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pay thousands of dollars to get on a charter boat to Guadalupe Island in Mexico to dive with Great White sharks.

So, tapping into such a self-selected group of divers avoids the problem of citizen science motivation here. We didn't need to motivate them—they were already self-motivated. The other key was: we made it clear that they were not diving 'for' Ocean Sanctuaries—which might create legal liabilities—but, diving for themselves and simply submitting the data to us from their dives, after the fact.

It seems to have been a successful strategy: we now have had over 80 underwater videos and 200+ photographs of Sevengill sharks encounters submitted to us from San Diego and Cape Town divers. The data will be processed and analyzed through Wildbook to determine which animals are returning from year to year to each location and we hope to publish the results soon.

So, in summary: it is possible to motivate people to dive with dangerous ocean predators as long as they are doing it for the thrill or enjoyment they derive from it and would have done it anyway on their own, regardless of whether they are contributing to a shark citizen science project.

Of course, the other key we always emphasize to everyone is personal safety. We caution anyone submitting data about sharks that they must never put their personal safety in danger to collect data for any project. Of course, the other advantage we have here is that most of the divers in this self-selected group of shark divers have prior experience diving around sharks and know when it's time to take a photograph and when it's time to get out of the water.

On Parenting From the Place Where Science, Medicine, and Love Collide

Hillary Savoie

When I decided to become a parent, I figured that I would become an expert in my child in the way of many mothers.

I imagined that, in her infancy, I would intuitively learn to read my daughter's expressions, predict her needs, and comfort her pains. I expected that this would bind us together, in the kind of ways I am bound to my own mother. At the time, I was in the last years of a doctorate in Communication and Rhetoric, and I imagined my daughter would grow up watching me advance my career, seeing me as an example she might follow for becoming independent and chasing her passions.

However, I did not think I'd find myself stepping away from my career and focusing entirely on my daughter's life, using what I learned in my doctoral research in an attempt to make the world a friendlier place for her. I did not imagine that seven years into her life, I'd still rely on my intuition in order to communicate with her. I never imagined I'd be raising a child who might never grow up and move out into the world independently. I did not expect how much I would have to turn my attention to the world of science in order to become an expert in my child.

However, this is what my daughter, Esmé, has required of me: combining my communication skills, mother's intuition, and acquired scientific understanding as a way of loving her.

Why Advocacy

Esmé's story is not one that can be told quickly or without the little details. It is in the twists and turns of her life, experiences, and diagnoses that important parts of who she is become clear—she is a child who is full of contradictions and mysteries. She is a child with a diagnosis and prognosis that remains uncertain and, seemingly, ever-changing in a way that has left me feeling like I am carrying out a long-term scientific experiment with my own child. Esmé was born full-term in January 2011. During my pregnancy, I was monitored closely due to a risk of growth restriction from a two-vessel umbilical cord. However, it was an otherwise unremarkable pregnancy. As far as I was concerned, I was expecting a healthy—if somewhat small—baby. Immediately after my daughter's birth, it was clear that she was struggling. At just over 6 pounds,

she was bigger than I'd expected, but her body was floppy and her skin color was dusky. She was immediately placed in an isolated nursery under an oxygen hood, and we were told that she'd need to be transferred to a Neonatal Intensive Care Unit (NICU) in another hospital.

After she was transferred to the NICU the differences in Esmé were listed for us: hydronephrosis, high arched palate, bicuspid aortic valve, poor suck and swallow, hypotonia, facial dysmorphism. We were told, repeatedly, that Esmé likely had some kind of genetic syndrome that caused all of these differences. Once we were able to bring her home the secondary diagnoses kept adding up: severe reflux, failure to thrive, and, eventually, repeat aspiration—all of which led to severe pneumonia and cardiac arrest at 3 months old. Esmé was resuscitated with three rounds of chest compressions in the Emergency Department and, during her subsequent stay in the Pediatric ICU, she had surgery to place an abdominal feeding tube.

In the weeks leading up to her cardiac arrest, I had known that something was wrong. I felt increasingly anxious and called her doctor daily about her low-grade fever, clamminess, vomiting, and the purring sound she made as she breathed. The morning of her cardiac arrest I'd been on the phone with the office several times. I was told that her fever was not significant and that she probably had a small virus. I spent so much time worrying that I was overreacting that I postponed taking her to the hospital—coming precariously close to losing her. So, I understood clearly what was at stake: Esmé's life would require me to educate myself medically and advocate fiercely. I realized that I could not rely exclusively on the medical professionals around us. I would need to become a specialist of a kind—an Esmé expert.

Although we hoped that the feeding tube would solve many of her challenges, at 9 months old Esmé began having seizures and a new chapter in her battle opened. Approximately once a week, Esmé would experience a series of events: she would become cyanotic, altered or unresponsive, and shake. I did research online, among other things, watching hours of videos on YouTube of children

having seizures, finally coming to the conclusion that Esmé's events were likely seizures. I'd recorded Esmé's events, but her then neurologist disagreed that these were seizures—going so far as to tell me to stop being “hysterical” after I continued asking questions when Esmé's first 30-minute EEG showed no signs of seizure activity. I was not going to miss another major health crisis because I was embarrassed into ignoring my intuition. We began bringing Esmé to specialists out of state at a major children's hospital. The doctors there agreed that these events were suspicious for seizure. A year after her first seizure, we finally caught several on EEG. And we understood why the seizures proved to be difficult to diagnose on EEG: they were originating from very deep in her brain. Confirming the seizures was difficult; however, the seizures were even harder to treat. After having terrible reactions to four anti-convulsants, we gained reasonable seizure control when Esmé was around 3 years old.

The Cute Syndrome Foundation

After years of genetic testing, we now know there to be four small mutations in Esmé's genes PCDH19, SCN8A, TBL1XR1, and MAP3K7. The disorders associated with these mutations are, each one of them, rarer than the next—with diagnosed populations as small as 6. Coming to know this information about Esmé's genetics was not an easy journey. While we began the process of genetic testing soon after Esmé's cardiac arrest in May of 2011, it was not until December of 2012 that we discovered the first mutation in PCDH19. The discovery of the SCN8A mutation came two years later. Both mutations were considered “of unknown significance,” and it was presumed that some other mutation must also be at work. The discovery of the two more recent mutations came in late 2015.

Early in the journey of trying to understand Esmé medically and genetically, I began to understand that I would have to learn the language of medicine, of science, of genetics, in order to find the kinds of answers I wanted. I often joke that my doctorate was great preparation for my daughter's skill at non-verbal persuasion. But, truly, it gave me insight

into how to try to grasp the codes that medical and scientific professionals communicate in. And I was determined to do so. At night I'd rock Esmé, often an hours-long process, while reading genetics texts or taking free online medicinal chemistry courses on my phone.

While Esmé was my muse in this work, for me it just never made sense to do this work for Esmé's benefit alone. I began blogging about our experiences early on, trying to capture a sense of what our life was like—what it meant to parent a fragile child. Then in 2013, a few months after Esmé's PCDH19 mutation was discovered, I founded The Cute Syndrome Foundation—an organization that has now funded scientific research into two of Esmé's four mutations: PCDH19 and SCN8A. In this role, I have found myself applying my doctorate in Communication and Rhetoric to decode the science of things like complex sex-linked inheritance patterns, the electrophysiology of gain-of-function SCN8A mutations, and the use of zebrafish genetic models for pharmacological testing. I'd attend scientific conferences, listening to things that went over my head, grasping what I could and forming connections with professionals who could help fill in the blanks later.

As I embarked on this work, it never occurred to me that my work with the foundation would never actually benefit Esmé. However, as Esmé's genetic diagnoses shifted over time, it became clear that this may be the case. The two mutations I have focused the foundation resources on are likely playing the smallest role, if any, in her disorders. This has meant that my role in the foundation has shifted as the SCN8A community has embraced the foundation as its own, and leadership from within has emerged.

Four Little Mutations

Esmé's mutations were so difficult to find because all four are very small, or point, mutations in obscure genes, three of which were only discovered within Esmé's lifetime. The early genetic testing we underwent was not looking for mutations in those genes. In fact, the last two mutations were found by two genetic researchers I'd connected

with through the Cute Syndrome Foundation who offered to sort through Esmé's DNA sequencing to see what they might find. It is not entirely clear what role each of these mutations—or the interactions between them—plays in contributing to Esmé's symptoms—and the professionals we've contacted in genetic testing, clinical neurology, and genetic research are of different minds about the role of each mutation. My daughter is, genetically-speaking, a mystery; she is the only documented individual with any combination of these genetic mutations. As a result, trying to understand how best to care for, communicate with, and advocate for her has required journeying to the ever-expanding edge of what we know about human genetics.

Living in the obscurity of the lack of diagnosis can make a person eager for the occasional short answer to the surprisingly frequently posed question: "What does she have?" (or its less-savory cousin "What's wrong with her?") In fact, this is where the name "The Cute Syndrome" came from. Coined by a dear friend of mine soon after Esmé's birth, we used to tell people who asked, "She doesn't have a diagnosis, but we say she has the cute syndrome because she's so darn cute!" There was something about this answer that both acknowledged that there was, indeed, something different about her, but also denied it as being her most defining characteristic, in favor of embracing her cuteness (which is epic).

Esmé's lack of a diagnosis has also meant a lack of prognosis. It has meant that nothing has ever felt entirely impossible with Esmé. As a result, while I am certainly clear-eyed about the realities of the dangers of living with epilepsy, severe low tone, and developmental delay, we have always approached Esmé's abilities with an open mind and presumed competence. It was experimentation that led to the discovery that by using flash cards, Esmé could identify colors and objects at age 2, letters and numbers at age 3, words at age 4, and sentences at age 5. She is now seven—she can sit up, crawl, pull to stand. She cannot stand independently or walk. Her words are not decipherable—but she is clearly trying—and she can communicate in limited ways using head nods, flash cards, and an iPad. She

clearly has cognitive differences and is not always available for communication. Esmé has no safety awareness and she cannot be left alone at all. However, she is doing things that seem improbable, if not impossible, given her history and presentation.

This journey with Esmé has led me to believe that there is more to be learned from her genetics than a simple diagnosis—they are teaching us a lesson about the meaning of what we can ever really understand about our genes. It is her determination that taught me to become comfortable living in the shaky ground built on the mysteries of diagnoses of small mutations in newly discovered genes. If she could, time and time again, do the impossible, it seems like a small feat for me to find ways to make our home in the territory of where science, medicine, and love collide.

Empowering Citizens at the Poles

Lauren Farmer

I'm lucky enough to be employed as a polar guide, spending a majority of my year in both the Arctic and Antarctic on small expedition vessels. Recently, this "dream job" has become even more rewarding with my involvement in developing and implementing citizen science programs on board these ships, which range across the most fragile ecosystems on earth.

It has long been recognized that from a data-collection point of view, polar regions are under-sampled. Polar tour vessels have the potential to address this relative lack of access and so historically, polar tour companies would provide berth space to researchers to carry out their own work. While this was certainly valuable, it was limited in scale of impact, and rarely engaged the guests on board with an opportunity to assist. Over the years, various efforts were made to create more participatory data collection programs, but these often failed to gain much momentum due to a

number of unique challenges our industry faces. Some of these challenges are a constant rotation of expedition staff coming and going from the vessel, leading to a lack of consistency in how the program is run, or whether it is run at all. Additionally, pre-existing cruise itineraries can be limited in the time available for additional activities such as citizen science, as well as a difficulty in being relied upon for projects that require location-specific data collection, as our whereabouts are often dictated entirely by weather and ice. In addition, companies would start their own in-house projects, meaning that projects would rarely if ever be implemented on more than one vessel. This meant that these projects could never take advantage of the biggest asset of citizen science on polar expedition cruise vessels; the size of the fleet. While there was potentially a challenge in asking competing commercial enterprises to collaborate on science projects, the reach of such a large and extremely experienced fleet of ice vessels makes the potential of the collective effort uniquely powerful.

In early 2017, myself and 4 other guides (Alex Cowan, Annette Bombosch, Bob Gilmore and Ted Cheeseman) began to seriously think about how polar expedition vessels could have a real impact. We, the collective fleet of tour vessels, spend five months a year in Antarctica and another five in the Arctic—regions that are logistically difficult and expensive for research vessels to access in the way that we do. Additionally, many of our expedition staff are trained natural scientists with research backgrounds. The natural progression of our conversation was a more coordinated effort leading to the development of science programs that would provide real value and trusted data to researchers while providing an enhanced travel experience for our guests.

The Polar Citizen Science Collective got to work and was officially launched in early 2018. This non-profit is an effort to grow citizen science programs in the polar tourism industry and to create efficiency around the development, implementation and data delivery of these programs. Rather than each operator "re-inventing the wheel" and setting