

Search





DONATE

WISHES WISH STORIES

I wish to be I wish to go I wish to have I wish to meet I wish to give I wish to visit Hawaii

I WISH TO HAVE

Local wishes like Nawai’s outdoor sanctuary are **UNDER CONSTRUCTION!** Help us bring magic right to our wish keiki’s homes.

GIVE NOW

WISH IN PROGRESS: SKYLAR’S CORNER

SHARE THIS PAGE

“Make-A-Wish encourages and gives families something to look forward to.”

Wish Mom Yuko

Skylar , 3

genetic disorder

I wish to have a therapy room

I wish to have

I wish to have , therapy room , Skylar’s corner

Honolulu - Oahu



1/5 Skylar (right), brother Kainalu and wish mom Yuko

Three-year-old Skylar embodies his Japanese middle name, Kiseki—or “miracle”—in countless ways. Described by wish mom Yuko as her “tiny, mighty, feisty warrior,” Skylar has been through more in the past three years than many people in a lifetime. Through it all, he’s been a fighter, staying strong for his family :

2,2
3,3
4,4
5,5

Previous
Next

JOIN THE CONVERSATION

This story makes me feel

Hopeful

Reflective

Inspired

LEAVE A COMMENT

Wish in Progress: Skylar's Corner



“He’s obviously been through a lot of procedures and a lot of hospital stays,” explains Yuko. “Every single time, the doctors tell us that he’s not going to come out the same way or as strong as he used to be, [but] he comes back. He fights; he’s a warrior.”

Before he was born, Skylar’s doctors noticed that he had a cleft lip palate, a common condition, and a thick nuchal fold. It was only after his delivery that doctors discovered Skylar has lissencephaly, a rare brain disorder also called “smooth brain.” The next day, Yuko found out that Skylar also has a very rare genetic disorder called Baraitser-Winter syndrome. His is one of only 20 cases of both lissencephaly and Baraitser-Winter syndrome in the world.

Doctors told Yuko and wish dad Brydon that Skylar would most likely not see his first birthday, which was devastating to the new parents. Yuko remembers, “You have a baby. That should be the happiest time of your life, and you’re being told ‘your baby is not going to make it to see one.’ I just broke down. He was only 13 days old. I didn’t sleep, and literally every single day I thought, ‘I’m going to lose him tomorrow, I’m going to lose him tomorrow.’”

Although the news was unimaginably difficult, Yuko and Brydon felt blessed by the amazing NICU nurses at Kapi’olani Medical Center for Women and Children who helped them through those difficult first weeks. After receiving training from the staff and staying by Skylar’s side for seven weeks in the NICU, they were finally able to take their new baby home.

Since then, Skylar has continued to defy the odds, though his journey has been far from easy. Last November, he ran a very high fever, which doctors diagnosed as a viral infection that eventually turned into pneumonia and threatened his life. Despite a difficult 47 days in the PICU, Skylar the warrior was finally able to come home just after Christmas. “The nurses are just amazed at how well he bounces back,” says Yuko. “He’s a feisty fighter, definitely.”

A normal day in Skylar’s life now consists of six different kinds of medications at the start of his morning, feedings four times a day, and play time with 5-year-old big brother Kainalu. Because of seizure precautions and a sensitivity to light due to an eye condition, Skylar enjoys outdoor time with his family during the cooler hours of the day and loves going on his favorite swing and playing with the family dog, Keiki. Skylar, also known as “Baby Sky,” adores his big brother, and Kainalu adores him in return. “[Kainalu can be] rough with Skylar [when they play], but Skylar does not complain. Every time Skylar needs something, or he’s in distress, I’ll say ‘go get the suction, go get this... anything’ and Kainalu will run and get it, or he’ll bring a stethoscope and thermometer and he wants to try take care of him,” Yuko says.

When Skylar was first referred to Make-A-Wish Hawaii, Yuko was excited but had to get used to her new position as ‘wish mom.’ “I was like, ‘oh, that’s me!’” Yuko laughs. The family knew that a dedicated therapy room in the house just for Baby Sky—one tailored to his unique needs—would be the perfect wish. Yuko hopes that a room just for him will not only make him happier and more comfortable but that it will also aid in his medical journey.

Skylar’s Corner will also allow Yuko and Kainalu peace of mind. Baby Sky is non-verbal and fed through a gastronomy tube, and his care requires many different types of equipment. In addition to having his items neatly stored and readily accessible to the family and Skylar’s nurses, Yuko also

thinks that a baby monitor in the room would make her feel even more secure. When Skylar has gotten sick in the past, Yuko has always trusted her instincts, even if things don't seem too serious at first. She has never been wrong and consequently stays on high alert. "[With] Skylar, [my] antennas are up 24/7. We're sleeping, but we're not really sleeping," she explains. "I think I'll be able to relax a little bit more [after the wish]."

Yuko is thankful that Baby Sky will soon have a special room he can call his own, tailored just for him. "With what these kids go through medically [and the] challenges that they have in life, to be accepted into Make-A-Wish, I mean, it's unimaginable," she says. "I only know because I'm blessed enough to have Skylar as my child."

Yuko has known about the life-changing impact of a wish through friends who also have children fighting critical illnesses. She is looking forward to Skylar's Corner coming to life and the positive impact it will have on him and the whole family: "Make-A-Wish is great for family support. It encourages and gives the families something to look forward to. What you guys are doing is amazing."

JOIN THE CONVERSATION

LEAVE A COMMENT

NEW WISH STORIES



[Wish in Progress: Skylar's Corner](#)



[Wish in Progress: Mano's wish for a Mustang makeover](#)



[A Christmas cruise with Mickey Mouse: Isaiah's Wish](#)

UPCOMING EVENTS



[Swing for Wishes](#)

October 22, 2020



[Jingle Rock Ride](#)

December 13, 2020

NEWS & UPDATES



[Summer 2020 Newsletter](#)

July 15, 2020



[Annual Report 2019](#)

May 06, 2020



[What COVID-19 Means for Wishes](#)

March 16, 2020



BECOME A VOLUNTEER

We are in need of volunteers on all islands! Sign up to become a wish granting volunteer today!

Stay in Touch!

Read wish stories and learn about upcoming events. Sign up to receive email from Make-A-Wish Hawaii.

[Like us on Facebook](#)

[Follow us on Twitter](#)

[Subscribe to our YouTube channel](#)

[Stay in touch via RSS](#)

[More ways to connect](#)

Make-A-Wish® Hawaii
P.O. Box 1877
Honolulu, HI 96805
(808) 537-3118 x100

©2006-2020 Make-A-Wish Foundation of Hawaii

Make-A-Wish Foundation of Hawaii is a Hawaii nonprofit corporation exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code.

[FAQ](#) | [Financials](#) | [Privacy Policy & Terms](#)