

The Jake Kruel Story

by Doug & Heidi Kruel



On September 22nd, 2000, Jake was born in Hawaii, from a healthy and uneventful full term pregnancy. Like all first time parents we were thrilled and enjoyed every minute of Jake. His infancy was entirely typical and he was (from an objective parental perspective) the perfect child. ☺

When Jake was 6 months old he got sick with croup. He was having some difficulty breathing so his pediatrician ordered x-rays of his throat to more clearly see the potential swelling. As luck would have it, the technician taking those images was the most experienced radiologist in Hawaii. While viewing the throat images he noticed a slight abnormality in the shape of Jake's vertebrae. He showed us the x-rays, explained his findings and asked if he could take more images because he suspected the abnormally shaped vertebrae could be caused by a "rare metabolic disorder" that he had some experience working with. Our pediatricians were shocked at the thought and slightly stubborn that anything could be amiss with Jake's health because we experienced nothing out of the ordinary during his young life. We quickly confirmed the radiologist's theory with a series of tests and I remember thinking "life just got serious". Naturally, the reactions ranged from disbelief to sorrow to practical strategies of treatments and solutions.

As Jake has dealt with the ongoing doctor visits through the years we come to the

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realization that an illness or diagnosis of our most cherished family member provides infinite perspective on our lives. Children know they are different but don't know a life any different than what they have. Jake's strength and resilience has been inspiring while giving us the opportunity to enjoy and appreciate every single moment we spend with him. The end result has been the most fun raising the greatest kid we know. Through his adversity, Jake has developed a keen sense of humor that everyone around him loves. He has wit and a comedic spin on life with respect for everyone around him. His joy of life shines, no matter what his physical limitations have imposed upon him. He is solely responsible for saving me from be a workaholic! Raising a child in Hawaii and enjoying the natural surroundings with an every-day appreciation of everything is the reward.

Over the past 4 years Jake has gone through 2 neck surgeries in an attempt to relieve potential pressure on his spinal cord and to fuse the C1 through C4 (top 4) vertebrae together. This is to reduce potential serious neck injury risk in the event of a hard fall or accident. There are no pediatric orthopedic surgeons in Hawaii, specializing in this type of procedure, so each operation involved a 3 week trip to Los Angeles. Jake spent about 5 hours in the operating room each time and had to wear a "halo" for 3 months afterwards. The halo is heavy and cumbersome for a small child, but his positive attitude was amazing and it did not cause any pain. The timing of the first surgery's recovery ran into one of Jake's school years, so we decided to hold him back and repeat that grade. Since preschool, Jake has attended a small private school in Kailua, Hawaii, called Le Jardin Academy. We are very fortunate that



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he was accepted into such a nurturing, intimate learning environment. They provide a challenging environment for all of their students while providing the highest teacher-to-student ratio in the state. The Le Jardin Academy campus is fairly spread out, commonly with 100 and 200 yard walks between classes. Since this is difficult for Jake, since Kindergarten he has used an electric “scooter” (joystick-driven wheelchair adapted with bright colors to look less medical and more fun) as transportation between classes. Before being able to use it on campus with a school full of children, he had to pass a driving test. He passed the test with flying colors and was quickly accepted as the cool kid on campus with his own mode of transportation.

Every aspect of Jake’s differences to other kids has given us an opportunity to maintain a positive “spin” on his situation. His day-to-day life takes more effort than an average kid and is more challenging for him to get around. However, even with the prospect of receiving treatment and getting stronger, healthier and possibly taller, his first response was: “I think I’ll miss being able to play hide and seek in smaller places than my friends”. Having the luxury of living in a small town and attending a small school, Jake is familiar with most of the kids he meets, but is also used to being stared at by kids who are new to him and/or his scooter. He has developed clever defense systems through humor to deal with other kids and has always maintained a healthy self esteem, which is our top priority. Our life mantra for Jake is: Do your best and have fun. We look forward to medical advances that will improve Jake’s quality of life, but we’re not waiting for anything to have fun appreciate all of our blessings every day.

Sincerely,

The Kreul Family