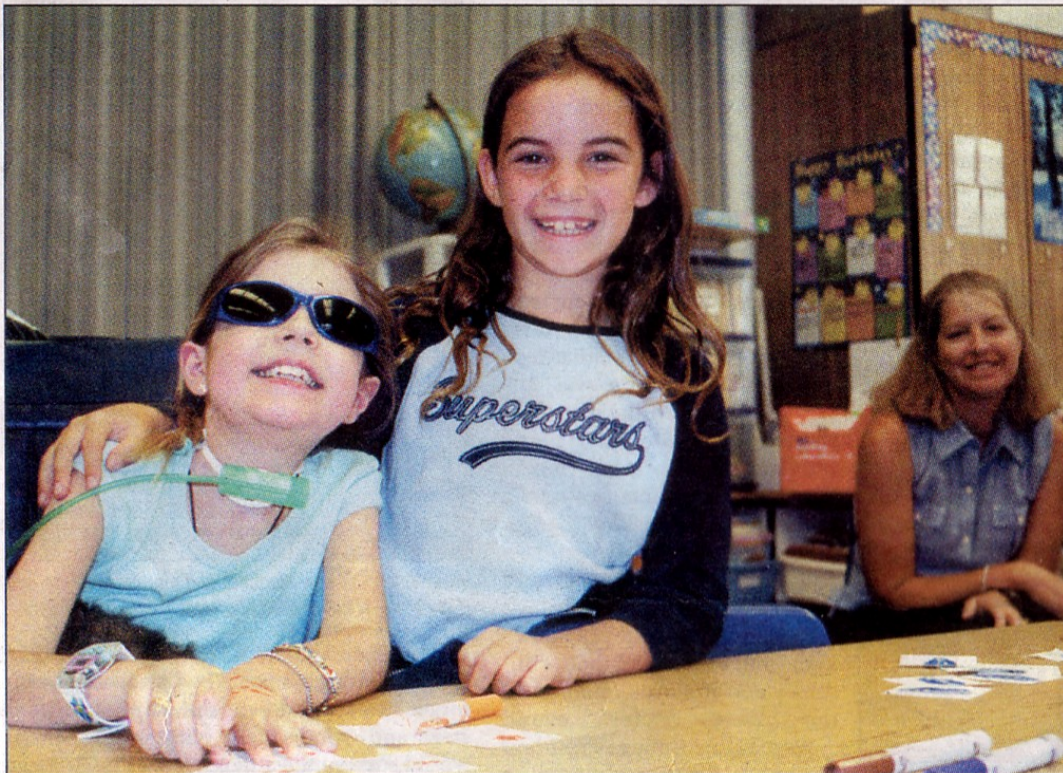


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Kaitlyn returns to school



Eight-year-old struggles to overcome devastating effects of severe allergic reaction

By Julie Davis Berry
Editor

At recess Kaitlyn Langstaff has always been one of the most popular kids on the Forest Hill Elementary School campus. And she still is, despite the fact that this fall she returned to school blind, mute and in a wheelchair after surviving a devastating allergic reaction to Ibuprofen. The fact that she is alive at all is a testament to a very courageous little girl, the strong love of her family and the amazing compassion of a community touched by her health crisis.

Physical issues

While out of town last April, Kaitlyn became ill with a very rare and severe allergic reaction to Ibuprofen, which is called Stevens Johnson Syndrome. She was airlifted from Fresno to a Los Angeles hospital where she spent several weeks on life support.

See **KAITLYN**, page 17

Kaitlyn is especially glad to be sitting next to her best friend Ariana Gomez in Mrs. Dorsch's third grade class. Her mother Kerry watches in the background.

Kaitlyn returns to school

KAITLYN, from page 1

Eventually she was flown back to northern California to Lucille Packard Children's Hospital at Stanford. These were very rough months for the eight-year-old and her family. She almost died several times, but each time she pulled through.

Dr. Benjamin Mandac is in charge of pediatric rehabilitation at Valley Medical Center. He heard about Kaitlyn's case and came to Packard after hearing that she almost died one night. Mandac took control of her case and had her transferred to Valley Medical Center. "He got her off of meds and he was the first doctor that told us what we had to do to bring her home," said Kerry. "Kaitlyn calls him the doctor that saved me."

After six weeks at Valley Medical Center she was released to go home. Her parents had to learn every aspect of Kaitlyn's care. They have been greatly helped by Kaitlyn's new pediatrician, Dr. Jennifer Foreman. "She manages all of the equipment," said Kerry. "She's terrific."

Kaitlyn has four main areas of concern: her eyes, her larynx, her esophagus and her lungs. The ocular surface of her eye has been permanently damaged and she is blind. She will need a stem cell transplant and then a cornea transplant on each eye.

With the political climate being what it is in regards to stem cell transplants the Langstaff's are looking at doctors in Italy, Japan and Taiwan where the use of stem cells is not as controversial. A

doctor at UC Davis recently told them that they should put off doing any surgery for a few years to benefit from any future technology advances. "He told us that he believes that at some point in Kaitlyn's life she'll be able to have some vision," said Kerry.

Due to the damage from Stevens Johnson Syndrome, Kaitlyn has no airway through her nose or mouth and she must breathe with the assistance of oxygen through a tracheotomy tube in her throat. Because of the lung damage it takes tremendous effort for Kaitlyn to walk. She uses a wheelchair most of the time.

She is unable to speak because of damage to her larynx. Sometimes she can whisper by blowing air lightly and she recently received a machine called a Dynawrite, which is an electronic text to speech keyboard. It's an assistive communication technique, which replicates a childlike voice. Some day she may be able to have surgery to enable her to speak in a monotone voice through a hole in her throat.

Damage to her esophagus prevents her from eating so she is fed through a gastrostomy tube in her stomach. Her taste buds were destroyed so she cannot taste anything anyway. She also has a slight hearing loss in both ears.

You can imagine the effort that it takes to go anywhere with Kaitlyn. She has to have her oxygen, a suction machine for her tracheotomy and a machine that gives her nourishment through her gastrostomy tube.



Kerry Langstaff (left) or her husband Brad accompany their daughter to school everyday and help Kaitlyn out with her class work. They say that they will come everyday until Kaitlyn feels comfortable without them.

Education issues

Kaitlyn's teacher Mrs. Dorsch has a reputation for being strict and a very good educator. How did she feel when she found out that Kaitlyn would be in her classroom in the fall? "We were all surprised that she was able to come back this fall. We didn't know how much she was going to be able to do," said Dorsch. "I don't tailor my lessons to her but there are certain changes I have made. For instance I do more oral descriptions of things."

Kaitlyn volunteers a lot and she is not shy in the classroom. "She's got chutzpah and she takes chances. She is incredibly sharp," said Dorsch. "It's sometimes hard to remember that she is only eight years old. She wants to learn cursive handwriting just like all third graders do. So we are trying to figure out tactile teaching methods. We use our fingers and write in the air something I never

gauge from the library. "Kaitlyn read sign language in eight minutes," said Kerry. "There are times when she is just bored with the curriculum because she is so advanced. She was recently tested and is reading at a sixth or seventh grade level. She'll learn Braille, but she doesn't want to be treated differently."

So far we are just figuring things out as far as the classroom is concerned. It's frustrating for her because everything used to come so easily for her."

Emotional issues

Kaitlyn was extremely excited to get back to school in the fall. Coming back to a school with people she knows and loves is the best thing for her spirits, according to her mom. So far there has been no problem "fitting in" at the elementary school.

"I have not seen any child doing any shunning or treating her differently," said Dorsch. "She's kind

and talk. We played talking battleship this weekend."

Arianna is in Kaitlyn's brownie troop and amazingly Kerry is still the leader of the troop which includes 14 third graders.

Another source of support has been her pen pal, a boy from Gilroy who also had Stevens Johnson Syndrome. His issues are not as severe as Kaitlyn but he recently came to visit and the two of them compared places where they'd had IV's inserted. Kaitlyn would love to meet another kid with a tracheotomy and she'd love to meet a blind kid.

The formerly very active family has started venturing out again. "Whenever we go out now everyone stares at her," said Kerry. "Fortunately she doesn't notice because she's blind, but we do. But, we are not going to let this defeat us. We take her out as much as possible. We have taken her to a movie, Valley Fair, Petroglyph and

Kaitlyn returns to school

KAITLYN, from page 17

But the family has not been able to access any financial help. "She doesn't qualify for social security benefits. She has a lot of problems but she doesn't qualify for government assistance because she doesn't have a developmental disability, just a physical disability," said Kerry. "A family of four cannot have assets of more than \$3,000 not including one car and a house. They said to call back when Kaitlyn is 18 or we have no income."

The ironic thing is that Kerry was scheduled to start a new job as a marketing director at Nuance the day that her daughter was airlifted to a Los Angeles hospital. Kerry feels that once Kaitlyn starts to feel comfortable being at school

without her in the very near future, she would like to return to consulting on a part time basis. Brad's specialty is putting on trade shows in the high tech sector and with that comes travel so it is unlikely that he will return to a similar job.

Kerry is looking to start up her marketing consulting business again. Find out more about Kerry's consulting business at www.langstaffcommunications.com

In the meantime the family says that the donations have been helping them to pay for things like the mortgage and food.

Community Support

The outpouring of support from family, friends and the community in general has been a real source of solace for the family during this extremely difficult time.

"It's impressive to see how nice people can be in this day and age," said Kerry. "All of these people, some who we barely know, are reaching out to help us. We are so grateful for this great community."

When Kaitlyn was first sick a family friend, Tammy Davies, flew down and

ended up staying for a week while Kaitlyn was transferred to Los Angeles. "It was a very awful week," said Davies. "I was just there to let Kerry vent because it was so tough. They are quite remarkable people. Kerry and Brad have always just given, given, given to the community. Now that they are in need the community is responding and they are reaping what they've sown."

Kerry has led Brownie troops, Destination Imagination groups and produced the school play last year for Rolling Hills Middle School. Brad was in charge of Indian Princesses at the Southwest YMCA and has coached Bobby Sox teams. They have touched many lives in the community and people have responded in droves.

Three times a week people bring dinner to the family. "Even the principal of Rolling Hills, Mrs. Atkinson, brought us dinner!" said Kerry. And, twice a month a group of moms the family met through school and brownies comes over to clean the family's house. These are all organized

by the Langstaff's neighbor Karen Pasos. "It's pretty easy because I can send out messages over the Internet and people just sign up," said Pasos. "We have people from Forest Hill, Rolling Hills, Indian Princesses, Bobby Sox, Brownies and everyone just wants to help the family."

Kelly's Girl Scout troop is putting together all of the cards and letters in scrapbooks for the family. "There were over 814 get well cards sent to Kaitlyn," said Kerry. "The cards were just amazing. They were all so supportive."

Davies said that the other day she was thinking about the Langstaff's and she thought, "They could really use a miracle. But, you know they already have a miracle. Kaitlyn is still with us."

If you would like to donate money to Kaitlyn and her family send a check to Kaitlyn Langstaff, c/o Forest Hill Elementary School, 4450 McCoy Avenue, San Jose, 95130.



Kaitlyn is one of the top students in Mrs. Dorsch's third grade class. She constantly raises her hand to participate in class discussions. Her aide Nicole Zannini is always at Kaitlyn's side to verbally paint a picture or to take care of her physical needs.

to do before. Nicole Zannini is her full time aide. She has been an aide with the district for nine years.

"I'm used to working with children who are born with disabilities. It's second nature to me," said Zannini. "When I found out that I would be working with Kaitlyn I knew it was going to be a challenge because of all of the adjustments that Kaitlyn was going to have to make. But, she is a great kid. And her family is really awesome. They don't baby her. They want her to be independent. They are very upfront about her issues."

Kerry recently took out a book on sign lan-

of a celebrity on campus. And her parents came in the first day and explained things to the class and told the kids about things they might see and hear which was very smart. They don't over accommodate her."

Kerry is overwhelmed by the support Kaitlyn gets from the other students. "The kids have been very supportive from the very first day. At recess the kids would take the bracelets off their arms and give them to Kaitlyn," said Kerry.

Her best friend Ariana Gomez sits next to her in class. They were on the same soccer team last year. This year Kaitlyn will have an honorary T-shirt to wear on the sidelines. "I saw her at Valley Med and she looked better than I thought she would," said Ariana. "I like Kaitlyn because she is really funny. Now I can understand her sometimes but not all of the time. Now we hang out at recess

to our older daughter Kaitlyn's play practice."

Since she was in the hospital Kaitlyn has had a dream of having a Golden Retriever puppy like her dad had when he was growing up. She would name the puppy Daisy. The family would like to make her dream come true soon.

Financial issues

The family is also struggling with devastating financial issues. Both Kerry and Brad were unemployed when Kaitlyn's illness occurred. They have been unable to work since then due to the 24-hour care that Kaitlyn's illness requires. "We have exhausted our unemployment. We have been living off of donations and our savings and they are almost gone," said a weary Kerry.

One would think that there would be help from social security or some other government assistance in a situation like this.

See KAITLYN, page 19