

Good afternoon, and welcome to the annual Reach for a Star Luncheon. I am very excited, and extremely honored to be able to speak to you today. As I look out into the crowd, I see so many familiar faces and am reminded of the great impact The Henry Viscardi School, and The Viscardi Center has had on my life. I truly believe that I am the person I am today because of HVS.

I started at The Henry Viscardi School when I was only three years old. Even at that young age, I knew I was different, but I didn't really know why. I remember playing with other children in the apartment building where I used to live and being the only one who wasn't able to run. Although I was never treated any differently than the other children, I knew that I was not able to do all the things that they were able to do. When I first visited Viscardi, I remember being amazed to see so many people like me. People who weren't running on their feet, but people who were speeding down the halls in their motorized wheelchairs. It only took a matter of seconds to realize that this was the place I wanted to be, and this is where I belonged.

I attended HVS from pre-k until 12th grade, and I graduated in 2014 with a regents diploma. During the fourteen years I was at Viscardi, I experienced some of the greatest moments of my life and created some of the best memories. I was also able to create countless life-long relationships with the Viscardi students and staff, many of whom are in this room right now. These relationships are ones that I will cherish for many years, and quite possibly my entire life. At Viscardi, our bonds are so strong that we consider each other to be one big family.

You may be wondering what its like to be a student at Viscardi. To be honest, it is not much different than being a student in any other school. We learned all the same material, we were stressed about tests, we had “cool” teachers and not so “cool” teachers, there were the popular kids, the nerds, the jocks, the music kids, and the artistic kids, and yes, we even had the unnecessary and overblown middle school drama. But one thing we all have in common is our love for each other.

One thing that makes Viscardi stand out from the ordinary school is the fact that we have to make our extracurricular activities fit our needs. One of these activities is wheelchair basketball. When I was in third grade, I joined the Cubbies, which is Viscardi’s elementary basketball team. For the first time, I was able to participate in a sport! I undeniably loved being on the court and speeding up and down with the ball and making shots. I was on the Cubbies until 6th grade, and in 7th grade, I moved up to the Cougars, which is the high school team.

Now that I was on the Cougars, the game became more intense and a lot more competitive, and I absolutely loved it. Being a part of the team, with the guidance of coach Joe Slaninka and the other coaches, instilled in me a sense of teamwork and an incredible amount of sportsmanship. When I was in 10th grade, I received the Bubba Award, which is given to a player each year that exemplifies not only great skill, but also great sportsmanship. This award is named after one of the best wheelchair basketball players to have passed through The Henry Viscardi School, Scotty Pollock. Receiving that award was a huge accomplishment. It has been almost four years since I last played wheelchair basketball, and it is definitely one of the things I miss most about my time as a student at Viscardi.

Another activity that I participated in was Friday night rec. One Friday of every month, students were able to stay after school for a few extra hours and have fun with their friends, and peers. There, we would split up into groups depending on what we wanted to do. we could either play sports in the gym, go to the computer room, dance, or engage in other activities. I always stayed in the gym because where else would I be able to play sports and not be the only one in a wheelchair? But whatever we chose to do, we were together. This program is so important to the students at Viscardi because we all live so far away from each other, and since distance and transportation options were limiting, we would otherwise rarely ever get to see our friends outside of school.

The independent living house, which is run by the wonderful Mrs. Albrecht, was another activity that I participated in. There is a house on the school's campus at which juniors and seniors have the opportunity to spend a weekend there with their friends. Everything in this house was built with our abilities in mind. It has an accessible kitchen, which has a sink you can roll right under, as well as two accessible bedrooms and bathrooms. As a student, I spent three weekends there. Being in the house meant being together and living independently in an adaptive setting. The point of the independent living house is to give students a glimpse of what life is like living on our own, and to practice our independent living skills. There, we were responsible for food shopping, making our own meals, planning out our activities for the next day, which included making sure we had a clear way to get to our destination, and budgeting our expenses.

These extracurricular activities are great. However, they would not be possible if it were not for the amazing therapists, who are always thinking of ways that will help us participate. I

remember one of my fellow teammates was physically unable to push the basketball into the hoop himself, so a team of occupational and physical therapists brainstormed and came up with a genius solution. The solution was to use one of those toys where the head pops up if you press a button. They attached the toy to the side of his wheelchair and added a small plastic ring to the top of the toy to hold the ball. They then hardwired a tiny switch into the toy and programmed it so that when the player pressed the switch, the toy popped its head up and would push the ball into the hoop. Pretty amazing, right?

This is just one of the many ways in which the therapists help us. There are also speech therapists who assist students who have trouble speaking or are non-verbal. These students are taught to communicate by gesturing or gazing at pictures on a board. Some are even taught to communicate with a device called a Dynavox, which speaks for them.

In August of 2014, a new chapter of my life began. I started college at Hofstra University. Not only was I now taking college classes, but I was living on campus! This was a very exciting, but also terrifying time for me. The transition from high school to college was not easy. This transition is hard for anybody, but for people with disabilities, it is ten times harder. Everything I knew about life was suddenly changing, which wasn't a bad thing! I no longer had my parents present at my side. I no longer had someone to advocate for me in the moment. I no longer had teachers reminding me when assignments were due. I was on my own, and I had to learn how to get by on my own.

Attending Viscardi for fourteen years, I was comfortable and confident in myself. Making friends and socializing came naturally. Now, I was at a university where I was one of

over ten thousand students. As social as I was at Viscardi, I found myself struggling to find my place. I was no longer in my comfort zone. I tried my best to go to as many events and clubs on campus in hopes of connecting with other students, but I never really clicked with anyone. In my junior year, I joined a national community service fraternity called Alpha Phi Omega. It was in this fraternity that I found my new home. I finally found a place where I belonged at Hofstra, and people who I could actually call my friends, some of whom are here today. Being part of this fraternity has completely changed my college experience, and I am incredibly grateful for that. In fact, I am currently acting in a leadership role as Vice President of Fellowship.

One of the main reasons I chose to attend Hofstra, was because they have an outstanding office for students with disabilities, or as they call it, Student Access Services. This office is led by Julie Yindra, who is also here today. She has become an invaluable part of my college career and has been by my side from the very first day we met. I would not be as successful as I am without her help, and I want to say thank you.

Student Access Services makes sure I receive the accommodations that I need to succeed. These accommodations are ones that I had at Viscardi, such as extended test time, a scribe, and frequent breaks. At Viscardi, everyone had accommodations, and there was no questioning why. However, at Hofstra, I have had experiences with a few professors that were not understanding of my needs. For example, I had one professor who could not understand why I needed accommodations, and even compared my disability to someone who has a stomach ache. It was clear she was just not willing to work with me and give me what I needed to do well in her class. I had to prove that I wasn't looking for any special favors or trying to get out of doing any assignments. But this professor just didn't get it. My first meeting with her

ended when she refused to acknowledge that there were times when I had to leave the room out of medical necessity.

I realized early on that the only way I was going to succeed in her class, as well as other classes, is if I advocate for myself. I was unable to get through to her, so instead I took it to the next level. I brought the matter straight to the head of the department and to Julie Yindra. It felt great knowing that I stood up for myself and gained confidence in knowing that there were others willing to hear me – even when the professor wouldn't. Hopefully this professor took something from my time in her class too, and she will be more understanding and appreciative of individuals who may cross her path in the future who, like me, need special accommodations.

Outside of school, I am just a normal person, with a normal life. I live at home with my wonderful and amazing parents, and my two younger brothers, Sam and Jack. Over the years we have gotten many comments about how inspirational our family is. And while we do appreciate these comments, it also takes us by surprise because we don't see or consider ourselves any different from other families. My parents have never treated me any different than my brothers. My brothers and I even have that typical sibling rivalry. My family definitely has to deal with more than the average family, but we always make the best of every situation. Like that time we got to the Bahamas, only to find out a piece to my ventilator was broken. A story which sent my father on an adventure raiding the storage closets of the two island hospitals, and my mother raiding the mini-bar, but one which turned out okay in the end. We surely do have some crazy stories.

For those that don't know, when I was one, I was diagnosed with one of the rarest forms of muscular dystrophy called Nemaline Rod Myopathy. NM effects all of my skeletal muscles. These muscles are the ones we use to move our body. It effects my ability to walk, as well as my ability to eat and speak. Only one in 50,000 people are born with NM, but with the help of social media, our small and widely dispersed community has become very close with each other. We consider each other a big family, just like we do at Viscardi. Every few years there is a conference, and every summer there is a gathering for individuals and families affected by NM. People from all over the world come to attend these events. I have met friends who have come as far as Brazil and Sweden! In fact, I met my boyfriend, Justin, at the 2013 NM conference in Canada. Since 2016, I have been a part of the planning committee for these events.

Because of my disability, I am required to have assistance with almost every aspect of my life. For many years, I had private duty nursing. Not only were they in my home, but they also went to school with me. At Viscardi, I didn't really mind having my nurses around because there were other people with nurses as well, so it was never a big deal. However, being in college, I felt like I was being held back from doing what I wanted to do and was not able to be as independent as I wanted to be. While I have been blessed with having some amazing nurses over the years, having nurses was no longer fitting my lifestyle. It took a while, but after a few months of convincing, and assurance that my health and care would not be jeopardized, my parents finally agreed with the switch.

I currently have aides during the days and nurses for the overnight shifts. Honestly, this has been one of the best decisions I ever made. I feel so much freer, and I am able to do so

many more things. With nurses I felt as if I was living by someone else's rules, but with my aides I am able to live by my rules. I have done so many things, and have travelled to so many places independently with the help of my aides, where before I wasn't sure if I would be able to travel without my parents. And with the change over to aides, I also took on more responsibility for my care. I became the primary contact, recruiter and trainer. I am now in charge of the schedule, which my mom previously took care of for nearly two decades.

Although it may look like this transition was easy, it was not. It took many months for my family and I to make sure everything was in place, and to find the right people to help with my care. This was, and still is, a very tedious and time-consuming process. I will always need help and will always be looking for new people. So far, I have been very lucky with finding amazing people. However, not everyone that I find ends up working out, and there are still times where I do not have coverage, and my mom has to come to my rescue...literally.

In December, I will be graduating with a bachelor's degree in Public Relations with a minor in Civic Engagement. At the moment, I am not exactly sure what I want to do next, but I am so excited to see where life takes me from here. I am very passionate about beauty and travelling, and even more about advocating for the rights of people with disabilities, and I hope one day to use my expertise to advance the quality of lives of people with disabilities around the world.

I would like to thank Iris Katz, Ruth Geismar, and Denise Wolfbiss, as well as the entire Reach for a Star committee for having me here today. What an honor it is to be up here. I would especially like to thank Claudia Poglianich for reaching out to me and helping me with

whatever I needed to make this day possible. Thank you to Mr. Kemp, and the staff and administration for making Viscardi what it is today.

I want to thank Mrs. Amanda Jung for coming to evaluate me all those years ago and not giving up when my father wouldn't let her touch me, and for the many years I had her as a physical therapist. I want to thank my awesome friends who came out to support me today. I want to thank my lovely aides who go above and beyond for me. Words cannot describe how thankful and appreciative I am to have you in my life.

I want to give a super special thank you to my family who has been there for me through thick and thin. Your love and support has made me the strong woman I am today. Mom and Dad, thank you for always being there for me. Thank you for all the years of sleepless nights, doctors' appointments, hospital visits, and always fighting for what's best for me. I am so extremely grateful and blessed to call you my parents, and I love you so very much. Sam and Jack, I want to thank you for never looking at me as different. Thank you for being my best friends, and each of you for being someone I could always count on. Thank you for always going with the flow when the unexpected happens. And, thank you for being the best brothers a girl could ask for, even if we get on each other's nerves sometimes. I love you both so much.

Last, but not least, I want to thank everyone for coming here today. I loved sharing my story with all of you. Although I have my challenges, I never let it stop me from living my life in the best way possible, and I hope that I inspire other people with disabilities to do the same. Thank you, and have a wonderful rest of the day.