

**AMY & GANNET...A sampler of a memoir in progress, *Please do not copy***  
**Art & Words: Amy Hosa © Amy Hosa 2017 • Contact: [amyhosa@gmail.com](mailto:amyhosa@gmail.com)**



## Introduction

Long ago I came to terms with the birth of my son. I'd been hijacked into the Twilight Zone, and accepted the challenge of raising an alien from another planet. That Gannet was "an extra-ordinary visitor I'd taken into custody by choice" was a fictional construct, but that concept kept me sane during the wildly emotional and trying times while figuring out how to parent a child like no other. I'd gotten stuck with "the puzzle baby", caught between a knife piercing my heart

and a whirlwind of confusion in my brain. The fiction of "external choice" between mother and son gave me the opportunity to step outside, process the data, and strategize a plan. Whether or not you've lived with a parent, child, or sibling from another planet, my hope is that parts of our story might mirror a path you've been on at one time or another.

This collection of art and words offers insights about a mother's journey through life with her son. The illustrations portray my perception of Gannet's character, ability and disability. The writing offers insights into how we learned to cope with each other, learned to deal with challenges and jumped hurdles, and how we succeeded or failed. We didn't skimp on love and laughter, and despite hissy fits galore, survived 'til yet another morning to tell this tale.

**Welcome to "Gannet's World."**



## What Is a Gannet?

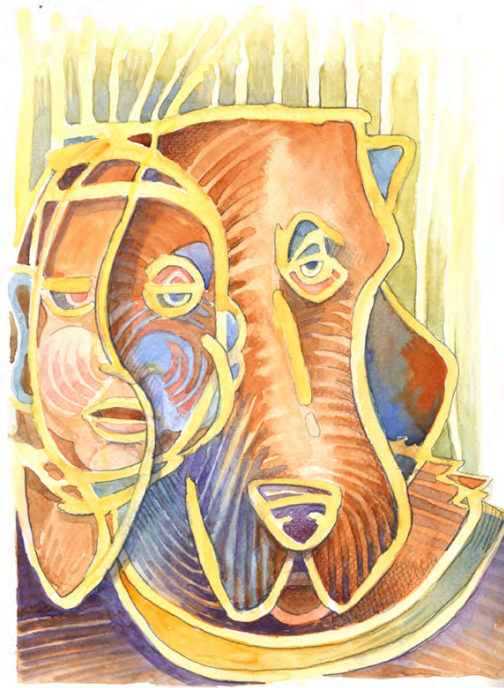
The Gannet is a beautiful white albatross-like sea bird. We liked the brisk sound of its two-syllable name, and gave it to our son. Gannet's are gregarious by nature, and congregate in noisy colonies atop rugged cliffs. Awkward at liftoff, they jump off the edge to take flight. Once airborne, graceful soaring and diving swoops make them excellent fishers with voracious appetites. As life unfolded for our boy, the bird's traits became more and more synonymous with his own. One night at dinner a Scottish friend blurted, "My God, he eats like a Gannet!" and instantly got whacked by his wife. Translation: he eats like a pig. Spastic arm movements were described as, "You know, it's like he's flapping his wings, but he can't get off the ground." But, oh, could he ever fly - just play Stravinsky or Thelonious Monk. The spasticity melted into swooping and soaring gestures. Like a Gannet circling in a thermal, he glided on currents of sound, and was drawn into a higher realm. Back on solid ground, it took eight years of patiently manipulating

and strengthening his muscles, before his first halting steps were achieved. Even today he stands then stops, as if at the edge of a precipice, and requires a light push off the edge before taking flight.

For the first twenty-four years the source of Gannet's disabilities and anomalies was a mystery. It was a comfort to find shared familial traits, even if they were ascribed to a species of bird. I keep a postcard of a North Sea Gannet rookery high atop wave-battered cliffs, and picture my son today at home amidst the cacophony of his flock. Despite the fact that we now know he's part of a genetic syndrome, Gannet continues to honor his namesake with the voracious appetite. With a birdlike frame, and weighing only 106 pounds, he still inhales food and eats like there is no tomorrow.

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## FIRST SON

*Gannet's first day...*

Woody, the burly Chesapeake Retriever, was stretched-out asleep on the floor. He thumped his tail to welcome us home, "Good to see you, all is good." When I leaned over to show him the bundle, he startled. When the new pup was propped up against his belly for the family "I'm home" portrait, he froze. Woody's plaintive gaze followed me as I stood to snap the picture. The furry one was demanding an explanation with his irresistible eyes. "Yes, puppy dog, you're still #1. But, one day this little guy is going to grow bigger than you, walk all over you, and even talk...something you'll never do." I stooped down to scratch the dog's head, to soften the blow, "And someday, he's going to eclipse the best of your licks and tricks, and

you'll have to settle for second fiddle." Immediately I felt guilty, what a cruel thing to say. But honestly, isn't that how life was going to pan out?

True to my prophecy, the babe grew into a boy, eventually walked when he was 8, and now sputters words and ideas through augmented communication systems. Not quite exactly how this starry-eyed new mother thought life would unfurl, but she did allow the boy to worm his way into her heart. However, the part about demoting Woody to second fiddle was plumb wrong. My boy didn't like to make eye contact. Between strangers and loved ones alike, we all know that eye contact is the most important gesture that sparks a connection and invites one in for intimacy. Gannet never stood a chance against the dog's eyes boring straight into mine with a look of anticipation and unconditional love. Woody kept his #1 first-son status for the rest of his days.

I have a line of photos on my desk: boy, dog, family. A wet and wild Woody looks out from a dusty picture frame. He's standing in the crashing ocean surf ready for action, intently searching my eyes for what comes next – a stick? a ball? a run down the beach? The sound of the ocean roar and smell of damp fur swirls in the air. I feel the dog's eyes locked onto mine. That tug of unconditional love – that goes both ways – still plays on the strings of my heart.

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## First Vision Test

### *Gannet at 6 months*

In the darkened room a mechanical toy monkey clanged cymbals on command, while a series of light bulbs flashed on and off. Dr. Hsu's white lab coat created a strobe effect as she wove in and out of the beam. The pin-point light and magnifying glass attached to her forehead formed a third eye befitting a Cyclops. Repeatedly, she circled the room like a predator to observe, then swooped in to peer into one of Gannet's eyes, if only for a second, before he jerked away. Today was Gannet's first vision test. He was six months old and still not making eye contact. If only the doctor could see beyond the optic nerve into his brain.

Dr. Hsu presented her prognosis: abnormal reactions, not tracking, pale optic nerve. That was a bombshell, but not a detonation, as there were more sophisticated tests scheduled in the future. In the meantime a caseworker for The Blind Babies Variety Club would be contacting us. Who, what? I didn't know whether to laugh or cry.

When you leave the house in the morning, drive down the freeway and get to your destination, you expect that the road back will look pretty much the same. I looked at my baby boy strapped into his car seat, turned the key to head home but had no idea where this fork in the road was going to take us. Speeding down the freeway, I kept glancing from Gannet's eyes to what should be "his view" out the window, thinking that every color and object in the landscape, those rooster-tails of fog billowing over the hills, might never be his. Gannet seemed unruffled by any of this. He was content to stare off into the bright blue sky as if it was the most wonderful display in the universe. Perhaps it was? The possibility of a blind baby – one who was at risk for other issues - was sinking in. The view of the road ahead clouded over, and a shower of tears began to fall.

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## Creature from the Black Lagoon

*Gannet at age 22...*

He has a cerebral palsy shuffle, slightly spastic arm and head movements, a slack mouth that drools, and a wandering eye that never quite focuses. With all that and more - there is no guessing why this skinny man turns heads, and elicits finger-points and stares as he walks down the street. If that isn't bad enough, now he is going to look like The Creature from the Black Lagoon, wearing a bright-blue padded helmet, tinted-swim goggles with holes punched for ventilation, and blue full-length arm splints with thick Velcro straps so his hands can't touch his face. Staff explain, "You just had cataract surgery. We need to keep your eyes safe." Gannet understands, but that doesn't stop him from growling 24/7. Wearing this gear is meant to thwart his compulsion for slapping his face and cracking his head against walls like a demolition ball on speed. The loss of all that intense pain is like going cold turkey for a junkie experiencing withdrawal. If getting his eyesight back is worth the suffering and humiliation, Gannet certainly isn't letting on.

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