

Self Advocates Newsletter

"Don't talk about it, be about it"

www.yai.org

The YAI Polar Bear Club

by Allan Fraser

My grandpa used to do the Polar Bear Club on Coney Island every year in March. They used to do it without bathing trunks!

This year I went with my girlfriend, her name is Mary Klerese. I had a good time, the water is cold. My feet got numb so I went back out. It was freezing cold. And also me and my girlfriend had fun. That day was sunny, but then clouds, and cold. A lot of YAI staff was there, Sean Keller was there, and Jace was there. I would do it again next year!



Allan and Maru Klerese test out the cold water!

2018 Baseball Season

by Ismael Nunez

While everyone in Houston celebrated the Houston Astros 2017 World Series victory, both New York baseball teams, the New York Yankees and New York Mets, were going through major changes.

NY Yankees: Terminated their manager, Joe Girardi, and hired first time manager, Aaron Boone.

Continued on next page



Seeing beyond disability.

Upcoming Events

May 1

Mental Health Awareness Month

May 24

Manhattan Self Advocate Meeting

June 2

Central Park Challenge!

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Boone has no managerial experience. His main highlight was when he hit the game winning home run in Game 7 of the American League Championship series against the Boston Red Sox. The NY Yankees in the off season made a major trade by obtaining 2017 Most Valuable Player Giancarlo Stanton from the Florida Marlins. For many this is the sign of Murderer's Row, with Rookie of the Year outfielder Aaron Judge who hit over 50 home runs and Catcher Gary Sanchez who hit over 30 home runs. Yet remember, talk is cheap. Let's wait until the season starts and ends.



As for the New York Mets, they'll most likely need a prayer. It's true they have a fine starting rotation, yet what's important is for their starting rotation to be healthy! Good pitching stops good hitting yet one has to wait and see if this will happen with this rotation. The new NY Mets manager is going to need a lot of help from his coaching staff. The area is hitting! This team needs to work on their hitting especially with men on base.

Chat with Car'Melo: Meet YAI Staff Megan Cerezo

by Car'Melo Grau-Puig

On March 14, 2018 I had the privilege to interview one of the members of the YAI Advancement and Communications team and she's going on almost a year with the agency. She discussed working on projects, events and fundraising and that person happens to be **Megan Cerezo**. She explains what the future holds for YAI and how we can continue to carry on its legacy. Everybody pay close attention on what we discuss...

You are already going on almost a year with YAI. What is your role in the agency?

I was hired as the Director of Special Events for YAI and my job is to oversee fundraising for the entire network and all our affiliate agencies. Essentially my plan and goals are to create fundraising plans for YAI Network and for the other agencies which include MSA (Manhattan Star Academy) and I oversee all the regional fundraising so when any region host any kind of fundraiser or event, big or small, we try to support them the best way we can.



Car'Melo and Megan strike a pose

What is your background before joining YAI?

My background is in special events and fundraising and I was the associate director of special events at the Montefiore Medical Center and so actually I ran all the events at Montefiore and I was there for 5 years and then I came to YAI.



With 2018 YAI Central Park Challenge coming in June, what can we expect for this year's event?

We're trying to do whatever we can to make the event even better and we really want to see 7,000 people at Central Park cheering and having a good time. We're working on getting new entertainment and just trying to figure out on how we can get people excited, and making sure that people are engaged and they're supported in their fundraising and just really excited about the event. We want to build as much momentum as possible and so for the event we're going to have new activities such as an African drum circle and we're going to do zumba that day as well and we're going to make sure that we have a DJ. We're just trying to bring out a bunch of new activities that we haven't seen before and we want the Central Park Challenge to be a day where people of all abilities are celebrated. We're looking to get more runners at the event because we just really want to increase the involvement of the running community, and we want the people that we support to have a wonderful time, and we want their families to have a great time, and we want to really just to make it a huge celebration of everything that YAI is all about!

What is the process for hosting a fundraiser at YAI?

For anyone who is interested in hosting a fundraiser at YAI, the first steps is that they can go on to the Intranet under the "Advancement and Communications" and they can fill out the fundraising questionnaire. That's usually a necessary first step so once someone fills out the questionnaire, that'll give us the title of your event, the day you want to host, and potentially the time you want to host your event, and the type of promotions that you want. For example, do you want us to create flyers, do you want us to create your invitations, and do you think that we should promote it in Network News?

So after we look at the fundraising questionnaire we'll get back to you within 48 hours and we'll give you a call to talk about your goals and what we can do to best support them. Then we work with you on doing a fundraising plan. We'll work with people to set everything up on social media, we'll create your marketing materials, and for some events we will also work on a plan for some social media presence. That's basically the first step. Also, it gives us the chance to collaborate and really work together with people who work in programs and people who are working in different departments. It's a great opportunity to just really bring everyone together and to collaborate on things, and again, for everyone to feel supported in what they're doing. What I find really amazing is that we have a lot of people who work in different day habs, different departments, and different residences, and that people get excited when they want to host an event for CPC. They want to fundraise for their teams and for their programs and I think that's the real testament to the passion that people have for YAI, and I just want to do what I can so that everyone feels they are supported in that.

Can you explain FIT's partnership with YAI?

Currently, we're working with the FIT students. We're trying to build a relationship with them and just really work with them to figure out what we can do to help expand YAI's brand presence and how we can help to elevate our events. The students are actually volunteering their time and they obviously get class credit, but they work with us on a project and we're their client. It also gives them an internship opportunity and a lot of them want to get into marketing and events fields. They get to work with us to get some kind of real world experience and we get an opportunity to get other people's perspectives on what we're doing, so we're very proud of this partnership and it's really exciting.

What advice would you give a person with a disability that is pursuing goals like jobs, college, etc?

I would tell them always be genuine and always stay true to who you are because I think that, in my experience and my career, when you're genuinely yourself and people get a greater sense of who you are, you're more likely to succeed. Another important thing is trying to focus on doing something that you really love so that you're really, truly passionate about it because that passion will speak for itself

What is your opinion with people using the "R" word?

I honestly think using that word makes people feel like they're not even human and I wholeheartedly believed in the campaign to eliminate the "R" word because I think that people just want to feel like they're included in their own community and they belong there. When you do something like use the "R" word you put that kind of negative label on a person it makes them feel like they're not welcomed. It makes them feel like they don't belong and that's very alienating.

What other plans are you working on for YAI in 2018?

Definitely right now the number one thing on my list is making sure that we have a very successful Central Park Challenge, and just looking into the future and seeing how we can grow and how can we continue to raise more money for the agency. We definitely want to make sure that we're expanding our fundraising efforts and we're trying to bridge a gap between how much money, like 98% of YAI funding, comes from the government and also from the OPWDD and Medicaid and Medicare. We want to bridge that gap and figure how we can grow actual fundraising dollars.

Don Cornelius

by Kenneth Youngblood

The Soul Train host was Don Cornelius in 1971-2006. He was born in September 27, 1936 from Chicago, Illinois but he was dead in February 1, 2012 in Sherman Oaks, Los Angeles, California.

They got soul train scramble board, soul train gang and soul train line.

I will love to see the soul train line of dance with people with disabilities. I will like to do soul train scramble board and break dance.



Black Panther

by Michael Howard

Black Panther should be an inspiration for people with disabilities. The day I went to see it was March 4th. The movie was good, but I fell asleep on some parts because it was long. I was kind of tired also. I caught the very first show at 12:00. I saw it at Main Street Cinema in Kew Garden Hills.

I've been a Queens guy all my life, since I was born. I kind of like it, but I wish I was living in Brooklyn. I've been living in various places in Queens. I was born in St. Albans and then I lived in Jamaica Estates temporarily and then I lived in Woodside from 1991-2013. From Woodside I moved to Far Rockaway since 2013. It's hard for me to choose my favorite thing about Queens, but my favorite part is Long Island City on 48th Street. They have restaurants, clothing stores, they also have toy stores, but Toys-R-Us is going out of business. Right now they are liquidating in order to go out of business.

People will want to see the movie because the people are fighting back from what is going on in Washington. The fighting going on is using words not fists. Also, most of the main characters are African American with a few whites sprinkled in. So that makes this movie somewhat different from other action movies. This movie reminded me a little bit of the movie Dare Devil because both have a lot of action scenes and science fiction. I liked Dare Devil and anyone who liked it would also like Black Panther. The fact that Black Panther has made over a billion dollars at the box office, I would give it 5 stars.

Interview for Johanna Berglein, MPA

by Janice McPhillips

How long have you been with YAI?

I have worked for YAI for 10 years. I started as an Assistant Supervisor at the East 15th Street Residence in Brooklyn and was the Supervisor of the Avenue Z Residence in Brooklyn for 7 years. It's been a privilege to meet all the wonderful people we support and to work with all the great staff.

How long have you been with the United Nations?

I don't work for the United Nations, but I have been attending their disability related events since 2010. I completed the application for YAI to receive consultative status in 2012. YAI was approved and has had consultative status with the Economic and Social Council of the UN since 2014. This status allows us to advocate for the needs of people with I/DD. We can advocate at meetings, organize panel discussions, and make official statements. Many countries still have large institutions for children and adults with



Johanna (second from left) and others at the UN!

disabilities. Many families still don't get any support. Many countries do not have ANY services. Much needs to be accomplished.

What are some activities that you have had with the advocates in partnering up with the United Nations through YAI?

Since 2015 YAI self advocates have been attending different events at UN Headquarters. Groups from Queens, Brooklyn, Westchester and Manhattan have attended World Down Syndrome Day on March 21st, World Autism Awareness Day April 2nd, and World Disability Day December 3rd. These days were dedicated by the United Nations to raise awareness for the needs of people and their families. They are celebrated around the world and everyone is encouraged to organize their own celebration event to draw attention to the topic. Any of you can decide to organize your own celebration of the day as well. The UN organizes an event for each of these days and you can register to attend. Attendance is very important to show that the people who are affected by disabilities are advocating for their needs. These days are very interesting because you can hear about how people in other countries live with their disability. Often time you hear very inspirational stories.



In 2016 self advocates had the opportunity to speak directly to the YAI audience during a panel discussion. Janice, I remember you were one of our stars on the panel together with Ismael and Stephen. The panel was during the Conference on the Convention of the Rights of Persons with Disabilities. The Convention is an agreement that many countries have signed. It states that the countries who sign it will support people with disabilities in their country. The government then has to report to the United Nations at the annual conference on what they are doing to improve the lives of people with disabilities in their country.

If you want to attend events at UN Headquarter you can email: international@yai.org and we will send you invitations to upcoming events. Just be aware that you will have to register online with your personal information. I will not know that you registered unless you email me and let me know. The registration is handled by the UN and I don't know who registered. To enter the UN you need a state picture ID like a non-drivers license or passport. You have to follow the instructions in the confirmation email and have to be there on time at the UN to collect your pass. You will also have to go through security similar to the airport. It is a very exciting adventure and you can reach out to me if you have questions.

What is your favorite activity with the United Nations through YAI?

My favorite activity is to learn about how people with disabilities in other countries live. I enjoy advocating for the needs of people with I/DD by asking questions during meetings and speaking to people at the UN about ways to improve the lives of people with I/DD. The needs of people with disabilities have been ignored for a long time and in recent years a strong advocacy movement has formed. Advocates from many countries speak up to ensure that governments and societies pay more attention to the needs and value of

people with disabilities. With the right supports every person is able to bring value to their community and everyone deserves that chance. People with physical disability who are in wheelchairs, deaf or blind have very strong self advocates at the UN. People with I/DD are still not very well recognized and I want to support the movement to give people with I/DD a voice at the United Nations. But I cannot do that without your support.

What made you decide to get a job with the United Nations?

I do not work for the United Nations, only for YAI. As the Manager of International Affairs, I develop international relationships for YAI to support the person centered service development all around the world. Working at YAI and meeting all the wonderful people over the past 10 years makes me believe that YAI can be a great support to other countries and raise awareness at the UN for the needs of people with I/DD. After seeing the terrible conditions some people still face I feel compelled to be part of the change. To bring YAI's great mission of living, loving, working and learning to the international community and reach people beyond NYC is my motivation. Anyone who wants to be part of this change is welcome to join me in this effort. Only the presence of self advocates gives me as a staff person the legitimacy to speak on your behalf.

All About My Parents

by Jennifer Naftelowitz

My dad was very important to me. He was married for 42 years to a beautiful woman, my mother. I was lucky to have a dad that I love. I am glad that I got to know him. My dad was important to me because he was my teacher and mentor.

My mom is the best woman ever. She has been my best friend and role model in the whole world. Mom has been there for me because she gave me life and taught me how to be independent. I love my mom forever and ever because she is my #1 mom ever. Me and my mom spend a lot of time together going out for dinner or to sporting events.

The Car Auto Show

by Jennifer Naftelowitz

Rene and I went to the Car Auto Show last Saturday when we were off on spring break at the Javits Center. We hung out all day there walking around every floor looking at different kinds of cars. Rene and I went to the Toyota Live listening to trivia questions for great prizes. Rene looked great up there dancing with my sunglasses on in front of the audience. We went for a drive in a car with a guy named Mike.



Arsenio Rodriguez

by Ismael Nunez

In the borough of the Bronx, NY, a street is dedicated to a gifted musician, bandleader, and an inspiration to all people with disabilities. His name: Arsenio Rodriguez.

If one travels to the Bronx, gets off at the Number 6 train stop on Longwood Avenue, and walks to Dawson St. between Intervale and Longwood Aves. near Rainey Park, you will notice Arsenio Rodriguez Way, which is dedicated to the late salsa singer and Cuban bandleader musician.

Rodriguez, who had been blind since the age of seven, would go on to make a tremendous impact on the world of Latin Music. He was a composer and it has been reported he wrote over 200 songs.

According to www.bailasociety.tv, he developed the son montuno, and other Afro-Cuban rhythms, and is often said to be the true creator of the "Mambo. "The conjunto format, son montuno, and mambo are three essential elements of what would later be called salsa."

Rodriguez was also a gifted guitar player, conga drummer, and bandleader. While living in New York City, he will go on to play with notable musical giants and fellow Cuban percussionist Chano Pozo and other great musical artists of what became Latin Jazz like Dizzy Gillespie, Tito Puente, and fellow Cuban Mario Bauza.

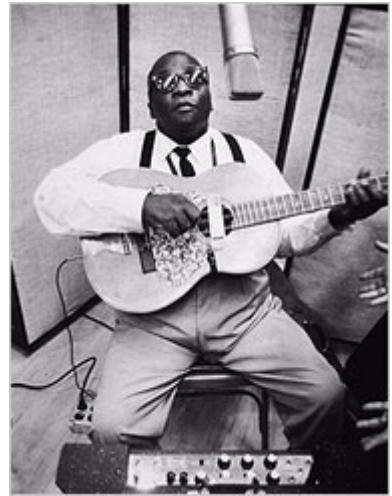
Before there was Helen Keller, there was Ragnhild Kåta: Defying the Odds and Breaking Curses

by Car'Melo Grau-Puig

There were a lot of famous people that were born deaf-blind that have received a lot of achievements. They succeeded and didn't stop from reaching their potential. They continue to break barriers and not let people stop them from what they're going for and reaching their goals.

Ragnhild Kata (05/23/1873 – 02/12/1947) was born in Norway and became the 1st European deafblind woman to ever receive proper schooling. She was able to talk despite having a condition. This inspired Helen Keller (who was also born blind) to do the same, as well as Laura Bridgman, Aslaug Haviland, Julia Brace and the rest of the disability icons.

When Ragnhild was 3 ½ years old she lost sight and hearing as well as her sense of smell and taste, probably the result of scarlet fever. In 1888, she was terrified by strangers that she didn't want to be touched



by. She managed to be calmed by the Norwegian administrator Elahas Hofgaard. She learned to understand others by placing her hand on their lips as they spoke. She also learned how to write and read Braille (tactile writing system). Hofgaard had employed the "speaking method" on very talented deaf students with good results. Still, it surprised many when he declared that he would use the method with Ragnhild. He was the reason why a deaf and blind child would learn to speak (rather than using the finger alphabet).

Hofgaard first taught Ragnhild to pronounce letters, then to combine two letters into a syllable, and finally multi-syllabic words, before trying to attach meaning to what had until then been presented as a complicated game. The first words used were: ur (watch), fot (foot), and bord (table). The words were associated with the objects over several days until Ragnhild understood that the words named the object.

During the summer of 1889, Ragnhild met Mary Swift Lamson (1822 – 1909), who was a teacher that had taught Laura Bridgman at the Perkins School for the Blind. At that time, Mrs. Lamson witnessed that Ragnhild could already speak simple sentences. In addition to her speaking and writing, Ragnhild became aware of knitting and weaving and received compliments for her works. An exhibition was set up in Skien, Norway in 1891.

Later in life she earned enough money from using her crafts to financially support herself. In her final years, Ragnhild had to leave school and her development became stagnated before getting help from Hofgaard and coming back to live at the school for another couple of years.

On December 3rd, 1900 she was listed at school in the census data as a talented deaf (and seeing) person, something previously believed to be impossible. She died in February 1947 after a bout with bronchitis. She was described as almost always smiling and good humored, talkative, with an unshakable faith in God.

Curtis Pride

by Michael Howard

Curtis Pride is a person who managed to overcome a disability to become a successful person. Curtis was born deaf from rubella. He grew up in Silver Spring, Maryland, and played many sports as a youngster. They included baseball, soccer, and basketball. He was a point guard on his basketball team.

Curtis used his 5% residual hearing to help him communicate. He also reads lips.

Curtis graduated from high school and went to the College of William & Mary where he continued to play baseball.

After graduating from college he signed a minor league contract with the NY Mets. He was traded to the Montreal Expos. He then went to the



Detroit Tigers where he continued to play. After the Tigers he went to the Boston Red Sox. He then went to the Atlanta Braves. He bounced around a bit with other teams before retiring. He ended up with a career batting average of .250 with 20 home runs and 82 RBIs in 420 major league games.

What makes Curtis special is that he was a good player with a disability, and he didn't let that disability hold him back. He was loved by the fans in every city he played and that also makes him special. His fans treated him like a human being as he is. Also, after not playing anymore, Curtis started a special foundation to help children with hearing problems. That also makes him very special. This is someone I would love to meet and talk to one day. He is an inspiration to me.

Salsa

by Ismael Nunez

Salsa, the hot sexy Latin dance, is the current rising fad and one of the most popular social dances in New York nowadays. There are plenty of Latin clubs, and plenty of great salsa dancers! But don't get it confused with "ballroom" salsa.

*Salsa/Mambo is the dance that came to popular attention in the '40s, as Americans became fascinated with the exciting rhythms emanating from Latin countries, like Cuba. For the mood of Mambo, just think Havana in its heyday, and the famous Palladium dancers of NYC in the '40s, '50s and '60s. "Shines" refers to the fancy steps that partners do when they break away from each other to dance separately. Our Shine classes offer a great opportunity for students to really familiarize themselves with the rhythm of the music, and learn how to move creatively, or "play" with steps within the rhythm of the music.

(*Excerpt from www.splittree.org and www.lorenzdancestudio.com)

This past April 6th at Lorenz Dance Studio in Manhattan was this reporter's birthday week. The present from the studio was a circle dance, a tradition for anyone celebrating their birthday. That night Jose, one of the instructors at the studio, mentioned to me "Hey, I know it's your birthday. It was announced in Facebook. Wanna go for it? Let me know!" Rosh, another instructor, asked "Did you do anything on your birthday?" I stated, "No, yet would've loved to have celebrated!" She added "Then this is the right present for you! You got this. Remember, you're around good people!"

Then Val a good friend/supporter who I had the honor of dancing/performing Bachata at this past Summer Show, added "Hey. Go for it. I will be there with you just like this past summer! Just have fun!"

Fun I did! With birthday circle dancing I don't remember the count, yet who cares! I had fun, no complaints, no sadness, no nervousness or shyness. I just had fun! Then I got a message from the studio. "We're so proud of you! Lorenz Dance Studio!"

Thank you so much! It was the perfect birthday gift!



Ismael with one of his dance partners!

A Giant Love

by Chris (Guest Writer)

A Giant has (a) human friend
His name is Jim
They play a lot of game (s)
The giant cares
They both believe in love
The human jumps
Into the lap of (the) Giant
Jim has a wife
Jim and Giant make fire
To warm up
Giant and Jim's wife sing
A nice lullaby
Jim and wife have (a) son
He weighs (a) ton
Of course they live in (the) woods
They have (the) goods



Beauty and The Con Man

by Chris (Guest Writer)

Beauty, she is so beautiful
Con man knows she's cheerful
Con man he took her heart
Know she part of his
Beauty
She calls Tim
Con man knows to be physical
She made him social
Beauty drives a nice car
She drive far
Con man can be a(n) act
It not pact
Con man does make her his
Can be right
Beauty changed his real world
His toes curled

**CON
MAN**

Jose Feliciano

by Ismael Nunez

*One of the most prominent Latin-born performers of the pop era, singer/guitarist Jose Feliciano, was born September 10, 1945, in Lares, Puerto Rico. He was the victim of congenital glaucoma and left permanently blind at birth. Five years later, he and his family moved to New York City's Spanish Harlem where he started to learn to play guitar, making his first public appearance at the Bronx's El Teatro Puerto Rico at the age of nine. (*Excerpt from www.allmusic.com)



**Feliciano's many awards over the years are a testament not only to his talent as a musician and singer, but to his generosity as a human being. However, to show all of his awards would take an entire web site. He has received virtually hundreds of awards, honorary certificates and expressions of thanks for his charitable work.

He has received a total of eight Grammy Awards thus far in his career, two in English and six in Spanish. He has won 17 Grammy nominations over the years, an accomplishment that he treasures dearly. Awarded through NARAS, the National Association of Recording Arts and Sciences, this is the music industry's own recognized standard for greatness among its participants. (**Excerpt from www.JoseFeliciano.com)

He has also been known for his charitable work supporting children with disabilities.