

DRIVEN

**Jon Singer is
DRIVEN**

**Read excerpts from DRIVEN, Jon Singer's new book,
coming soon.**

DrivenStory.com
DrivenStory.com
DrivenStory.com

Are You Driven?

In *Driven*, I will share life lessons to be applied to overcome virtually any obstacle, transforming problems into challenges to be solved. I will share my stories and stories of other like minded "Driven" people.

Your story may be featured in Driven.

Do you have a story of overcoming obstacles and beating the odds?

[Share your story on Facebook.com/DrivenStory](https://www.facebook.com/DrivenStory)

The ten stories with the most votes will be included in the eBook version - the author will include up to five stories in the paperback.

Keep checking back at:

[DrivenStory.com](https://www.drivensstory.com) and **[Facebook.com/DrivenStory](https://www.facebook.com/DrivenStory)**

Thanks,

Jon "Driven" Singer

DRIVEN

From *Driven*, a soon to be published book by Jonathan Singer. © 2012 Jonathan Singer. All rights reserved.

Disclaimer - All characters appearing in this work are real. Any resemblance to real persons, living or dead, is purely intentional. The actions of individuals named in this book should not reflect upon or be an indictment of the institutions they are or have been affiliated with in the past.

The views expressed in this book are those of the author and do not represent the views of his wife or children and should not be held against them.

It's all Jon's fault. Period.

What would you do if you heard any of the following?

Don't have any hope for your daughter Rebecca to live a productive life; we don't want to work with you anymore to open a new school; she doesn't belong in this camp; Rebecca is not eligible to participate in a program that holds the greatest promise for her life (and your son can't have M&Ms on the side with his Blizzard at Dairy Queen).

Would you feel defeated and give up hope? Would you accept plain vanilla ice cream?

Jon Singer didn't. He met all of these challenges head on and won. Jon is a tireless advocate who has fought many times on behalf of his clients, his children and others (including making sure his son could get his M&Ms on the side).

Praise for Jon Singer

"The only reason I agreed to see you was that if you called one more time I would have jumped out the window" *Lloyd Tulp, Jon's first boss*

"He has an answer for everything. He should have been a lawyer. Or a doctor would have been okay too" *Rhoda Singer, Jon's Mom*

"I am writing the real story - 'DRIVEN CRAZY'" *Michey Singer, Jon's wife*

Introduction

About Driven

In 1997 a young couple was told that their beautiful baby girl was one of 30 individuals around the globe having a rare genetic disorder with no name. **Although little was known about this condition at the time, the doctor said “if you have any hopes of her having similar intelligence to either of you, it is doubtful, and she may never walk.”** Imagine the impact that this cruel and callous statement could have had on these emotionally fragile parents, and how it might have killed whatever hopes and dreams they had for the future.

And imagine how many other families since that time had their hopes and dreams crushed by that doctor (I will refer to her as Dr. W.), and other insensitive doctors. Think of the lost potential of so many children whose parents may simply have given up upon hearing such news because they were convinced that their efforts would be futile.

That sweet little girl was our daughter Rebecca, and fortunately for her, that experience only served as my challenge to prove Dr. W. wrong. Today, with some assistance, Rebecca roller blades, skis, rides horses and a bicycle, and sometimes breaks out into a little jog. And ironically, almost 14 years later to the day, in the same hospital where we heard those incredibly painful words, there was new found hope for Rebecca in an exciting clinical trial that recently began. At the time, we were told we needed to have a genetic workup done by Dr. W. Rather than having a highly charged confrontation, we refused to meet and they arranged for us to see another geneticist instead.

For you doctors who would like to learn something from this experience, what Dr. W. could have said differently was something along these lines - “I have done some research and have discovered there are only 30 cases of what Rebecca has in the entire world. Unfortunately, while there are too few cases to really know the long term prospects, from what we have seen so far these individuals are significantly affected by this disorder. Perhaps things will be different for your daughter but we really just don't know. We hope and pray for the best for you and for her.”

Years ago we learned from Drs. Arnold and Sandra Gold, founders of the Gold Foundation for Humanism in Medicine, that the best doctors are not necessarily the ones that win all the awards or nominations in magazines or other reports. While the best doctors are highly qualified and have achieved excellence in their chosen field, their level of skill must be matched by their level of humanity and kindness. I will always choose the doctor with the second or third best reputation for excellence in their particular area of speciality if they are known to have the best bedside manner. No one deserves to be treated poorly by a medical professional and especially not parents of children with special needs.

Finally, in these exciting times, with all of the advances in medical technology and the study of genetics, doctors must choose their words carefully and not pretend to have a crystal ball. You never know what may happen, every child is different, and never ever discount the power and passion of a driven parent.

Why Driven

Over the years I have had to overcome many significant obstacles, mostly ones involving my daughter. I wanted to share my stories and the stories of other like minded Driven people about transforming problems into challenges to be solved. Our experiences can be instructive and the lessons applied to many different types of situations.

Words used to describe me by various people in my life have included “resourceful,” “creative,” “politely persistent” and “incredibly impatient” (some of my friends and family members would probably add “annoying” to this short list and my wife Michey is convinced I am crazy). My greatest achievements over the years have come about when I have been able to apply these capabilities all at once (and a little crazy probably has been helpful too!).

How I Became Driven

If 20 years ago a fortune teller told me “one day you and your wife are going to have a daughter with significant special needs, establish a foundation to help her and many other children and families, raise over \$1,000,000, help open a new school, drive across the country, twice, holding fundraising events in several cities, and write three books sharing your experiences” I would have said “I’m not having kids”.

I joke but, back then, my wife Michey and I never could have imagined the life long journey we would begin after learning that Rebecca had this extremely rare genetic disorder, later called Phelan-McDermid Syndrome, that caused severe developmental delays. We embarked on an adventure that would change our lives forever, touching and inspiring countless others along the way, and we never turned back.

A few years before Rebecca was born, Michey was a rising star in the world of New York City fundraising, planning sometimes extravagant special events for the Museum of Natural History and The American Heart Association that were attended by New York’s financial and social elite. Meanwhile, I was selling insurance and helping to grow a family business along with my brother, my sister and our very entrepreneurial dad.

Little did we know how incredibly valuable Michey’s skills would prove to become one day when she would assume a leadership role in planning fundraising events for the school we were to help establish called REED Academy.

While I was never particularly charitable, anyone living on the Upper West Side of Manhattan could not help but notice the many homeless people in the neighborhood.

DRIVEN

I was particularly struck by the few regulars who reminded me of the inscription on the James Farley Post Office in New York City, "Neither snow nor rain nor heat nor gloom of night stays these couriers from the swift completion of their appointed rounds." Many of these individuals were always there even in the bitter cold.

I always felt accepting something to eat when no money was offered was what separated the "men from the boys", or the people who were really hungry from those that simply wanted money for drugs or alcohol. To illustrate the point, one night, when leaving a supermarket with my brother near Stuyvesant Town, we saw someone waiting just outside of the entrance asking for money. I handed him an apple and moments later, while walking away from the store, the apple came rolling by.

Instead of giving money to homeless people, I began offering to buy them something to eat and typically my offers were eagerly accepted. I also started bringing our leftovers from restaurants to hungry people on the street. The unfortunate prevalence of people struggling to survive in New York City inspired my first charitable initiative called Take Out for the Homeless.

I created a program to encourage restaurant patrons to wrap up their leftovers or order something extra to go to bring to a homeless person waiting outside. I was interviewed on a PBS television station and a number of restaurants agreed to post notices to promote the idea. Take Out for the Homeless was short lived however because soon after the idea was conceived, my attention shifted to focus on our long and painful effort to have children and start a family.

Rebecca made it clear very early on that anything that had to do with her wasn't going to be easy. After two miscarriages, and with the advice of a fertility doctor, Michey ended her fundraising career to reduce stress and help increase the odds of having a successful pregnancy. We even started exploring adoption as an alternative.

After learning that adoption laws were more favorable at the time in New Jersey than they were in New York, we moved to New Jersey. . Soon after we moved, and before we had started looking into adoption, Michey became pregnant with Rebecca.

Rebecca was a beautiful baby but after several months it became apparent that something was wrong. She did not seem to be developing the way she was supposed to. After many visits to New York City specialists, Rebecca was diagnosed with her rare disorder. Our hearts stopped, tears flowed and at that moment our lives changed forever. The doctors said she would be significantly challenged for the rest of her life. We had no idea what that would mean, nor did we have any idea of what was to come, and all of the work we had ahead of us, to help Rebecca and to help many other children with special needs.

The Roots of Being Driven (excerpt)

Driving Women Crazy Since 1964

Apparently it all started when I was very young. In nursery school, my mom received a call from a teacher saying that instead of doing whatever activity I was supposed to be doing, I was standing on my head.

Then in kindergarten they called to say something was wrong with me. When it was time for all of the kids to take a nap I refused to lay down.

These were clear and early signs that something was amiss, and that my mom should have sent me back while she still had the chance.

Creativity

An early example of my resourcefulness and creativity was when I was probably seven or eight years-old. One of our neighbors was having a small carnival to benefit Ronald McDonald House and they were holding a raffle for a Big Wheel. If you don't know what a Big Wheel is, imagine something that nearly every kid wants - a really cool cross between a tricycle and go cart with a high back plastic seat, low to the ground, and a really big black front wheel. I wanted one really really really badly.

While most kids were spending their pennies playing the carnival games, when I found out it was one penny per raffle for the Big Wheel I hightailed it back to my house to empty my piggy bank. I ran back to the carnival as fast as I could and bought 100 raffle tickets.

Later that day I was downstairs in our home and heard my brother or sister yelling and screaming. No one had to tell me what all the commotion was about. I knew I had won the Big Wheel having stacked the odds in my favor.

Years later, when I was with my friends at a nightclub in Long Island, for some reason I wanted to win a windsurfer that was being given away even though I rarely went to the beach. I recruited my friends to fill out as many entry forms as we could find and, when they started reading out names of winners, it was no surprise that I won.

Confidence

High school may have been the time when I really began honing my creativity and resourcefulness and ultimately built my confidence. In retrospect it seems those were all survival skills. I wasn't very tall, wore horn rimmed glasses, and my mom dressed me funny. With a December birthday I was the youngest in the class, I wasn't tall, and

DRIVEN

there were some really big tough kids in school. Today I am over six feet tall but unfortunately I did most of my growing towards the end of high school and early on in college.

Since I was picked on, and some kids made jokes about my religion, and I didn't like getting punched in the arm or getting "dead legs", I avoided places where these things were more likely to happen, such as the gym locker room and the bathrooms. If I really needed to go to the bathroom, or if I knew I would have to go into the locker room during gym, I would fabricate a stomach ache and head to the nurse's office. Rather than returning to gym, I would spend the rest of the period in the computer room.

There were several entrances to the school and a few that some people avoided such as the Vikings Door, which was "reserved" for members of a white "gang" (mostly not so tough stoners), and the Black Door which needs no explanation (no, that wasn't the color of the door).

While I didn't like getting punched, I was a bit lazy. Looking back, it ends up that I was shaping my character and resolve, which would help me in many ways I never could have imagined at that time, in years to come.

For me, the Black Door was the one that was the most direct entrance to the school from where I lived, my locker was just down the hall from the door, and to avoid that entrance I would have had to walk halfway around the school and I really did specialize in laziness. In my warped mind I decided it was my door too. Without really thinking about it I boldly entered school through the Black Door every day. I felt it was my right to use whatever door I pleased. Maybe it also had something to do with the fact that I wanted to show the kids that picked on me that I wasn't afraid of them but it probably was mostly about being lazy and impulsive.

At first I encountered some resistance, receiving more punches in the arm, but never anything too much more physical. One time I even dressed like a rapper on crazy clothes day (the way a somewhat nerdy white guy might dress when trying to look like a rapper) which in retrospect probably wasn't the smartest idea. The guys didn't seem to think it was very amusing and pushed me around a bit more than usual but it was no big deal.

Over time however I seemed to have gained the respect of some of the most obnoxious guys who were always hanging out and trying to look tough and they eventually seemed to ignore me.

Driven Heroes (excerpt)

There are many “Driven” people in this world and there have been countless individuals throughout history who have inspired me and have given me the strength to forge ahead despite facing some seemingly insurmountable obstacles.

Many of these amazing people have overcome great adversity, having defied the odds, and in some cases they have risked their lives to fight for what they believed in and prevailed.

Practically every time I get into a situation where there is a difference of opinion or conflict with another party, but I know in my heart (and my gut) that what I am doing is right, I think of how relatively easy my life is compared to some of the most incredible driven human beings throughout history. Martin Luther King for example risked everything and tragically lost his life, fighting for what he believed. He made history, effecting change for millions from that day forward, and has inspired untold others to follow their dreams.

One time when my wife, Michey, was telling me to give it up and just give in on a particular issue, I replied “what would have happened if Martin Luther King just gave up” and I imagined the following conversation that his neighbors may have overheard in December 1955 if they had their ear to the wall when Coretta King was talking to him about Rosa Parks.

“Just because that girl Rosa won't give up her seat on the bus to a white man, don't you even think of doing anything silly Martin. You and your boycott - you've got the craziest ideas. Go boycott the supermarket about charging us .10 a gallon for milk.”

Or in August 1963 about the March on Washington. “You just bought those new shoes Martin. If you think you are going to March all the way to Washington in them you've got another thing coming. March back to the kitchen and do the dishes. I have a dream too Martin - that I married someone who wasn't so annoying.”

Just imagine what the world would be like today if he didn't follow his dreams.

Another one of my heroes is Steve Jobs who, according to his biographer, left lots of road kill as he was “Driven” to break new ground and change the way we use technology forever. Perhaps if they were paying attention, the neighbors could have overheard the following conversation in 2001 between Steve and his wife Laurene about the iPod.

“Now Steve, everyone has a walkman and people are perfectly happy with CDs. Don't reinvent the wheel. Who's going to want to download music. Stick to what you know you geek - computers.”

Or in 2007, maybe Steve and Laurene had a discussion along these lines about his

idea for the iPhone. “Who would want to play music on a phone. Or games. Work on getting AT&T to stop dropping my calls Steve. And who do you think you are that you think you can even make a phone - Alexander Graham Bell? Now he was a real genius. Get back to the drawing board, get yourself out of the house and go to work - drive someone else crazy for a change.”

The following story is about a far less famous couple but is no less inspiring. As a result of learning that their daughter had kidney disease, the Hils helped reinvent an industry and are saving lives.

Jan and Garet Hil are Driven

Explanation of kidney transplants from the Mayo Clinic

When your kidneys lose their filtering ability, dangerous levels of fluid and waste accumulate in your body – a condition known as kidney failure. A kidney transplant is often the best treatment for kidney failure.

Only one donated kidney is needed to replace two failed kidneys, making living-donor kidney transplantation an option. If a compatible living donor isn't available for a kidney transplant, your name may be placed on a kidney transplant waiting list to receive a kidney from a deceased donor. The wait could be a few years.

When their 10 year-old daughter was diagnosed with kidney failure, Jan and Garet Hil sprung into action. They immediately began an exhaustive and frustrating journey into the world of searching for a match for a kidney transplant. They didn't have a few years and were running out of time.

Despite some setbacks along the way, the good news was that Garet, a few uncles, and an anonymous donor all seemed to be good transplant matches. They were confident that they were on the right track and were making progress.

In the 11th hour however they received terrible news - all of the potential donors, including Garet, failed the crucial cross match test and they had no other options.

Rebecca Doesn't Belong Here (excerpt)

Rebecca has had some of the best times of her life and she is like the mayor of our local JCC. She goes there all the time, everyone is incredibly friendly, and we are so fortunate that there are such kind and caring people on staff who make sure she is happy and safe and they have become part of our extended family.

While she brings joy to so many people, especially with her infectious laughter and bright smile, we had a very rocky start when she first began going to the JCC over ten years ago. It took a great deal of effort and teamwork to overcome the bad attitudes of *a few misguided individuals that no longer work there*. Since that time however it has been mostly smooth sailing and a wonderful experience for her.

In the summer of 2001, when Rebecca was five-years-old, we encountered a number of challenges when we enrolled her in a camp for children with special needs. This was a particularly sensitive issue to me. This was the same JCC where I had been a member since it opened in the late 70s when I was a teenager, from where I have some of my fondest memories.

For two summers before starting in this program, Rebecca had been going to another terrific camp program for kids with special needs however it was quite a distance from where we lived. The JCC was just a mile away, it had a much larger facility with a huge outdoor space, it was my JCC, and we knew it would offer her many more opportunities for inclusion and fun.

Rebecca needs one-on-one assistance and help with practically everything she does. She is not completely toilet trained to this day, she needs someone to be with her to assist with meals, and for safety reasons she needs constant supervision because she might put something inappropriate in her mouth or wander off.

When Rebecca first started in camp the JCC helped us find an aide for the summer named Jeanine. At the time, she was doing making some progress at school and at home with toilet training, being taken to the bathroom at 40 minute intervals. Apparently Rebecca had a number of accidents and on the first day my wife received a call from the director who said "if Rebecca isn't toilet trained, she can't come to camp anymore."

It is well known that kids with special needs often have difficulty transitioning to new environments which you would think they would have known since it was a camp for kids with special needs. The call from the director didn't make any sense on another level because there was also a camp for typically developing children at the same location and the youngest children were in diapers and needed the same level of care as Rebecca.

What we learned was that they were discriminating against Rebecca in violation The Americans With Disabilities Act. Fortunately the head of special services at the JCC

finally chimed in and told the camp staff that kids with special needs sometimes need a few weeks to get comfortable and transition into new environments.

Over the next few days we kept hearing reports from her counselor Jeanine, as well as from others, that Rebecca wasn't having a good time and was not enjoying many of the activities. Jeanine also mentioned that she personally had "had a very stressful five weeks with gastritis, kidney stones, and that she was sick the other day and vomiting."

The next day we heard some disturbing news from our babysitter after she picked Rebecca up from camp. She told us that Jeanine said "Rebecca hates camp and she doesn't want to do anything."

Then our babysitter said "what's that in her mouth" and Jeanine said "it's probably a button from her sweater. She keeps trying to eat them and when I try to get them out of her mouth, she keeps biting me."

Our babysitter took the button right out of Rebecca's mouth and Jeanine said "she probably ate three of them today."

Why she didn't take off her sweater after eating the first one we'll never know. That was Jeanine's last day. Starting the next morning we sent our babysitter to camp to serve as Rebecca's counselor.

Meanwhile the administrators continued to tell us that the camp was not a good match, that there was too much commotion and activity, and kept trying to persuade us that it wasn't going to work out. We knew how much Rebecca was capable of and our babysitter kept giving us good reports so we persisted.

We told them that she was able to enjoy all sorts of different activities including going to very crowded places like the Bronx Zoo, Disneyland and that she liked being with other children and would just need some time to adjust and things would continue to improve with now that we had someone who could help her succeed.

At the same time our JCC had been advertising that they were proud of their inclusion programs, where kids with special needs would be integrated into programs with typically developing programs, and they had fundraisers to help support these programs. We knew about the many benefits of inclusion and were pushing for them to include Rebecca in their regular programs with the help of an aide and we were receiving a great deal of resistance from that perspective as well.

This led to a meeting with the assistant director of the JCC at the time who once again tried to convince me that camp wasn't a good fit.

Amazingly, sitting right across from me at her desk, she said "Rebecca does not belong here. I couldn't believe she said that to my face."

Chris Gagliardi and Lynda Grace Monahan are Driven

Chris Gagliardi is an accomplished actor, singer, and an outspoken advocate for people with disabilities and victims of bullying. A long-time Starbucks partner, Chris is a valued employee who has won recognition for providing outstanding service.

These accomplishments, the result of hard work and determination by Chris, with the help of his mother Lynda, are particularly remarkable because Chris has autism.

Lynda Grace Monahan was a single mother with no money, no hope for the future, and was about to end her life. The generosity of a stranger and the discovery of Buddhism gave her newfound hope and strength for herself and for her son Chris.

Despite being bullied in school, with the support, love and determination of his mom who was diagnosed with breast cancer, Chris went on to become student council president, raised funds for families of 9/11 victims and people with AIDS, and was the first individual with autism to run for public office in New Jersey.

Driven 'em Crazy (excerpt)

Making Apple Nutty

In 2002, we kicked off Drive4Rebecca, our effort to increase awareness for autism, raise funds for research and education and open a new school for children affected by autism. We set out on a cross-country tour and had events in seven cities in Whole Foods Market stores.

Nearly ten years later, to promote the importance of advocacy for parents of children with special needs, in conjunction with the publication of my first book, *The Special Needs Parent Handbook*, we once again embarked on a trip from coast to coast.

To generate publicity for our 2011 tour, and because Rebecca had recently begun using an iPad, we decided to stop at Apple Stores and invite parents to join us to highlight the amazing technology that was available to help kids.

I called the manager of our local New Jersey store who was very enthusiastic about the idea, I told him we wanted to start in NYC at their flagship 5th Avenue store and he recommended that I contact their local events person. I called and we had a nice conversation about what we wanted to do - essentially invite families that had children with special needs to meet us in stores across the country and let Apple do what they do best - have their very knowledgeable and patient staff members demonstrate and explain their technology and perhaps even highlight some apps and software that help children with special needs. He said we might even be able to use their computers to let customers enter a random drawing for prizes that would be provided by our Drive4Rebecca foundation including Apple Store and iTunes gift cards. He said he would check with corporate and get back to me.

A few weeks later I had my answer. Apple would be glad to host ten to twenty people in the NYC store for a workshop on how to use their computers. I could personally invite parents to attend but could not publicize the event. I explained once again that we were doing a cross-country tour, that a PR firm that was donating their time, and that with one event in NYC that we couldn't even publicize it would not do anything to accomplish our goals. He apologized and said that was the response from their corporate offices.

At that point I decided to go to the top. I wrote to Steve Jobs, who was quite ill at the time, and sent him a copy of my book. I explained how the iPad was helping Rebecca and that most of the other students in her school were using the iPod touch to help them learn and in some cases communicate. I also emailed two of his chief lieutenants, Phillip Schiller, the head of marketing, and Ron Johnson, the head of retail store, and called their assistants. After searching around a bit online, I came across the cellphone number of the head of global retail marketing and left her a voice mail

DRIVEN

message too.

I finally heard back from Amy in public relations who left me a voice mail message wanting to know what we had in mind and how she could help. That sounded very promising and we scheduled a time to speak. I explained what we had in mind and she told me some things they could and couldn't do and that she would get back to me. A few weeks later she called, told me how admirable everything was that we had accomplished through Drive4Rebecca, and in the nicest way possible she tried to talk me out of the idea of stopping in their stores.

Chrissie Wellington is Driven

In 2004 Chrissie Wellington was working for the UK Government. She was a runner, but she had never gotten on a road bike. She started swimming, she trained for a few triathlons, and quickly got hooked on the sport.

In 2007 Chrissie went on to win the Kona Ironman, and was the Ironman World Champion in 2008, 2009 and 2011.

I had the pleasure of hearing Chrissie speak at the NYC Triathlon Charity Appreciation lunch in early 2012 and we met briefly when she signed my copy of her new book, *A Life Without Limits*. John Korff, owner of the NYC Triathlon, was kind enough to put me in touch with her UK agent, Ben Mansford, and Chrissie agreed to the following terrific email interview.

Who and/or what inspired you to start training and competing?

As my autobiography *A Life Without Limits* shows, I have taken a rather unique path to professional sport. I didn't grow up like many other triathletes watching triathlons on television and wanting to qualify for the World Championships in Hawaii. Never in a million years did I imagine that I would become a professional sports person! A friend suggested I try triathlons in 2004, and I leapt at the chance. I was attracted to the new challenge, the opportunity to make friends and the desire to have a goal to train for. I did these first triathlons all on an old, borrowed bike and a very big wetsuit that didn't fit me! I really enjoyed it - but I also wanted to work overseas and so in September that year I went to work in Nepal for 16 months. Here I bought a mountain bike and cycled every single day before work. It was an amazing opportunity to explore the countryside, meet people and keep fit. I didn't do any structured training - just grinding up and down the hills was enough to make me super strong!

Starting a School and Drive4Rebecca (excerpt)

After Rebecca was given a diagnosis of having “autistic tendencies”, and Dr. Tom Boyle, a behavioral psychologist, recommended that we enroll Rebecca in an educational program using the science of Applied Behavioral Analysis (ABA), we started our quest for the best possible education for our daughter.

Our town recommended a county program for kids with autism and since we didn't know any better we went along with it. While there were some good teachers and therapists, by and large we were not very happy with the level of care or the quality of education.

We heard about a few private not for profit programs for children with autism that used ABA as their teaching method and found a small school in our area named Institute for Educational Development (IEA) which at the time was housed in an old church.

When I went for a tour during one of their open house days, I was blown away by what they were doing with the kids. I walked into the first classroom and asked why there were no cubicles. I thought all of the activity in the classroom would be very distracting to the kids. I was told that life is full of distractions so that is how they teach.

They said that their mission is to keep the family together, and they do everything in their power to help their students be able to succeed in every possible situation in life. For example, if a child had a difficult time getting a haircut, their teacher would start slowly, first visiting the hair salon and perhaps not even taking them inside. They would practice in a “barber's chair” at school wearing a smock, having their hair sprayed with water, brushed and blown dry. The teacher would accompany the family on several visits to a hair salon, working slowly towards getting the individual to step through the door, and eventually sitting in the chair for a haircut. The teacher would continue to assist the parents until everyone was confident that the family could handle the haircut on their own. The same would go for a trip to DisneyWorld. They would practice at a local park, walking around getting snacks, waiting on lines, until the child would be well prepared and the parents comfortable enough to enable them to take a family vacation.

It was on that day that I was inspired to start a new school.

Next I visited two other private not for profit schools, Princeton Children Development Center (PCDI) and Alpine Learning Group, the pioneers in using ABA to teach individuals affected by autism. After seeing all of the progress that the children were making, I knew I couldn't rest until I found a way to get Rebecca into one of those schools.

Aileen and John Crowley are Driven

In 2010, the world learned of the incredible accomplishments of Aileen and John Crowley. Their story was told in the film *Extraordinary Measures* that starred Harrison Ford and Brendan Fraser.

When Aileen and John learned that their two young children, Megan and Patrick were dying from a rare genetic disorder called Pompe disease, they stopped at nothing in their quest to find a cure.

John began working in the pharmaceutical industry, searching night and day for answers and racing to find a way to help his children while Aileen was home caring for them as their health rapidly deteriorated.

A Miracle on 99th Street

Emotionally, February 2012 was one of the most challenging times for our family and unlike anything we have dealt with for quite some time, perhaps since Rebecca was born.

Rebecca has a rare genetic disorder called Phelan McDermid Syndrome and there are only 700 individuals identified worldwide with this disorder. Going back a few years ago, we found out about some exciting research underway at Mount Sinai's Seaver Autism Center in New York. What they discovered was that when mice whose cells were genetically altered to simulate this disorder were given a human growth hormone for two weeks, their cells reverted to normal!

While what happens with mice does not necessarily translate to humans (nine cancers that have been cured in mice have yet to help cure people), it was amazing to find out that someone was paying attention to and cared about something so rare that affected our daughter. Phelan McDermid Syndrome has now been called a genetic based autism disorder and it seems that through these clinical trials they may be able to gain some answers about related disorders and perhaps unlock more clues about "classic autism" to help many more individuals and families.

We brought Rebecca in to see Dr. Alex Kolevzon and his terrific team at Seaver Autism Center for hours of psychological and genetic testing to confirm that Rebecca would qualify for the trial and she did. Fast forward to December 2011 - we found out that Seaver Autism Center had gained approval from the FDA to get started. We were told however that 30 families had visited Mount Sinai to be tested and evaluated but they only had funding to start with 10.

One major issue in our case was that we were in a bit of a race for time. Because the trial involves a growth hormone, IGF-1, and with Rebecca going on 16, there was a requirement that her growth plates had to be open otherwise it could be dangerous for her to take the drug and she might not be able to participate. As of the past summer, when she had twisted her ankle, an X-ray showed that her growth plates were still open so we were confident but still concerned.

We kept our fingers crossed, and at the end of January we received an email from Alex that Rebecca was chosen to participate in the trial. We were very lucky because one of the most important factors in their selection criteria was geography, meaning they would start with individuals living closest to their facility to allow them to participate without disrupting their normal routine (there are families living around the globe who would mortgage their homes without hesitation to get their children into this trial).

Aside from getting REED Academy started, this was probably the most exciting news we had ever had for Rebecca. Although we were not pinning our hopes on a miracle cure, it was remarkable to learn that there might be something that could help our angel of a daughter, the 700 other families, and perhaps many more individuals affected by autism some day.

While we were celebrating with tears of joy, and we gave our family and a few close friends the great news, just hours later we received a second email. Rebecca would have to take a few tests to confirm she was medically able to withstand the trial, and most critically they needed to reconfirm that her growth plates were still open. While we thought we were pretty much in the clear because of the X-rays from the summer, this put a bit of a damper on the big news and we were anxious to get these tests out of the way and proceed.

It was a Friday and we were told we could come in for X-rays early the next week. By Tuesday I was getting very impatient (no surprise) waiting to hear from their radiology department. I asked if we could go to our local Englewood Hospital instead, which was much more convenient and would be quicker and easier for Rebecca.

That night we went for the X-rays and I took a picture with my iPhone and emailed it to Alex. He was surprised at the quality of the photo and said he would email it right away to Dr. Rapaport, who was their consultant on the project and Chief of Pediatric Endocrinology at Mount Sinai.

Two nail biting hours later we received a devastating blow in the form of a phone call from Alex. He said "I'm so sorry to tell you this, but I spoke with Dr. Rapaport and Rebecca's growth plates are closed. Unfortunately she will be unable to participate in the trials. I can't tell you how sorry I am."

You can only imagine how incredibly upsetting this news was to our family, and in particular to Michey, now that our single greatest hope for Rebecca which was on the near horizon, was suddenly ripped away and was now gone forever. We were up all night and Michey was practically inconsolable. The next morning Sam, our 12-year-old son, cried hysterically when he heard the news.

I was incredibly upset and didn't know what to think or even which way was up or down. Once I gathered my thoughts I decided we would see how the trial went with the other participants and, if there were significant changes, we would somehow find a way to obtain the medication independent of the study.

I told Michey I would start looking into the potential dangers to Rebecca, so that we could do a risk/reward analysis and determine if it would make sense to pursue this course of action once the results of the trial were known.

Michey didn't want any part of this. She was finished. She said "I don't want to hear about it anymore because emotionally I can't take it. It's over for me now. Do whatever you need to do but don't talk to me about it, and don't talk to Sam about it anymore and give him false hopes. If something good happens as a result of whatever it is that you want to do that's great, but I am getting off this emotional roller coaster right now." I completely understood and respected her wishes (for at least a few days).

DRIVEN

50% of the proceeds from sales of DRIVEN will benefit Drive4Rebecca, Jon Singer's foundation that helps parents to become stronger advocates and supports charities that help children with special needs.

Learn more about Driven at DrivenStory.com.

Join our email list to be the first to know about fun events, to find out when DRIVEN is coming out and more - singer@eimpulse.com

DrivenStory.com
DrivenStory.com
DrivenStory.com