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# The Arnold Sentinel

CUSTER COUNTY, ARNOLD, NEBRASKA 69120

(USPS 032480)

THURSDAY, FEBRUARY 5, 2015

VOLUME 98, NUMBER 33

## A "RareJul"



Juliet Strasburg pictured at about eight months of age. She has spent many weeks of her young life in Omaha's Children's Hospital, being treated for complications resulting from Vici Syndrome.

By Janet Larreau

Juliet Perri Strasburg is a beautiful baby, with blonde, curly locks, big blue eyes and some of the longest eyelashes you've ever seen. She has a family that adores her, including two older siblings.

She's "one in a million."

In fact, she's one in hundreds of millions. Juliet has been diagnosed with a rare genetic disease. So rare, only 20 cases have officially been diagnosed in the world.

Juliet was born on the morning of May 15, 2014. She came to her parents, Justin and Jailyn Strasburg of rural Arnold, very similar to their two older children, Piper, who turns six in February, and Parker, 3 1/2. The couple had a nice middle-of-the-night drive to the hospital - just like the other two - but Juliet held on a little longer and

was born in the mid-morning.

Her newborn screen was normal, except for the dots in her eyes. The pediatrician wasn't concerned, but thought that they didn't look normal. Three weeks later, the dots were confirmed as cataracts. The eye doctor wasn't worried and asked to see her again in two months.

Around four to five weeks of age, Justin and Jailyn noticed that Juliet didn't seem to be gaining any weight, although she ate, or tried to eat, like any other newborn. A doctor's appointment was made and Juliet was admitted to the hospital for "Failure to Thrive." An MRI revealed that Juliet had ACC (Agenesis of the Corpus Callosum).

Months later, on December 11, Juliet was officially diagnosed with Vici Syndrome (VS). VS is an extremely rare multi-



Children's Hospital in Omaha has become a second home to Justin and Jailyn Strasburg and daughter Juliet, as Juliet faces medical challenges caused by Vici Syndrome. (Courtesy photos)

### Juliet Strasburg Struggles With Rare Disease

system disorder characterized by an absence of corpus callosum (part of the brain), low muscle tone, significant developmental delays, cataracts, heart muscle disease, abnormalities of the immune system, seizures, recurrent severe infections, and in some cases, loss of hearing. Life expectancy for children with VS varies between ages three through eight.

Juliet has been admitted to Children's Hospital in Omaha eight times in seven months with each stay being at least a week. The longest stay was two days shy of a month. She has taken two helicopter and two ambulance rides.

"One thing we can say is that she has definitely had the best flight attendants in the skies," Justin wrote on a blog titled *RareJul*. "We have started to become known at Children's to the point that the doctors and nurses will come and visit us even if they are not taking care of Juliet at the moment. I guess it's good to have them on your side when you need them. We

have, however, spent nearly as much time with them as we have at home, so they truly are our second family."

Justin said that Children's Hospital has a mixed emotional feel every time they are there.

"On one hand, you have the best care in the best possible facility there is," and on the other you have "I'm in a hospital where it's never just the common cold." You pass other parents in the halls or elevator, and we all have that same thought or look in our eyes, wanting to ask the question, "What is your child here for?" Sometimes you do, but most of the time it's just understood that no case is better or worse than the other. We all have a sick child and no parent wishes that on anyone. We wish we could just take it away and make it be us instead of them, at times feeling helpless."

Doctors at Children's Hospital are not familiar with the disease due to its rarity, but are in full research mode.

"Vici is a fairly new syndrome and not a lot of research has been done; the diagnosing gene was only found a couple of years ago," said Justin. "We are trying to start the process of helping to raise awareness."

Justin said the hardest part of all of this journey has been to understand why God chose their little girl to be diagnosed with Vici Syndrome.

"Of all of the things that could happen to a child, why this?" he said.

Justin and Jailyn's deep faith will carry them through in the challenges that lie ahead. On his blog, Justin posted a Bible verse from Ps 55:22: "Cast your burden to the Lord and He will sustain you." While in Omaha with Juliet, Jailyn texted the words, "Our Lord is mighty! At the same time so personal! He continues to show how much He loves us!"

Both Justin and Jailyn are graduates of Arnold High School. Jailyn's parents are Keith and Jodi Carlson, and Justin's parents are Penny (Crow) Allen and Kevin Strasburg.

#### Benefit Planned

With bills mounting for the family, Jailyn's classmates from the Class of 2000 are showing their support for the family by hosting a benefit scheduled for February 28 at the Arnold Community Center. Ironically, organizer Ashley Meyer said the date was unknowingly set on the observance of "Rare Disease Day." The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

A soup, sandwich and pie supper will be served from 5:00 p.m. to 7:00 p.m., for a free-will donation. Silent auction winners will be announced at 7:00 p.m.

If anyone would like to donate an item for the silent auction, please contact Ashley Meyer at 308-660-5936.



The Arnold Community Center was filled to capacity last Friday night for a benefit for Alan and Becky Dailey. (Marcia Hora photo)

## Residents Show Support at Dailey Benefit

Six hundred people filled the Arnold Community Center, Friday, January 30, to show their support of Alan Dailey in his fight against cancer.

Alan was diagnosed with prostate cancer in 2010. He has undergone treatment for cancer in his bones and is now undergoing treatment for cancer in his brain. He is currently undergoing chemotherapy.

All Point employees who work with Alan and his friends put together the "pulling" for Alan benefit. The pulled pork sandwich meal was served prior to a silent and live auction. Brad

Atkins served as auctioneer. Kim Beshaler and crew helped take in and line-up the items.

Numerous items were donated by many people in the area.

Peg Scott said the response to the meal and auction was overwhelming.

"Thank you to those who attended, brought in food, donated auction items, helped serve, set up and clean-up, or helped in any way," Peg said after the benefit. "It was greatly appreciated."

"You could feel the love from everyone," Alan's wife, Becky

said. "We had no idea there would be this kind of turnout. The food was great and Brad and Kim organized an amazing auction in a very short amount of time. The entire evening was remarkable and our entire family feels very blessed."

Alan and Becky and their family are taking it one day at a time. They are thankful for the prayers, generosity and support of Arnold and surrounding communities.

In addition to the benefit, Alan has had people volunteer to drive him to treatment and people have brought in meals.

### Benefit Planned for Zach Lewis and Kayli Paul

A benefit for Zach Lewis and Kayli Paul, of Maxwell, will be held at the Maxwell School on Friday, February 6. A soup and pie supper will be held from 5:00 to 6:00 p.m., right before the Maxwell/Hershey game.

Kayli is carrying identical twin boys and has been diagnosed with rare TRAP Sequence (Twin Reversed Arterial Profusion Sequence), which will require a delicate surgical procedure in Houston, Texas.

Zach graduated from AHS in 2008 and is the son of Pat Turley of Arnold.

### Weather Summary

Kendra Veirs  
Cooperative Weather Observer  
WEATHER STATION  
LOCATED AT MILLS' SHOP,  
ACROSS FROM  
ALL POINTS CO-OP

DATE	H	L	M
27	65	27	0
28	73	27	0
29	66	28	0
30	46	18	0
31	48	17	.08
1	38	9	0
2	20	-7	0

Two inches of snow was received on the 31st. Total moisture received in January was .12 of an inch. The high was 73 degrees and the low was -16.

### Applications Now Being Accepted for Good Neighbor Awards

Omaha - The AKSARBEN Foundation, in association with the *Omaha World-Herald*, is now accepting entries for AKSARBEN Good Neighbor Awards. The program honors individuals nominated by neighbors for performing unselfish, neighborly deeds without compensation or personal gain.

Nomination forms can be obtained from your local County Fair Board Office or online at [www.aksarben.org](http://www.aksarben.org). All nominations must be received at the AKSARBEN Foundation offices no later than May 1, 2015.

Founded in 1895, the AKSARBEN Foundation is the premier philanthropic organization for the region's top corporate and community leaders.