannah Larson, left, Tessa Kanwischer and Karlie Hoyle in music class. Brenna's face remains slightly distorted; her bones have stretched, but her skin hasn't quite caught up and pulls taut around her eyes. Over the coming months, her skin will relax over her new bones. Meanwhile, Brenna says: “If they stare, I'll smile and then maybe they'll recognize my smile, and I'll just tell them, ‘I'm Brenna.’”



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ABLE TO BREATHE AND RUN AND PLAY with abandon after eight years of limitations and surgeries, Brenna is wild on the playground. “What's the best part of third grade?” Robyn asks in the car on the way home from school. Brenna thinks hard: “I guess I'd have to say definitely the bumpy slide.”

The RED has been off for a few weeks now, and the girl in the reflection is no longer a stranger. But she's not quite Brenna either – not yet. She still catches herself by surprise sometimes.

Her face is a little puffy. Two small bandages score her cheeks. The skin around her eyes is pulled taut from being stretched over the new bone, but this will gradually soften over the coming months.

Robyn returns from tucking Brenna's brother in his first-grade classroom and is exasperated to find Brenna the last straggler in the hall. She hustles her into Mrs. Vanderhoff's room.

A front-row desk carries Brenna's name. She walks to it slowly, bracing for the other kids to gasp, to shout, to stare. But they are so absorbed in their new pencil boxes, sharp school outfits and neighbors, they don't even notice her.

Mrs. Vanderhoff asks the students to share something special they did this summer. When it's Brenna's turn, she answers succinctly: “I went to Seattle to see friends and doctors.” Later, she kicks herself that she forgot to mention the most important part: She picked out a spaniel named Lea La, and once the puppy is big enough, she'll come live with Brenna and maybe she can bring her to school for show-and-tell.

Brenna is quiet in class that morning. But come recess, she is a whirlwind. She launches herself at the sandbox, dragging her best friend, Lainey Blancher, behind her by the arm. They conquer the slide, the swings, the whole playground.

On the way back to the classroom, both girls are breathless, holding hands and knocking into each other. Lainey leans over and tells Brenna: “I think you look really pretty.

“And those are really cute earrings.”