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SETTING SAIL

Rockin'#21



The Moms of Rock the 21 with their children during a sunny summer day in Columbus Park

# Rockin'#21

# Moms on a mission to raise awareness and celebrate Down syndrome

BY ALYSSA BREDIN QUIROS IMAGES BY TBISHPHOTO

T ara Stauber is a Hoboken mom of three. Her eldest, Emma, like a lot of seven-year-olds, plays tee-ball and soccer, and loves her friends and her dolls. She also happens to have an extra 21st chromosome.

When Tara's daughter was born with Down syndrome (DS), she did not know what the future would hold for her baby. "I didn't even know how to be a mom, let alone a mom to a child with DS," she says. But the worst part was feeling like she had no one who could relate to what she and her husband were going through. "Everyone I had seen in Hoboken looked perfect and perfectly happy pushing their fancy strollers around town," she says. "I thought the odds of finding someone in my one square mile who knew what I was feeling was next to impossible."

With some digging, and help from the National Down Syndrome Society, Tara realized that she was not alone. She met Ana High, cofounder of Hoboken Grace Church, and mother of three boys, one with DS; Stephanie Dotto, whose adopted daughter has DS; as well as Elizabeth Freeman, mother of twin daughters with a rare form of DS. "These families have become my forever friends," Tara says.

### AN ORGANIZATION IS BORN

Elizabeth Freeman, like Tara, was completely overwhelmed when her daughters were born with DS. "Outside of what I learned in school, I didn't know a lot about Down syndrome," Elizabeth says. She was discouraged to learn that most of the information about DS was clinical and focused on the limitations of the condition. "I wasn't first and foremost told that my babies were healthy," she says. "They would play and go to school. They would laugh and love. They would be successful." She spoke to several professionals who were insightful and helpful, but she still had the takeaway that something was *wrong* with her daughters. She needed support.







The Kids from Rock the 21 share some hugs and smiles during their photo shoot for Hoboken 07030.





President and founder of Rock the 21 Elizabeth Freeman with twins Micayla & Harper

Elizabeth discovered there were no support groups or organizations for DS in our area. Her parents encouraged her to take action. She recruited Ana High and Tara Stauber, and together they organized the first Rock the 21 Gala in 2015 to raise awareness and funds for Down syndrome. They had hoped to raise \$20,000 and instead raised a whopping \$50,000. It is now an annual event.

Their initial gala eventually grew into a full-fledged non-profit organization. In the three years since, Rock the 21 has done an incredible amount through their own initiatives as well as by supporting various organizations for DS nation-wide. They've provided scholarships for adults with DS to participate in job training programs, as well as scholarships for toddlers to attend the Stepping Stones early intervention program—which provides critical speech, occupational, and physical therapy for young children with DS. They have also helped to aid more than 30 DS individuals and their families affected by last year's hurricanes in Texas and Florida.

The organization has an international outreach, dubbed the Rock the World Initiative. Last year, Rock the 21 traveled to the Mustard Seed Community, an orphanage for children with disabilities in Nicaragua, to donate supplies and clothing. This is the orphanage where Stephanie Dotto adopted her daughter, Alicia. (Read the story of Alicia's adoption on Rock the 21's blog.) They also donated funds for a child with DS in Africa to have a life-saving heart operation.



Vice President of Rock the 21 Tara Stauber with Emma

### **BUILDING A COMMUNITY**

"We've recently been contacted by two families moving to Hoboken from other states," says Tara. "The fact that we have a network here to welcome them is something I'm very proud of."

One of their first projects was to deliver diagnosis support baskets to local hospitals. The baskets included a personal letter from one of the moms, a Sophie the giraffe toy, as well as books and other valuable resources.

They have also hosted numerous events and activities, including an eight-week dance program for adults with DS and a dinner for World Down Syndrome Day.

Rock the 21 also strives to make our school systems more inclusive for children with special needs. In 2015 the group donated an iPad to a legally blind Hoboken student with DS. The iPad enabled him to read e-books in large print. It also donated a copy of 47 Strings: Tessa's Special Code by Becky Carey, a children's book about DS, to more than 100 local schools. As part of its Inclusion Rocks initiative, it organized a seminar for local educators to learn how to make classrooms more welcoming for students with Down syndrome. In 2017, former Mayor Dawn Zimmer honored Rock the 21 for its outstanding efforts in the community and officially recognized March 21 as World Down Syndrome Day in Hoboken.

"Your child will encounter the same journey as everyone else, it just may take more time or a different path to get there."

-ELIZABETH FREEMAN



Vice President of Rock the 21 Ana High with Cael





Treasuer of Rock the 21 Stephanie Dotto with Alicia



# CELEBRATING THE JOURNEY

Rock the 21's mission is "Educate. Advocate. Celebrate." It encourages people with Down syndrome to not just accept their differences but to celebrate them. Elizabeth encourages people with DS to "Rock that 21st chromosome!"

On Rock the 21's blog you can read each of the mother's stories and how their initial trepidation of the diagnosis turned into a deep love and admiration for their children. Ana writes, "We have learned to embrace this journey and enjoy it! We are better people because of our son, Cael, and could not be more grateful for the gift he is to our family."

"It's not a diagnosis to be scared of," Elizabeth says. "Your child will encounter the same journey as everyone else, it just may take more time or a different path to get there."

## Learn More:

Rock the 21 ROCKTHE21.ORG

National Down Syndrome Society

NDSS.ORG

