Honolulu Star Advertiser
Thursday, September 18, 2014 85.0°F

www.staradvertiser.com > FeaturesPremium >

Transplants transform a family

New kidneys give a Big Island brother and sister hope after years battling a devastating condition

By Steven Mark

POSTED: 01:30 a.m. HST, Sep 18, 2014
LAST UPDATED: 02:28 a.m. HST, Sep 18, 2014

MEGAN SPELMAN / SPECIAL TO THE STAR-ADVERTISER

Now free to play like other children, Dominic Faisca, left, and sister Julia roughhouse with brother Alex in the yard of their home in Hawi on the Big Island.

The miracles of modern medicine sometimes need a bit of help from serendipity.

Just ask the Faisca family of Hawi on Hawaii island, now enjoying a life free of the worry and anxiety that had dogged them for nine years. The family's two eldest children, 9-year-old Julia and 8-year-old Dominic, have survived a diagnosis of terminal kidney failure and are now thriving with transplanted kidneys they received in separate operations over the past year and a half.

Laughter comes easily now for Natasha Faisca as she talks about the children she is raising with her high school sweetheart and husband, Kapono Faisca, in the tiny town at the northernmost tip of the Big Island.

"They're so different now than before transplant," she said. "With my daughter, she was so quiet, she didn't really do much. ... Now she wants to get into hula, she wants to wear makeup, she wants to do dress-up -- typical 9-year-old girl things.

"With Dominic, he reminds me of one of those kids on the (Bill) Cosby show, 'Kids Say the Darndest Things.'"

It was in the midst of a flu outbreak nine years ago that Julia, then just 6 months old, stopped eating, recalls her mother. After a few weeks the infant was still unable to keep food down, and her weight, normal at birth, was dropping. Even extended hospital stays couldn't turn things around.

Julia was medivaced to Honolulu and admitted to Kapiolani Medical Center for Women & Children "to make her comfortable so we could say our goodbyes,"Natasha Faisca said. "They told us she was in complete renalfailure."

But at Kapiolani, additional testing -- which took almost a month, with Julia hanging on -- revealed she was suffering from cystinosis, a rare hereditary disease that causes crystals of cystine, an amino acid, to build up in the body. There are only about 800 cystinosis patients in North America, including another one in Hawaii, said Dr. Paul Grimm, medical director of the pediatric kidney transplant program at Lucile Packard Children's Hospital Stanford in California, where the Faisca siblings were treated.

Dominic, born 20 months after Julia, was found to have the same condition but with complications. He had to have a shunt placed in the back of his head to relieve a buildup of fluid around the brain, which made him overly sensitive to light and gave him headaches.

Over the years, the Faiscas' lives were consumed with finding help for their children. They went online to find out about cystinosis and consulted with online support groups. They traveled to Honolulu frequently and to the National Institutes of Health in Maryland for checkups.

Their physician here, Dr. James Musgrave, recommended they go to Stanford, where they were given advice that enabled the children to keep their kidneys for several years.

"There are treatments that can be used to get the child to nearly optimal health," Grimm said, citing mineral supplements, tube feeding and growth hormones. "Some people who are kind of lucky, they make it without a kidney transplant ... but for the most common kind of kid, they need a transplant before or just into their teenage years. The kidneys just burn out despite the best medical management."

For Julia, that began to happen in early 2013. She was put on the transplant list and received a new kidney at Stanford in the summer of 2013. Her recovery since then has been "awesome,"said her mother. "She's grown just about 6 inches and gained 23 pounds in the first year."

A few months after Julia's transplant, Dominic's kidney functions began to deteriorate, and though he, too, was on the transplant list, doctors determined he needed to go on dialysis.

Dialysis can be particularly hard on children, Grimm said. Dominic would have had to remain attached to the dialysis machine for four to six hours during treatment, three days a week. To accommodate the machine, a catheter is inserted into the skin, and with Dominic's shunt, the catheter would have to go into his heart.

So when the Faiscas landed in California on a mid-June evening for Dominic's initial treatment and noticed a nurse from Stanford had texted them during the trip, they reacted with a bit of gallows humor.

"We thought they were just checking in," Faisca said. "We were just joking around, and so we replied, 'We just landed. Do you have me an organ?'

"She didn't answer, so we get our luggage, head to the Super Shuttle, load everything and then she calls me: 'How soon can you get to the hospital?' I was like 'You have to be joking!' They told us they had an offer from Pennsylvania for him."

By the next morning, Dominic was on the operating table for the 51/2-hour transplant surgery.

"It's never routine," Grimm said. "It's always exciting when you put in the kidney and you see the first few drops of urine. People are clapping when that kidney wakes up."

Faisca recalled, "The doctor comes out and said, 'Well, Mom, everything went well. He peed all over the OR. ... That's a good thing. That means the kidney is awake.'"

Not only is his kidney awake, but to Dominic it seems to be an entity unto itself. He named it Sam, and "every time someone came into the room and starting talking about his kidney, he'd say, 'His name is Sam,'" Faisca said.

The children still need to go to Oahu every couple of months and to Stanford twice a year for checkups. The life span of a transplanted kidney is about 20 years, so they will need additional surgery.

Though insurance paid for the transplants, treatment and other major expenses, the Faiscas drained their bank accounts and moved in with family to save money. Fundraising drives have helped some, but Kapono and Natasha Faisca, both 29, have been unable to keep steady jobs, as they've needed to go off island for their children's health care.

"We end up digging ourselves a pretty big hole, and then we try to climb out of it slowly but we never fully get out of it," Natasha Faisca said.

Still, it's worth it to see the kids thrive. Dominic is not allowed to run yet, and he and his sister will have to avoid activities that involve frontal contact, but otherwise any activity is allowed. The Faiscas have a third child, Alex, 6, who is not afflicted with cystinosis. He looks out for his siblings.

The children are back in class at Kohala Elementary School, which has provided them with school supplies and takes extra care to watch over them.

Columns

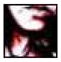
Kokua Line
1 fare system for rail, bus but actual price unknown

Ferd's Words
Ain't too tough to love

View All | Columns »

Blogs

Warrior Beat
Travel day



Fashion Tribe
Fashion Tribe: Every fragrance tells a story

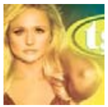
Volley Shots
Toyota 3, Hawaii 2

View All | Blogs »

Like 53k

'Soul Sessions' featuring Tavana

In the Mix: The Sticklers reunite



This Week in TGIF: Miranda Lambert

Social Encore: Moon Collective shines bright

Grind Time: Hakone hosts sake dinner

PICS: Dancing for the Future at M Nightclub

PICS: 'Sunny Daze' CD Release Party

This Week in TGIF | Calendar of Events

StreetPulse

Like 11k

"Everyone there knows what's going on," Faisca said. "They knew when Julia was sick; they knew when Dominic got sick. Everybody came together."

Print Email Comment | View 3 Comments Most Popular Save Post Retweet

COMMENTS (3)

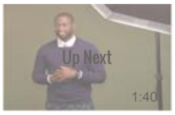
You must be subscribed to participate in discussions

Click to view comments [+]

IN OTHER NEWS

Dwyane Wade on His Fashion Sense

NBA star Dwyane Wade admits he hasn't always had fashion sense, but now he has two watches from Hublot that bear his name and everyone wants to see what he wears at his post-game press conferences. (Sept. 18)



HOME PAGE
- Back Issues
- Corrections
- Special Projects
- Photo Galleries
- Calendars
- TV Week
- Movie Theaters
- Weather and Surf
- Traffic

SOCIAL AND MULTIMEDIA
- Facebook
- Twitter
- Google+
- YouTube
- Scribd

HAWAII NEWS
- Newswatch
- 911 Report
- Vital Statistics
- Obituaries
- Island Images
- New York Times
- Facts of the Matter
- flASHback
- Incidental Lives
- Keep Hawaii Hawaii
- Kokua Line
- Ocean Watch
- Skywatch
- Volcanic Ash

COMICS
- Bento Box
- Calabash
- nemu*nemu
- Trouble in Paradise

SPORTS
- Hawaii Beat
- Scoreboards
- TV and Radio
- Ferd's Words
- Further Review
- Hawaii Prep World
- Hawaii Warrior World
- Hawaii Grown Report

BUSINESS
- Business Briefs
- Real Estate Sales
- Akamai Money
- Buy Local
- The Buzz
- Tech View
- Wealth of Health

FEATURES
- Weddings and Anniversaries
- Be Well
- By Request
- By the Glass
- Eat Your Veggies
- Electric Kitchen
- The Green Leaf
- Hawaii Gardens
- Health Options
- K-Drama
- Looking Back
- On Tap in Hawaii
- Outtakes
- Show Biz
- Urban Gardener
- Wood Craft

EDITORIALS
- Our View
- Insight
- Guest Columns
- Off the News
- Letters to the Editor
- Name in the News
- On Politics
- Kauakūkalahale

HAWAII FIVE-0

PULSE
- TGIF
- Photo Galleries
- On the Scene

TRAVEL
- Isle Hoppping
- Staycation
- Hawaii's Back Yard
- Las Vegas Advisor

INFORMATION
- News Tips/Contact
- Advertise
- Terms of Service
- Privacy Policy
- About Us

OTHER FORMATS
- Print Replica
- iPhone/iPad/iPod
- Android
- RSS/XML

DINING OUT
- Weekly Eater

GAMES

HOMES
- Hawaii Renovation
- Place My Ad
- Listings
- Rentals
- Foreclosures
- Find an Agent
- Homes

JOBS
- Place My Ad
- Monster.com

CARS
- Place My Ad
- Hawaiis Cars
- AutoTrader.com

CLASSIFIEDS
- Place My Ad
- Obituaries
- Cars
- Jobs
- Foreclosures
- Homes

MEMBER SERVICES
- Log In
- Log Out
- Change Password
- Forgot Password
- Manage Online Account

ADVERTISING MEDIA KIT

News | Jobs | Cars for Sale | Hawaii Rentals | Customer Service

500 Ala Moana Boulevard. #7-210, Honolulu, HI 96813 Telephone (808) 529-4747