Down Syndrome News

NEWSLETTER OF THE

NATIONAL DOWN SYNDROME CONGRESS

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In this issue

Annie Forts

"I hope to have as many friends as all the stars in the sky. I think I am getting very close."

At the age of seven, Annie Forts began using a crayon to cross out the word "Down" on the National Down Syndrome Congress Newsletter, and replace it with the word "Up". This was the beginning of a long and happy relationship with our organization — and we didn't even know it yet!

Her story began when she was born in March of 1967, the baby of four children belonging to Bernie and Shirley Forts. Their daughter's diagnosis was given by a doctor who recommended she be institutionalized immediately, before they could become attached to this child who would never amount to much and would only be a hindrance to raising their other children.

To the betterment of everyone (including those of us who never even met Ann Forts), the family dismissed this doctor's advice and took Annie home, where she was loved and included and absolutely thrived.

In 1988, Annie became an "Associate Director" on the NDSC Board of Directors, a title then given to self-advocate representatives. She became a sought after public speaker and would go on to create the Annie Forts UP Syndrome Fund, a non-profit dedicated to:

1. *The education and assistance of individuals with Down syndrome so that those individuals may realize their full potential to live independently and to contribute to their communities and to society at large.*
2. *The encouragement of a better understanding of Down syndrome and support of the study of the treatment and rehabilitation of individuals with disabilities.*

Beneficiaries of the UPFund included self-advocates who received funding to attend the NDSC Convention and other enrichment programs. The fund also provided tuition assistance for students studying to become special education teachers — she was a true pioneer in this philanthropic field!

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Letter from the President

Summer is here and that means our "Giant Family Reunion" is just a few weeks away! I can hardly wait to see so many of you once again, as well as meet new families and self-advocates in Orlando. We are busy getting ready for what is slated to be our biggest convention yet!

If you haven't registered, there is still time. Take a look at the outstanding line up of workshop presenters and plenaries and come and meet the self-advocates from the hit A&E Television series, "Born This Way"! It will be a wonderful weekend full of hopes, dreams and realizations of everything people with Down syndrome can do!

Your Board of Directors has been hard at work this year, collaborating with other national and international partners to ensure we are moving the Down syndrome movement forward.

We have increased our presence in Washington, D.C. — focusing on employment and education initiatives. We have continued to improve the Adult Sibling Toolkit, and increased our outreach to African American and Spanish-speaking families.

Our ambitious Strategic Plan that we developed in the fall offers new opportunities for learning and growth and we can't wait to announce some of these new opportunities at the Convention! We are so excited about the future and are honored and humbled to serve as your national organization focused on families and making the world a better place for individuals with Down syndrome.

As we busily prepare the last minute details for Orlando to ensure it competes with "the happiest place on earth," I hope the beginning of your summer is filled with sunshine, warmth and love. I hope to see you there (come and say hello to me!), but if you are unable to attend, stay in touch via our website, Facebook and Twitter pages.

We appreciate you and your continued support of the NDSC!

See you real soon,

Marilyn Tolbert

Marilyn

Down Syndrome News

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Mission
The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome.

Vision
The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.

Annie Forts

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In 1993, Annie was elected to serve a three-year term as a full board member of the National Down Syndrome Congress. She became the co-editor of the newly created "D.S. Headline News," whose masthead famously proclaimed, *"A publication of the Citizen's Committee of the National Down Syndrome Congress to promote success stories about people with Up syndrome written by people with Up syndrome."*

In her very first article for D.S. Headline News, Annie wrote, "I think that it is very important for everybody to be "Up" people if they would like to be happy and have lots of friends. I don't think people want to be friendly with other people who are not happy."

In 1994, Annie was appointed by President Clinton to serve on the President's Committee on Mental Retardation, just the second self-advocate ever appointed to the committee. She would go on to serve for seven years, proudly representing her fellow self-advocates. She said her goal was to "get as many people in Washington, DC, and around the country, to listen to what we have to say. Then, maybe they will realize that there are lots of young people just like you and me, who they should listen to BEFORE they make any decisions that concern us".

Her skills as in inspirational speaker motivated and challenged researchers, educators, parents, professionals and other self-advocates to work together to improve the lives of ALL people, including those with Down syndrome.

When Annie passed away in May 2016, we were contacted by so many people who knew and loved her. We know her legacy is long and long-lasting. Annie wrote, "You must make things happen — don't wait around for someone else to make things happen for you. While you are waiting, you will be missing out of some great things that you could have made happen for yourself." That is exactly how Annie lived.

Editor's Note:

In this issue, we are happy to share three very different stories written by fathers of children with Down syndrome. First, Kevin Alviti, President of the Down Syndrome Society of Rhode Island, spoke passionately about his young daughter Natalia, in a speech to the diocese of Providence, RI, and you'll find that in written form here.

Steve Logue is writing an entire book about his experiences raising his son, Casey, and we've excerpted a part of it in the second article, The House of Wong. His engaging style will put you right in the room with him and his wife as they process the news of their son's diagnosis.

And last, we have reprinted a very moving recollection from the past — an article from 1985, when NDSC Board Member Tom Elkins shared his thoughts about human potential, including this: "In a highly competitive society, we tend to emphasize the grade point, the physical fitness test, and the ability to be attractive. Our children with Down syndrome teach us that personhood is a much more meaningful quality that is only minimally tied to human expectations of performance."

What these three stories have in common of course, is a father's love of his child. But more than that, it is a commitment to help the wider world understand that the value of people with Down syndrome is intrinsic, and that like all people, those with Down syndrome are deserving of respect and the same opportunities given to all people.

Happy belated Father's Day to all of the Dads out there.

A Father's Speech to the Diocese of Providence

Kevin Alviti, President, Down Syndrome Society of Rhode Island

"This child will be a burden to you and your family. This child will never walk, will never talk, and will never tell you she loves you. She may be bedridden for the rest of her life. You may have to institutionalize her. You have older children, think about them, and think about the burden that will be left behind for them when you are no longer here. I know you are religious people, but put your religion aside, think with your head and not with your heart."

This is what a genetic specialist told my wife and me after finding out the news that our third daughter would be born with Down syndrome. You would think the story that I just told you happened long ago, another generation even; but it actually happened less than three years ago.

There are many medical issues associated with Down syndrome: cardiac issues; GI issues; compromised immune systems; low muscle tone; diabetes; and an increased chance of childhood leukemia. But something you can't find in any medical journal, no matter how hard you look, is what a child with Down syndrome brings to your family.

I didn't always feel this way. I remember getting back in the car after talking to the genetic specialist and my wife said to me, "You are awfully quiet; what's going on?" I told her, "I don't think I can do this; I don't think I can raise a daughter with all these disabilities." I also told her that I wanted to learn everything I could about Down syndrome. And so began a two month internal battle I had with myself. I can remember driving to work in the mornings thinking, "How could I convince my wife to have an abortion?" And driving home at the end of the day wondering what Natalia would be like.

We reached out to Dr. Tracy at the CNDC at Rhode Island Hospital and Claudia Lowe at the Down Syndrome Society of Rhode Island — who lives three streets over from us! I joined social media groups, read books, did research on the Internet. I joined a dad's group on Facebook, where I met a local dad who invited my family to meet his wife and their two year old son, who is living with Down syndrome.

The greatest gift that my wife ever gave me was not a flat screen television or that autographed picture of Rob Gronkowski. The greatest gift that my wife ever gave

me was the ability to process this news on my own, at my own pace. Not once during this process did my wife say to me, "I am going to have this baby with or without you." Not once during this process did my wife say, "How can you ask me to abort our baby?" (Not that I ever did, but she knew what I was implying when I would say, "I don't know if I can do this.") Instead, we would go to every appointment together; she would hold my hand and she would let me ask the most ridiculous questions. Sometimes we'd get back into the car and she would say, "I can't believe you asked that lady that question!" I would reply, "Well, they said I could ask anything."

Months after I came around, I remember I was beating myself up by allowing that doctor to get into my head the way he did. My wife said, "You have to stop doing that! I always knew you were going to come around." How did she know that when I didn't know that? She said, "Every single night you would kiss my belly and tell Natalia that you loved her. I just knew that your mind had to catch up to your heart." Thank you for that, Marianna.

I joined the DSSRI in January of 2014, before Natalia was born. My goal has always been to never let another parent feel the way I felt. I am happy to announce that on April 4, 2016 we met with social workers from Women & Infants Hospital. We couldn't have asked for a more positive outcome from that meeting! Going forward, when a diagnosis is made, either when a baby is born or

if a prenatal diagnosis is given, DSSRI's New Parent or Prenatal Packet will be given to the families along with our contact information.

When Natalia was born, we had our challenges. When she was two days old, they took Natalia for an echocardiogram and performed a routine blood test. When the cardiologist returned he told us that he had some good news and bad news. The good news, Natalia did not have a heart defect. The bad news, he did not like the way her lungs didn't completely inflate. He told us that they would be putting Natalia on oxygen therapy, and unfortunately the only place they could do that was in the NICU.

When we arrived at the NICU, her doctor told us about the treatment and what they would be doing; then her demeanor changed. She told us the more concerning thing was Natalia's white blood count was 76,000 with 47% of them blasts, also known as cancer cells. The average person's white blood count is between 6,000 and 16,000. She said they had a pathologist standing by to look at Natalia's blood under a microscope. A few hours later the pathologist's report came back and they told us that Natalia had AML, Acute Myeloid Leukemia. They told us that the prognosis would be six months of chemotherapy in the hospital and Natalia would not be allowed to leave.

That night I prayed to God like I never prayed before in all my life. I told him that I gave up, that I surrender, that I no longer assumed responsibility. This was all in his hands, it's all on him. I raised the white flag! Well, I got the best night's sleep ever in the hospital, and the next morning we woke up and went downstairs before rounds. The room felt different. I asked Natalia's nurse what was going on and she told us that Natalia's white count was now 43,000 and 23% of them blasts. I said, "That's great, isn't it?" She said, "You don't understand, her white blood count should not be coming down. We don't have her on any kind of treatment." They had no idea what was causing this to happen. The head of the Hematology Oncology from Hasbro Children's Hospital took over Natalia's case. She told us that she did not believe that Natalia had AML but more testing would have to be done. After a few days, Natalia was transferred to Hasbro where multiple tests were performed on my daughter. A few days later they told us that Natalia was born with TMD — Transient Myeloproliferative Disorder.

TMD is almost exclusively found in children with Down syndrome and they are born with it. It's a type of leukemia and very rare. That extra chromosome? That thing that the genetic specialist called a burden would ultimately save her life! That extra chromosome over time would fix her white blood count and get rid of the blasts — acting like an internal chemotherapy. A few months after Natalia's birth, her white blood count was perfect and all the blasts were gone! I am happy to say that on March 28th we took Natalia for her two year check-up and her white blood count is still perfect!

Natalia was born on March 6, 2014; weighing 6 lbs., 12oz. Natalia rolled over at three months, sat up unassisted at nine months, and said her first word, "Da-da" at nine months. She crawled at 12 months and was walking at 18 months. Natalia uses sign language and can speak words and her receptive language is spot on. She loves Minnie Mouse and her big sisters.

I have two favors to ask all of you:

1. Please remove the R-word from your vocabulary. This was a word I used all the time. I never meant to insult a person or a group of people; it was just a word I used. It is no longer used in our home. If you use the word, I want you to think of Natalia's face. If you don't feel ashamed, sad, or feel like you are making fun of her, then continue to use the word. There isn't anything else I can teach you. If you feel any of these emotions, then please, find a different word.
2. Maybe you have a friend, a friend of a friend, a family member, an acquaintance, or a coworker who tells you they have a child with Down syndrome or they are expecting a baby with Down syndrome. Congratulate them! You will be one of the few that do. Tell them that the journey they are about to embark on is one that they would have never asked for in a million years, but one they will never give up in two million years! Please have them contact the Down Syndrome Society of RI and we will offer them the support they need. We will show this family what having a child with Down syndrome is all about.

Natalia has a Facebook Page where I post photos, videos and share Natalia's journey. If you would like to follow her, it is called Team Natalia Warwick RI. You can also follow the Down Syndrome Society of RI, Inc. on Facebook and Twitter.

And last, I would like to share a favorite quote of mine with you, "Down syndrome is a journey that I never expected, but I sure do love my tour guide."

The House of Wong

This is an excerpt from Steve Logue's upcoming book, ***The Joy of Having a Child with Down Syndrome*** *© 2016*

One night Joanie awoke screaming, barely catching her breath and immediately began explaining, "I was in a swimming pool and there was a raft above my head and I needed to come up for air. But I wasn't able to. I thought I was going to suffocate. It was a boy with Downs on the raft. But he didn't know that I was underneath. He couldn't see me. It wasn't his fault."

She was perspiring profusely, and breathing like she couldn't. I attempted to comfort her, "It's okay, just a dream. You're okay now, go back to sleep."

The doctor had concerns. "We should perform an amniocentesis," he said.

"What's that?" I asked.

"We go into the womb with a needle, draw out amniotic fluid, and test. We'll learn if the baby is healthy or has Downs."

"What are the odds, our baby has Downs?" I asked.

"One in a hundred," he said.

"We don't have that," I thought. Maybe this is a company doc, padding the take of the hospital, adding on unnecessary tests for extra fees.

"Ok, what are the odds, the needle going into the womb injures the baby? Maybe pokes his eye out?"

"One in a hundred," he answered.

Another 1 percent chance, so now we have two 1 percent chances! Where might this end? Is there a test to determine if the test is safe? Is there a Department of Redundancy Department?

I felt the doc was a shill; his profession, a carny show. He'd gone to university, earned A's, went to medical school, endured residency, practiced medicine for decades, and delivered thousands of babies. Or perhaps…the doc was a late bloomer?

Certainly not my first rodeo, I've had two babies, earned a 2.0, got a Bachelor of Arts in Acting. I decided to educate the doctor.

"There's a 1 percent chance the needle will injure the baby. Also, a 1 percent chance the baby has Downs. Doc, by testing, we double the odds of something bad happening. Why?"

The doctor said; "If the baby has Downs, you would be better prepared for his birth."

We were not having one of those. Thus, we elected not to do the test.

When I was growing up in San Francisco, doctors encouraged parents to send mentally disabled children to institutions instead of raising them like actual sons or daughters. It was thought that an institution was a superior place to deal with mental disability because there was nothing that could be done. Where better to do nothing than an institution? Near my school, there was one such institution where society had placed them, like lepers or criminals.

At the age of eleven, walking to school, I actually saw them for the first time. It was as if they were not human. There were five of them, lurching down my side of the street. None of them had a normal gait. One appeared hinged at the elbow, shoulders immobile, and his hand stood fixed in an awkward, standoffish shape at the end of his arm. Their leader, chin grousing from side to side, drooled from his mouth like he was hungry for prey.

They conversed in undecipherable, garbled noise, as if they had marbles in their mouths. It was apparent that not even they knew what was about to happen. They might even kill me. Luckily, they turned down Sharks Alley before our paths crossed. When I arrived at the alley they were half way down and laughing.

Joanie said, "I went to St. Joe's to pray and saw a kid with Downs. Steve, what if our baby has Downs?" Every week for months my wife asked me the same question. The damn doctor put it in her head. I wish he never mentioned Downs. There's only a one percent chance. "Joanie, if the baby has

Downs, we'll just love him like the other two." As it turned out, Down syndrome was not to be our only concern.

"They say he's breech," Joanie said.

"Like father like son. I love the beach, too."

"No Steve, breech. He's backwards, coming out feet first."

"He's going to be a sprinter!"

"The doctor said 90 percent of babies have turned by now. It's a problem. They may have to do a cesarean. I have to go in next Friday for another ultrasound."

Joanie called me the following Friday from her doctor's office.

"The baby's turned," she said.

"That's great, no C-section! Let's go out and celebrate!"

"They just want to keep me here and run some tests. You go out with your friends and have dinner. I'll see you at home."

Every Friday night since moving to St. Louis, I'd had dinner with a group of men. The size of the group varied from 4 to 20. We'd go to The House of Wong for Chinese. Joe, an advertising fellow liked to say, "You can't go wrong at The House of Wong." We had T-shirts made. Over dinner I told everyone, "He turned!" Their joy warmed my heart.

Arriving home that night, I called out Joanie's name, but there was no reply. Odd, nobody was home. The land line rang. (I didn't have a cell phone back then.) I picked it up, "Hello?"

"Where are you?" My wife asked, proving once and for all, that there is such a thing as a stupid question.

"I'm at home," right where you just called me. "Where are you?"

"I'm at the hospital."

"What?"

"The doctor heard something in the ultrasound. I have to stay overnight for more tests. The kids are at Mom and Dad's. Please come down to the hospital and spend the night with me?"

"I'll be right there."

I went to the hospital and spent a sleepless night in a chair next to my wife's bed. At 11:00 AM, the doctor came in, and said that they needed to do an amniocentesis because the baby was having an irregular heart beat. After completing that test, he returned and said it was imperative they perform an emergency cesarean because there was meconium in the amniotic fluid surrounding the baby. In terms that I could understand, the baby had pooped his crib.

The immediate danger was to his lungs. As you might imagine, dung in the lung is funky. Since the fetus inhales amniotic fluid, and our baby's amniotic fluid was discolored, they had to operate immediately.

Awake now for 33 hours, I wanted to be rolled into the operating room, but walked alongside the gurney.

They put up a screen between my wife's chest and tummy, like you might put in a car window to keep the heat off the dash. This screen was to prevent Joanie from seeing her pregnant belly. Standing at the screen, I had a bird's eye view. Joanie asked me, "Did they start yet?" I said, no, but I lied, and watched, as they cut her open, pulled out different organs and set them aside. While blood rolled onto the gurney, they pulled out our baby.

Immediately, the doctor carried him over to the incubator to suck out his lungs. The incubator looked like a chicken warmer. It was open with a bright heat lamp, and all I could see was the baby's forearm. His arm didn't look right. Joanie asked, "Is he ok?"

"I don't know. His arm looks funny."

The doctor cleared the baby's lungs, turned towards my wife and me at the gurney.

"Does he have Down syndrome?" my wife blurted out.

"There are a couple of preliminary signs, but we need a blood test for confirmation. That takes three days."

I walked around the foot of the gurney, crossed over to the incubator, and looked down to where the chicken would be. He's got it. No, he doesn't have it. He's got it. No, he looks fine. I don't know if he has it or not. No, he doesn't have it.

"It's been a long night, and you need your rest," somebody said.

After that, they whisked the baby away to the neo-natal intensive care unit (NICU). I presume they sewed my wife back together again, but have no memory of them doing so. I do remember we returned to our room, the chair, her bed, and no baby.

"Did he look all right to you?" my wife asked.

"I don't know. What did the doctor say?"

"He said they had to do a blood test, and they won't know for three days."

"Yeah, that's right. Well, maybe he doesn't have it." I said.

"Let's go down to the chapel and pray that he doesn't have it. Come on, let's go."

"Don't you want to rest a little?"

"No, this is important. Let's go right now, ok?"

"Ok," I said.

At the chapel we prayed a rosary. Nobody in my family had Down syndrome. No neighbors. I didn't know anyone with Down syndrome. The only interaction that I'd ever had, if you can call it that, was with those men on the sidewalk when I was a frightened little boy. At this particular moment, I was afraid, sick, and overwrought. My future legacy hung in the balance. My namesake's epitaph might simply read 'FAILURE.'

To my knowledge, people with Down syndrome could not

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The House of Wong *continued from page 23*

speak or read and were dangerous, because neither they, nor anyone else, knew what they would do. Hence, my prayer could not have been more fervent. Please Lord, if you can hear me, do not let our child have Down syndrome.

After we prayed, I walked my wife back to her room, and then went to the neo-natal intensive care unit. The room was loaded with babies, and one of them was mine. There were no other parents in the room. A nurse brought me to my baby's incubator. "Can I hold him?" I asked the nurse.

"Absolutely," she replied.

Somehow, a chair appeared and I sat holding my son. "What are you going to name him?" she asked. "I don't know," I answered. I'd now been up for 40 hours. I couldn't remember eating since Friday night at The House of Wong… can't go wrong… Everything seemed wrong. I sat down and the nurse put the baby into my arms.

When I looked down at him, everything seemed okay. His eyes looked into mine and erased all that was wrong with the world. When I was in the Navy and sailing across the Pacific, I came up top and as far as the eye could see in every direction, there was no movement; not a single wave. The Pacific Ocean looked like a pond. The only motion in the water was our ship cutting through the glass. That was the calm that filled my senses when I looked into his eyes. I was overwhelmed with a spirit of love. This baby was special. Sometime after midnight, I walked back into my wife's room and sat in the chair.

"Do you think he has Down syndrome?" she asked.

My gut flipped. "No." All night long my stomach and mind churned.

The nurse waltzed in the next morning, "What are you going to name your baby?"

"We don't have a name," I said.

"It's been a whole day," she said.

"What time is it?" Joan asked.

The nurse looked at her watch, "it's 10:45." Joan, bleary eyed, jumped to attention.

"Today's Pat's birthday! Steve, you have to pick up the cake at Dierbergs. I'll have mom bring Julie and Patrick home. There's 25 kids coming to our house at noon, and everyone's going to The Point to swim. Quick, you have to leave right now!"

I had not slept in 53 hours. Pat's birthday had been planned, but I couldn't remember. I just ran out of her room and wondered where I'd parked my car.

When I got home it was 11:20 AM. Would I have time to go pick up the cake? Everyone was coming at 12:00. I drove to Dierbergs and ran inside to get the cake. It was a chocolate sheet cake that said "Happy Birthday Patrick, You're 6". Back to the car with the cake; I raced home, and instantly started looking for candles. I was just at the store! Why didn't I get candles?

Every birthday party had candles. In the movies there were always candles on cakes. My Aunt's 90th birthday had three candles for what mom called "health, wealth and happiness."

But there just wasn't enough time before people started to arrive. I looked everywhere, but we did not have candles. Not a single, freaking candle. It wasn't important that I hadn't slept in 54 hours, that a nameless baby was in intensive care, or that I'd watched my wife's stomach get cut open. Right then, the most important thing in the world was candles.

I didn't have time to go to the store. What would people think if I wasn't there for my son's birthday party? What would they think if they knew that I had a baby with Down syndrome? He doesn't have that. What would they think if I served a birthday cake without candles? I knew what they'd think, "what a schmuck; what a loser."

Neighbors! Maybe a neighbor had candles!

I ran over to the Lyons', but they weren't home. I sprinted to another neighbor, no answer. Then, I charged to Mike's house. Mike and I have talked before. Mike's married with grown kids. He put siding on his house, all by himself. I knocked on his door. And then, I opened his front door.

Of course, I was out of my mind, and I have no idea what Mike thought when he turned the corner of his hall and saw me panting and gasping as the front door closed.

"Do you have any birthday candles?"

"Huh?"

"Birthday candles? I gotta have birthday candles. It's Pat's birthday, and I don't have any candles." No mention that I had a new son, Down syndrome, or that I hadn't slept in two days.

"I don't think so," he said.

"You have to look." Suddenly, candles were more important than my safety, Mike's right to privacy, breaking and entering, or polite civil discourse. He opened a drawer right where he happened to be standing and looked down.

"No, sorry. No candles."

"Mike, it's really important. It's Patrick's 6th birthday. I got a chocolate sheet cake with 25 kids coming any second. Please, I don't have any candles. I just need 6."

"Well, I might have some dinner table candles."

"I'll take them!" I shouted.

He walked to another room, opened a drawer, and pulled out six, one foot long, red table candles, meant for Thanksgiving dinner. It was August 1st. He'd have time to replace them. I grabbed the candles out of his hand, garbled, "Thanks," ran out of his house and across the street, filled

with stress, fear, and a profound sense of accomplishment.

Everyone arrived. I stabbed six candles into the cake. They looked like tiki torches. Pat blew out the candles without complaint. Three parents accompanied all 25 kids and me to The Point. They swam. We came home. I don't remember sleeping, eating, or waking.

The next day at the hospital, Joanie's parents, sister and brother were there. Everyone was assigned to pray that the baby not have Down syndrome. The nurse came into our room: "You will want to roll small blankets under his shoulders because of the weak muscle tone common in Down syndrome. They tend to have shoulders that slope. The towels will help develop good posture. What are you going to name him? It's been two days…"

The blood test was not back and wouldn't be until Wednesday. I resented this biddy who talked about my son having Down syndrome. It sent a lightning rod up my spine, but I didn't say anything until she left. Joanie felt it, too.

There was no name for our baby. Knowing that it was going to be a boy, I had wanted to name him Dan after my brother, but I couldn't. What would I say? Dan, he's retarded and you were the first person I thought of?

On the third day, I was sitting in the NICU. Holding our baby was peaceful. They had a rocking chair in there, and so I held him and rocked. Holding him was best. Everything slipped from my mind as he slept in my arms. Time passed slowly. I noticed our doctor's name written on the incubator, Doctor Casey.

Long before, when I was in college, a friend of mine and I used to go down to Fisherman's Wharf. We dressed with big ties, red noses, and large suspendered pants. We fancied ourselves as "Hit Clowns for Hire," and would perform Shakespeare, Stage Fight, and otherwise make spectacles of ourselves. A number of Japanese tourists took pictures. We earned beer money (our goal) and had a good time talking about our photos being displayed on Japanese coffee tables and walls because that's where all the vacation highlights belong. We called ourselves Casey and Bimbo. I was Casey.

"Joanie, what do you think of the name, Casey?"

"I love it."

"I was Casey the Clown in college."

"I forgot about that."

"And what about my middle name, Joseph, for him? It would be like naming him after myself, my clown self."

"I love it."

Later that afternoon, a doctor came into the room and gave us the details of the blood test. I don't recall what he said. Casey had Down syndrome.

The news was an earthquake of sorts, you know they will come, but knowledge is the booby prize of the universe and

does nothing to dull the shock of the shaken. I felt like the fratricidal Cain, doomed to walk the earth with a mark on my forehead.

The following Friday night, I met the guys at The House of Wong. I didn't want to say my son had...In one week it became like a dark secret. There was a large group at dinner, maybe 20. It had to come out, and I cried as the words left my mouth …Down syndrome. Tears rolled down my cheeks, as if I'd lost a son. These guys all spoke up. "Steve," said Frank, "You have just received the Cadillac of disabilities."

Don said, "You know, Steve, I was at a funeral for a girl who had Downs. The parlor was packed. There was a plaque on the wall stating room capacity was 100 people, but there had to be five hundred jammed tight. People got up and told stories about this girl. Well, young woman really, she was 24. Everyone had a wonderful story about this woman's life. I wish that you could have been there."

Then John spoke up, "Steve, right now you guys are in shock, and that's understandable. All of us want a son that will have records stenciled on the school gymnasium. Casey won't give you that kind of satisfaction. But, and you don't realize what I'm about to tell you now, but you will. You and your family have just received a tremendous gift from God. Those kids are a tremendous blessing. When I was a little boy, I had dyslexia, but in those days nobody knew dyslexia, so kids would tease me and make fun of me because I couldn't read. So, I'd hit 'em in the mouth. That didn't go over well. They ended up putting me on the short bus with all the other slow kids. And those kids were great. They didn't care if I couldn't read. They couldn't have cared less. Those kids are beautiful. I still see them today."

That night, I felt almost human, leaving the House of Wong.

*Steve has also written a children's book, **The Boy Beneath the Moon** © 2015.*

SELF-ADVOCATE CORNER

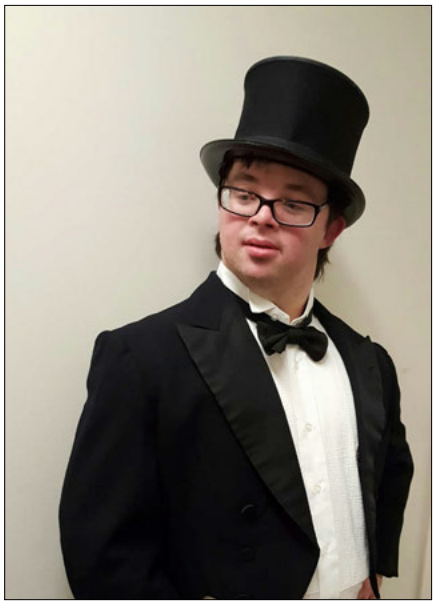

PHOTO CREDIT: JACKIE SAUTER

Steven Sauter

Interviewed by John Berbrich for the SLC Arts Quarterly. This interview is reprinted from their Summer 2016 issue.

Steven and his parents are long-time members of the NDSC, and Steven looks forward to attending the Youth and Adults Conference at our convention every year. Just this month, he received the St. Lawrence NYSARC 2016 Community Spirit Award, as well as citations from his New York State Senator and Assemblywoman. This was a huge honor for Steven, celebrating his work as an advocate for others with disabilities and his leadership role in the community.

FEATURED ARTIST

John Berbrich: So Steven, how long have you worked for the St. Lawrence County Arts Council?

Steven Sauter: I have worked for the SLC Arts Council for nine years. I started my interest in the workforce in my Canton High School class called S.A.I.L. (Students Actively Involved in Learning). I looked for jobs at many different Canton businesses. And in October 2010 I got my first Employee of the Month for my dedication and loyalty and commitment to SLC Arts.

JB: What's your favorite job at SLC Arts?

SS: I love to do mailings because I see my friends on the address labels and fold the letters and also do the renewal mailings and fold the new newsletters in thirds and tape it and do other mailings.

JB: Being at SLC Arts so often you must see a lot of different kinds of art—painting, sculpture, fabric-making. What are some of your favorites?

SS: At St. Lawrence NYSARC's Community Center, with Susan Freego and Abby Powers, I help to make paintings, fabric, sculpture, drawings, sketches, landscapes, horizons, any kind of scenery, costume design, modeling, and self-portraits.

JB: What sorts of art are you personally interested in making?

SS: Paintings of different scenes, landscapes of sunrises, sunsets, evenings and other topics of landscapes. Making jewelry of many shapes and sizes.

JB: When making jewelry, what do you use for material?

SS: I help make shapes in clay and mold clay in the shape of bracelets, necklaces, and rings.

JB: Steven, I saw your picture in the newspaper a month or two ago. What was that all about?

SS: Actually, John, I was in two newspapers. The first story was called "Pursuing A Passion for History," about my volunteering at the Canton, NY, Town Hall in the office of Town Historian Linda Casserly. The second one was about the local production of *Spirit Whispers on the Grasse,* a local play that is based on research that I have been helping with on the St. Lawrence County Home and the cemetery that was, and still is, there even though the building is gone.

JB: What part did you play in *Spirit Whispers on the Grasse?*

SS: I was the Modern Day Historian and I was the St. Lawrence County Home Funeral Director.

JB: So you played both parts in the play?

SS: Yes I did. The Director Elaine Kuracina created both characters for me to portray.

JB: Did you find that playing two parts was a challenge?

SS: Yes, John, it was a definite challenge for me. It was hard memorizing lines and my hands began to shake while I was saying my lines in my second character as the Funeral Director, but I overcame my fears and my shyness and being nervous in front of a huge crowd from the community. I learned the skills in the St. Lawrence NYSARC theater program. We had a wonderful show; the cast and crew did an amazing job together. I'm very happy I got to be in a majestic production.

JB: Ah, it's an excellent thing to overcome one's fears. What was the other article about, the one where you volunteered for Linda Casserly?

SS: That story with Linda is all about my greatest passion in my life. I really love History — I really do — and so Linda asked me if I wanted to help her. The article talked about my dedication and my disability and the research on the St. Lawrence County Home and how I love doing online research on history.

JB: What particular topics or time periods in history attract you the most?

SS: The age of the places that have been standing through many years and have historical records of longtime residents or a family that is well known in society. They sometimes start a town or a city that bears their name.

In addition to his part-time work with SLC Arts and his volunteer efforts with the Canton historian's office, Steven Sauter participates in St. Lawrence NYSARC's art, dance, and theater programs for young adults with intellectual and developmental disabilities in Canton and at SUNY Potsdam. He enjoys piano lessons with a private teacher. As a young adult with Down syndrome, he is an advocate for full community inclusion of all people with disabilities.

Steven is a 2004 graduate of Canton High School. He lives at home with his parents, Bob and Jackie, and cat, Shadow. He has a brother, Michael, who lives in Brooklyn.

Are You Ready to Be in the Spotlight of Our Self-Advocate Corner?

We love to share stories and articles written about and by people with Down syndrome. If you, or someone you know, has something to share with our members, please send it our way! People all over the country will read it!

Send your original story or article, or article that we can reprint to:

Editor, Down Syndrome News
National Down Syndrome Congress
30 Mansell Court, Suite 108
Roswell, GA 30076
or sue@ndsccenter.org

Don't forget to send your name, age, address, phone number and a photo of yourself to go with your article!

Beyond Coping: Parental Potentiality

Tom Elkins, MD

*This article originally appeared in **Down Syndrome News,** Volume 9, Issue 9 in November 1985. Dr. Elkins served on the Board of Directors of the NDSC for nine years. He passed away in 1998 at the age of 48.*

In the summer of 1983, at a hot and dusty airport in Ouagadougou, West Africa, my family waited in a long line to have our luggage checked by the customs officials before we could enter the country of Upper Volta and begin medical volunteer work. We had brought with us 13 containers of food, clothing, and medical supplies to take into Northern Ghana. We shuddered as we watched the armed customs officials go through luggage ahead of us piece by piece and confiscate those items that appeared interesting to them. We hoped that they would not want to open any of our luggage and became increasingly anxious as we moved steadily forward in the line.

When the customs official finally came to us, he demanded that all of our luggage be opened. After looking into each container, he would apply a large check mark with chalk indicating that this bag was "ok" for entrance. Our three year old daughter with Down syndrome watched this in amazement. After watching him check two bags, she perched herself on top of the third trunk and held her tiny stuffed bear aloft begging for it to receive a check mark, too. The customs official gently tried to push her off of the luggage, and she only grew more persistent, pushing the bear directly into his line of view. The struggle continued for several agonizing moments. Finally, a multitude of Africans dressed in military uniforms all began snickering and finally gave our daughter a hug, proudly put a check mark on her stuffed bear, and waved the remainder of our 13 bags through the long line of customs checks without further inspection. People had told us what a burden our daughter with Down syndrome would be on our customary trips to do medical volunteer work in West Africa. That tiny burden had become our great benefit.

In my dealings with physicians and other health care professionals concerning Down syndrome, I have come to recognize that there is much we have to learn about the potential for growth that parents experience as a result of being able to raise a child with Down syndrome. We all consider ourselves able to cope with hardships, but we have the potential to go beyond coping in our understanding.

In a recent survey in the mid-south region of our country, 84 of 101 mothers of children with Down syndrome stated that being such a parent had been a very positive experience overall. Only seven of the replies in that survey indicated that such a parenting process had been discouraging. We seem to try so often in medicine to objectify the potential for the "quality of life" of a person born with a handicapping disability. But, in so doing, we tend to overlook the potential for growth that parents possess who give their love and their time to a child, like one with Down syndrome.

Our little girl, and those like her, have done much more for us than help us get into Northern Ghana with needed medical supplies. Through them, we are able to recognize our own fragile normalcy and better understand the sense of profound gratitude that we should feel about many of life's simple blessings. Through them we learn patience. By helping them accomplish many of the tasks which we take for granted, we learn a persistence and a determination that we would not have otherwise. In a highly competitive society, we tend to emphasize the grade point, the physical fitness test, and the ability to be attractive. Our children with Down syndrome teach us that personhood is a much more meaningful quality that is only minimally tied to human expectations of performance.

Our child with Down syndrome has reminded us more completely than anyone else that God created personhood and tolerates our performance. By experiencing their accomplishments in life, be they the expected or the surprises, we share in their excitement and joy on a daily basis. Finally, my daughter and so many others like her, lead us into a more thorough understanding of true parental love that is based on unmerited favor. It is a concept that is closely related to the philosophical ideal of unconditional love or the theological concept of grace. Therefore, to our children with Down syndrome, we as parents, say a profound thank you for allowing us to reach some of the potential for growth which we all possess in our human endeavors.

Sembrando semillas de esperanza

Por: Jennie Banks

Mi nombre es Jennie Banks, también conocida como la madre de Hope (Esperanza). Hope es nuestra hija, tiene 23 años y se encuentra en su último año de universidad dentro del programa ClemsonLIFE de la Universidad de Clemson (Carolina del Sur, EE.UU.). Lo único diferente es que Hope tiene síndrome de Down. Es la segunda de tres hermanos, Blake tiene 24 y Davis, 20, con los que tiene la típica relación hermano/hermana. Bromeamos sobre su futura graduación en el "programa de capacitación" en resistencia mental. Hope no ha recibido ningún trato especial en absoluto; no obstante, reconozco el mérito de sus hermanos por darle la confianza, el coraje y la perseverancia que han hecho de ella la joven fuerte y equilibrada que es hoy.

Hope creció con los amigos de sus hermanos jugando al fútbol americano en el jardín trasero y haciendo placajes a los mejores de ellos. Ellos nunca se percataron de sus diferencias hasta que fueron más mayores; fue entonces cuando aquellos amigos se convirtieron en sus mejores defensores, al igual que sus hermanos. A menudo me he preguntado cómo podría afectar a mis hijos crecer junto a una hermana con una discapacidad intelectual. A lo largo de los años, he visto a Blake y a Davis relacionarse con personas a las que algunos podrían considerar "indefensas"; eran sus amigos no por pena u obligación, sino conscientes de lo beneficiosas que son estas relaciones. Blake y Davis necesitan rodearse de personas que entiendan de qué se trata en realidad la vida. Nuestros hijos con discapacidad son maestros y mis chicos han sido dos de los beneficiarios.

Mi marido, Reid, y yo siempre hemos deseado que Hope se educase en un entorno escolar inclusivo, dados los muchos beneficios que tiene de aprender junto a sus compañeros. Pudo hacerlo durante la educación secundaria casi en su totalidad. Además, competía en el equipo de gimnasia durante high school y fue porrista del equipo de fútbol del colegio. Por supuesto, ninguna otra madre se ofrecería como voluntaria para entrenar a las porristas así que lo hice yo. (¿En qué estaba pensando? Esa es otra historia…)

Cuando empezamos a comentar con la escuela pública nuestro deseo para los siguientes cuatro años de Hope, encontramos el primer gran obstáculo: la extrema negatividad de la directora de educación especial. Permítame que la cite textualmente:

"¿Por qué quiere que Hope estudie álgebra? Hope no puede hacer ejercicios de álgebra. Es más, ¿por qué piensa en la universidad? ¿Qué sentido tiene?"

Eran profesionales formados especulando sobre el futuro de Hope sin saber nada sobre ella. Afortunadamente, contábamos con otra opción para el bachillerato. El colegio católico de Charleston (The Catholic High School) había iniciado un programa de educación inclusiva el año anterior. Rápidamente, concertamos una cita para reunirnos con la administración y nos recibieron con gran entusiasmo y optimismo. Querían a Hope en su programa. ¿No es eso lo que queremos para nuestros hijos? ¿Qué sean aceptados y no considerados como una carga? El plan de estudios daba algo de miedo —muy académico—: álgebra, francés, química, biología, economía, etc. pero fue modificado conforme a sus capacidades.

¿Por qué queríamos exponer a nuestra hija a estas clases? Hope adquirió unas habilidades de estudio y organización asombrosas; además, aprendió a emplear los recursos para encontrar las respuestas a sus preguntas —destrezas que le ayudarán a alcanzar el éxito en su vida más adelante. Tenía compañeros con los que comer y profesores que la orientaban en sus relaciones. También aprendió la importancia de servir a los demás en su trabajo como voluntaria. Fuera del aula, Hope era la capitana del equipo femenino de voleibol, miembro del club de francés y voluntaria en la Young Life (organización juvenil internacional de inspiración cristiana). Los profesores de esta escuela tenían grandes expectativas para los estudiantes, lo que contribuía al nivel de éxito e independencia de los mismos.

Continúa en la página 30

Sembrando semillas de esperanza

continuación de la página 29

Un día, en el primer año de clases de Hope, estábamos hablando con un grupo de estudiantes de último año sobre el síndrome de Down cuando uno chico le preguntó:

"¿Cuáles son tus sueños para tu vida después de terminar high school?" "Quiero ir a la Universidad de Clemson, conducir un Hummer naranja y casarme," respondió Hope hablando como una auténtica fan de Clemson. Por desgracia, ClemsonLife no existía por aquel entonces. Me aterrorizaba la idea de tener que decirle algún día que no podría ir a la universidad.

Aunque resulte difícil de creer, el año siguiente, las charlas en la Universidad de Clemson comenzaron hablando sobre un programa de estudios superiores para jóvenes adultos con discapacidad intelectual. Gracias al trabajo fructífero de muchas personas que habían ejercido presión para la creación de este programa, el ClemsonLife fue creado. La universidad pasó a ser una opción para Hope. De hecho, ¡Hope podía elegir entre cinco universidades diferentes dentro del estado de Carolina del Sur!

El último año de high school llegó rápido y, con él, el momento de aceptar la posibilidad de que finalmente se fuera. Así que teníamos tarea. Hope envió la solicitud de entrada a Clemson (su equipo de fútbol americano favorito) y a la Universidad de Charleston (el programa de estudios universitarios local). "Sería bueno para ella estar cerca de casa", pensé. Pero, como siempre, Dios tenía un plan mejor.

Tras la "visita oficial" de Hope al ClemsonLife, su entrevista con el entrenador Dabo Swinney (primer entrenador del equipo de fútbol) y su foto de familia con Deandre Hopkins y Sanny Watkins (los futuros receptores del equipo nacional de fútbol americano), Hope quedó enganchada, quería ir a Clemson. Los esfuerzos de su abuelo para que la aceptaran valieron la pena. Por suerte, fue admitida dentro del programa y dejamos que ella tomase la decisión final sobre su universidad de destino. ¡Eligió Clemson!

Como todos los que ustedes que son padres lo saben, el proceso de dejar marchar puede ser extremadamente duro y ese fue, en efecto, mi caso. Cuando crees que la universidad es el siguiente paso lógico después de high school, educas a tus hijos sabiendo que algún día se irán. Con Hope no fue del todo así. Reid y yo teníamos tan solo ocho meses para prepararnos para su salida del nido. Decir que mis emociones estaban totalmente descontroladas sería quedarme corta. Luché contra el miedo: miedo por la seguridad de Hope, miedo a que no fuese feliz, miedo a que no lo lograse y, sobre todo, miedo a la persona en la que me convertiría sin ella.

Hope Banks

El día de la ceremonia de bienvenida vino y se fue. Aunque Hope estaba inquieta, y también alegre, nunca miró hacia atrás. Yo pasé seis meses regodeándome en mi propia pena. Entonces me di cuenta de que mi hija era más feliz que nunca. ¿Cómo podía estar triste? Mi hija había hecho amigos de verdad, era miembro de la comunidad de Clemson y estaba progresando, aprendiendo y a salvo.

En Clemson, Hope ha aprendido todo sobre la vida independiente: Cómo ser una buena compañera de cuarto, cómo limpiar su apartamento de forma correcta, incluyendo el limpiar el baño.

Un día, en una clase sobre las tareas del hogar, la profesora estaba enseñando a los estudiantes a limpiar baños correctamente. Tras su demostración, pidió a Hope que lo hiciera. Hope respondió sin más: " ¡Yo no limpio baños!" Rápidamente, le corrigieron diciéndole que, si iba a vivir sola, tendría que limpiar baños. Su descaro a veces me asusta…

Además, está aprendiendo a crear menús semanales saludables, a hacer la lista de la compra según dicho menú, a hacer la compra sin sobrepasarse del presupuesto y a cocinar comidas saludables. Y hablando del tema de la comida y la nutrición, me gustaría comentar el desafío que supone para TODOS los estudiantes universitarios seleccionar alimentos saludables cuando salen de casa por primera vez. En la universidad, los estudiantes descubren muchas libertades. Hope y los estudiantes del ClemsonLife han descubierto los comedores (también conocidos como "dispensadores de todo lo que seas capaz de comer"), lo que supone una pesadilla para aquellos de nosotros que hemos controlado la dieta de nuestros hijos desde pequeños.

Durante las primeras cinco semanas de clase, Hope comía cada día todo lo que quería y más y bebía todos los refrescos que le daba la gana. Sufrió las consecuencias engordando 4,5 kg en esas cinco semanas. Dentro del plan de estudios, el personal incluye la nutrición, la alimentación saludable y el ejercicio, pero los estudiantes pueden tomar sus propias decisiones. Echando la vista atrás, desearía haber puesto más atención en enseñar a Hope hábitos saludables cuando era más niña, antes de que su peso se convirtiese en un problema. Creo que habría estado más preparada para tomar sus propias decisiones saludables. Hope suprimió los refrescos y perdió algo más de dos kilos en una semana.

Por otra parte, Hope está aprendiendo a ser una buena empleada: llevar una vestimenta adecuada al trabajo, ser puntual, trabajar duro, no enviar mensajes de texto en el trabajo y llamar a su jefe cuando esté enferma o llegue tarde. Actualmente, tiene dos empleos. Trabaja en el All-in Café, donde lava platos y en el Mr. Knickerbockers, una tienda de suvenires y ropa de Clemson, donde trabaja como cajera, poniendo los precios a los productos y reponiendo las estanterías.

También está aprendiendo lo que es una relación novia/novio adecuada y yo estoy aprendiendo aceptarlo sin quedar paralizada por el miedo, sacarla de su casa y ¡"encerrarla"! (estoy bromeando, aunque es mi primera reacción…)

Como he mencionado antes, el miedo es uno de mis mayores obstáculos y suele confundir mi razón y mi perspectiva.

Quiero que Hope experimente lo que es el amor verdadero pero al mismo tiempo siento que estoy obligada a ser la mamá sobreprotectora. Hope es muy vulnerable e inocente y, por supuesto, tiene hormonas como todo el mundo. Mi alivio, como madre, es la oración… rezo para tener sabiduría y orientación para saber aflojar las riendas pero sin dejar de protegerla.

La gran pregunta sigue siendo: ¿cómo será esto el próximo año después de que se gradúe y, con suerte, viva sola? ¿Cómo proteges a tu hijo? La educación y concientización que le damos nosotros como padres, así como el equipo de empleados y profesores del ClemsonLife continuarán siendo clave para que Hope sepa cómo protegerse a sí misma. No tenemos respuestas claras para su futuro más que un montón de gente apoyándonos con la que colaborar y una gran fe en un Dios que tiene el plan perfecto para el futuro de Hope.

A menudo, otros padres nos preguntan cómo pudimos dejar que Hope fuese a la universidad y dejase la seguridad y protección de nuestro hogar. Fue muy difícil y conllevó un proceso—especialmente para mí. Una vez hubimos encontrado un programa de estudios superiores que fuese adecuado para ella y supimos que la universidad era lo que ella realmente quería —no solo nuestro deseo para ella— fuimos capaces de seguir adelante. Ahora puedo ver el enorme crecimiento que ha experimentado Hope como resultado de estar lejos de mí. Por otra parte, es increíble ver el crecimiento que he experimentado yo como resultado de dejarla ir. Por supuesto, nosotros solo queremos lo que sea mejor para su futuro y comprobar los buenos resultados de su independencia en la universidad ha sido la confirmación de que subir el listón y dar ese salto de fe fue la decisión correcta para nuestra familia.

"¿Cuáles son tus sueños para tu vida después de terminar high school?" "Quiero ir a la Universidad de Clemson, conducir un Hummer naranja y casarme."

Para leer más sobre el camino de Hope hacia la independencia, ir a www.spreadingalittlehope.com (en inglés).

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NDSC 2016 Annual General Membership Meeting

Saturday, July 23, 2016, 5:30 pm ET

Mediterranean 6, Lobby Level

JW Marriott Grande Lakes
4040 Central Florida Parkway
Orlando, FL 32837

The General Membership Meeting will include the introduction of our newest self-advocate board member (elected by his/her peers and the Youth and Adults Conference); reports from our Foundation Trustees, NDSC Treasurer, and an overview of 2015 activities by our Executive Director. The Nominating Committee will present its slate of candidates, and the election of new board members will take place. Other business of the organization will be conducted as warranted. All NDSC members are invited to attend.