

ABILITY

JORDAN'S TIRO ARTS
KASSEM ISTANBOULI

**Segerstrom
Center for
the Arts**

interviews

**Casey Reitz
Chloe Saalsaa**

**MOST
LIKELY
NOT TO...**

...THE MUSICAL

**Sue Ann
PIEN**

The Ways She Sees It Actress, Model, Advocate



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Hello ABILITY readers, unfortunately, it has been a rough month for me and my family. My grandma passed away on January 24th. Something like this is never easy but I know that my grandma is not suffering any more and Heaven just added another beautiful angel. Her memorial will be coming up at the beginning of April so my family and myself will travel down to lower Michigan to all get together and celebrate her wonderful life!



I recently went to New York city for my friends early birthday celebration and it was such a blast! I haven't been to NYC in such a long time so it was definitely a treat to go! I forgot how much I loved to go there and what a fun city it is! We got to explore so many different places such as an 2 Omakase sushi places and different unique bars. I even won free martini's for a year at one bar because I posted a picture of my fabulous espresso

martini! My friend, Emily, booked us a trip on a tea town bus tour it was one of the most fun and funniest experiences! You taste all different kinds of teas and they provided some delish snacks too. It was nice to get out of my house and do some traveling but I have been



having some issues with my head that could possibly come from all of my concussions from racing. I have been having horrible migraines and seeing spots and almost passing out! Not a fun thing to happen. I have been going to the doctors to try and figure out what is going on with my head. Someone suggested I do a food allergy test and that I might be eating foods that trigger these migraines. I just ordered the test and I will soon be doing it to see if I can find any answers for myself. It's very cold here in Michigan right now so I am hoping when the weather warms up I will be ready to start riding! ■ **ABILITY**

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Dear employee,

We are delighted to inform you that your request for reasonable accommodations has been approved. Effective immediately, you can work your requested hours remotely, and your on-site office space has already been modified with the adaptive equipment you need. We also threw in a cabinet full of your favorite snacks as a little bonus.

Upon reviewing your employee record, we've additionally decided that you deserve more little treats, and we will be increasing your weekly compensation accordingly. To avoid any interference with your healthcare benefits, we are giving you this additional compensation in the form of cash, gift cards and passwords to all of the streaming services.

We also wanted to let you know that Alexa, your crush from high school, has moved back to town and lives right down the block from you now! She wants to get dinner with you at your convenience and is eager to become

close again. Don't tell her we told you, but she was also asking if you were single?

Later, as we were confirming your emergency contact, your dad asked us to tell you how proud of you he is and that he fixed your broken door opener button as well as the other door openers at your favorite neighborhood locations. Like your coworkers, he had nothing to say about you other than that you are delightful and a fantastic human.

We were hoping to deliver all of this news in person tomorrow, but unfortunately we have decided that our company will be closed for the rest of the month. All employees will receive paid time off for the next 29 days.

■ ABILITY



by Steven Verdile

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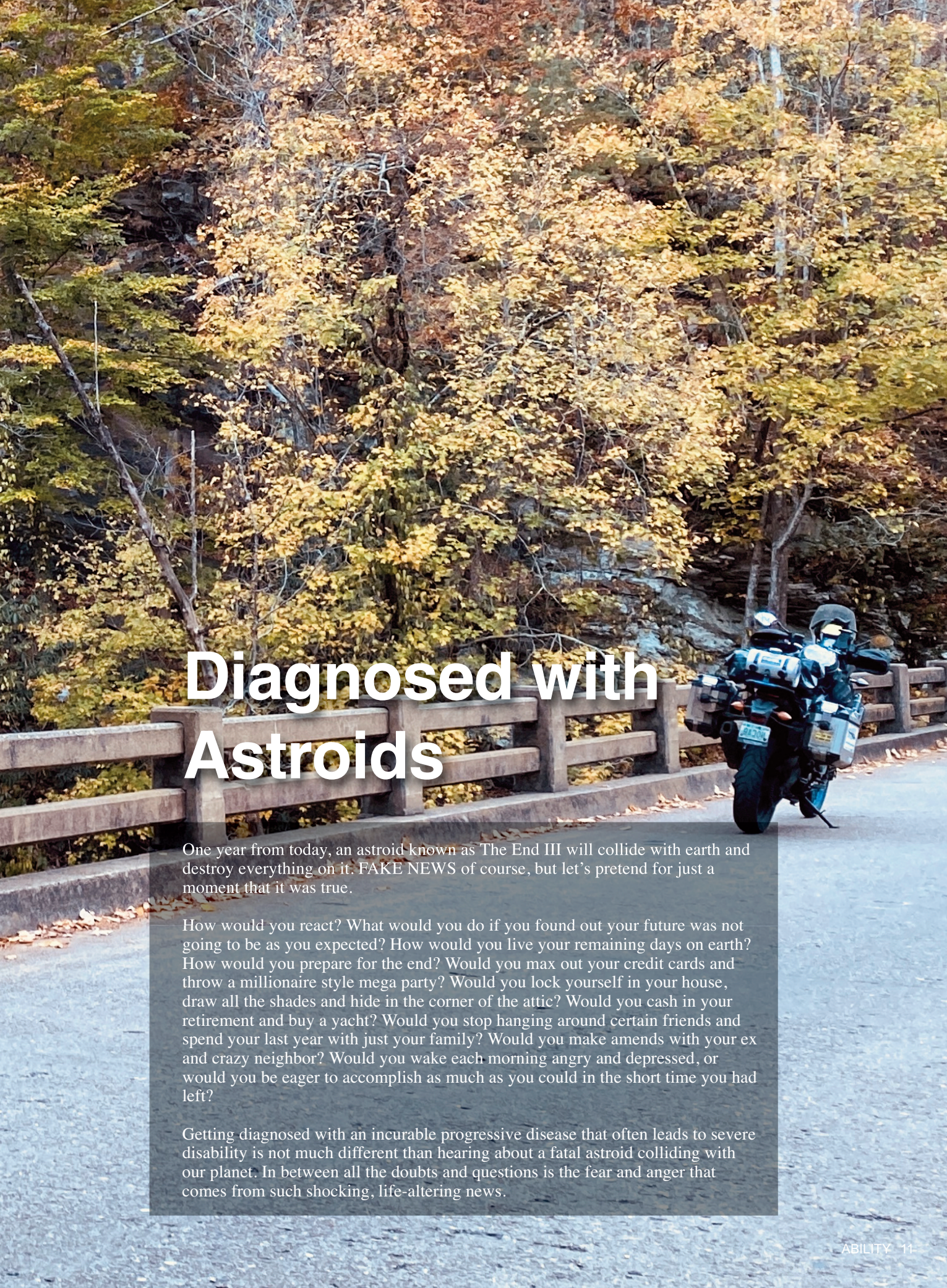


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Diagnosed with Astroids

One year from today, an astroid known as The End III will collide with earth and destroy everything on it. FAKE NEWS of course, but let's pretend for just a moment that it was true.

How would you react? What would you do if you found out your future was not going to be as you expected? How would you live your remaining days on earth? How would you prepare for the end? Would you max out your credit cards and throw a millionaire style mega party? Would you lock yourself in your house, draw all the shades and hide in the corner of the attic? Would you cash in your retirement and buy a yacht? Would you stop hanging around certain friends and spend your last year with just your family? Would you make amends with your ex and crazy neighbor? Would you wake each morning angry and depressed, or would you be eager to accomplish as much as you could in the short time you had left?

Getting diagnosed with an incurable progressive disease that often leads to severe disability is not much different than hearing about a fatal astroid colliding with our planet. In between all the doubts and questions is the fear and anger that comes from such shocking, life-altering news.





I have lived with Multiple Sclerosis for two decades. Although it has been twenty years since I first had to face the realization that my life and expectations for the future would change forever, I will never forget that fear, anger and depression that soon followed. An asteroid did indeed collide with my planet.

The first couple of years after getting my diagnosis were spent preparing for the end of the world as I knew it. I sold my small business, my motorcycles and prepared for the worse. I told all my close friends and family that the fun was over and I was destined for a life of disability and despair. My life and the future I had hoped to enjoy were about to be crushed by an unavoidable disaster and I had no means to control it's course. Any dreams I had of enjoying retirement later in life were shattered. I believed I would never make it to my golden years, and if I did, I would be physically unable to enjoy them. I certainly did not throw myself a block party during the first few years after getting my diagnosis.

Eventually, after getting on a disease modifying treatment and having little disease progression over the first five years, the fear and anger subsided. I realized I could possibly manage the severity of my disease and slow down the progression and level of my disability. I didn't expect my disease to go away, but I learned to live with it by taking care of myself physically and mentally. I learned how to make the best out of what having MS presented.

Better yet, I began to see how getting such a diagnosis made it possible for me to do some of the things I wanted to experience sooner than later in life. My MS diagnosis gave me special permission to live each day as if it might be my last. Knowing each good day was a gift, I tried hard to make each one count in a positive way. This is how I have managed to continue living well for two decades. So well in fact, I often forget to worry about the future!

There are no guarantees in life, and asteroids do happen. Life is short, so try to enjoy the ride.

■ **ABILITY**



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MOST LIKELY NOT TO...

“Most Likely Not To...” is a first-of-its-kind musical comedy centered around the difficulties of traveling with a disability. The musical was created in collaboration with members of the SMA (spinal muscular atrophy) community and the SMA My Way program founded by Genentech, a biotechnology company dedicated to discovering and developing medicine for people with serious and life-threatening diseases.

ABILITY Magazine’s Jennifer Woodall was joined in a virtual interview with Genentech’s Adam Pryor, creative director of the show, and singer-songwriter James Ian to discuss living with SMA, preparing for opening night, SMA My Way and advancing societal discourse around disability, visibility, and representation.

Jennifer Woodall: James, can you tell me a bit about SMA?

James Ian: Sure. SMA is degenerative, and so it affects muscles pretty much throughout the entire body. There’s various types of SMA, and I’m a type 3. I believe about 10% of people with SMA have my type, so it’s on the rarer side. SMA is a rare disease, it affects I believe one in 6000 births. My type is characterized sometimes as adolescent or adult onset, because I’ve had SMA my entire life, but the symptoms really become more prevalent as you hit puberty, which was very much the case for me. I had always kind of exhibited symptoms, but you really couldn’t tell. Then I had a growth spurt in high school, around the age of 14 going into 15, and I





Joel Manuel, Darlyn Castillo, Shannon DeVido

started to fall a lot more. My parents started to notice more symptoms. So with me, I have weakness throughout my body. I used to be able to run and use stairs, and now I'm no longer able to do those things. I fall sometimes, I can't get up on my own. I have difficulty getting up from a chair that's of regular height. It affects all the extremities.

Types 1 and 2 are typically characterized by from birth or you're using a wheelchair. Type 1s I think, always need assistance breathing, and then type 2s, sometimes they walk when they're younger, but then they pretty much require the use of the wheelchair from an early age throughout the rest of their life. So, it's characterized just by a progressive weakening of all your muscles.

Woodall: I listened to "SPACES", it's a beautiful song. Did you write it?

Ian: Yes, I wrote it. It was informed by a larger brainstorm with members of the SMA community. We had a brainstorm, took all the ideas and thoughts that people wanted to express, and boiled that into a song. I had two producers who are pros in the music industry that helped refine it, but I was the primary songwriter on that. The larger community, for sure, helped create that song from start to finish.

Woodall: Yeah, it's beautiful. Were you always into performance, or do you feel like this is something that you

came into later in life after you found out that you had SMA?

Ian: I've actually always been into it. I was into it before I found out I had SMA. I actually was a child actor. I was on a tv show when I was eight or nine, and I was in a couple of commercials. I had an agent that was very well known for representing child actors, so I started doing that at a really young age. I also started doing music at a really young age. I started taking piano at age of five, and I was singing even before then, so it's something that's been in my history for a long time. When I did get my diagnosis, I did think that those passions were off limits to me because of the really bad portrayals of disability in media. That's something I had to wrestle with and come to terms with as I got older, but always loved it and was always involved.

Woodall: That's wonderful. We interview so many people with various different disabilities, and a lot of them in the entertainment industry talk about that same sort of thing, where they come in with this idea of, "I'm never going to be able to perform. I'm not going to be able to do this," and then they end up finding their voice, and they find it so freeing.

Ian: Yeah. It was cool too, because SMA is progressive, it's actually been really beneficial to go back and see the difference in how my body has changed. I could do stuff when I was a kid, like scenes where I had to run for a bit

or get up off of a couch, and I did it with such ease back then. I'm kind of lucky in that regard where I can see that, because it's hard to remember. I don't really remember what it is like to run or anything like that, but I can see it on camera, so it's kind of interesting in that respect.

Woodall: What is the inspiration behind creating "Most Likely Not To..."?

Adam Pryor: I'm creative directing the musical. I've been working with James for a number of years now on Genentech's SMA My Way program, which was a program created to authentically represent members of the SMA community. SMA—spinal muscular atrophy—is a neurodegenerative disease. The company (Genentech) I work for makes a therapy for SMA, and it's part of my job to make sure that we go beyond those medicines. A lot of what SMA My Way is, is interacting and working with community members and representatives like James to create programs that help address how they want to be seen, and what programs and resources are most relevant to them. So through that, we created our past two programs which were an original song and music video called "SPACES", which James wrote and sang, and then a fashion show at New York Fashion Week in September of 2022, which was a first of its kind show called Double Take that featured the SMA community on the runway.

The inspiration for "Most Likely Not To...", which will be a first-of-its-kind musical comedy, was to authentically represent members of the community on stage and advance societal discourse around disability, visibility, and representation in a different area. So, it was music, music industry, fashion, and now on stage. The play really focuses on what it's like to live with SMA and especially when it comes to traveling. We wanted to advance discourse around disability and travel and just the issues that members of this community and the disability community at large have. The musical was actually inspired by some real examples of participants of the fashion show who were trying to get to New York for the show and ended up having these crazy travel issues that impacted their trip there. So, we knew that the next thematic area we wanted to pursue was around travel and this representation conversation.

Woodall: What do you hope to achieve with the musical? What are you hoping that the musical inspires in other people?

Pryor: I think predominantly, we want the musical to showcase members of the SMA community as talented, creative, multifaceted individuals. Also, we want to help move this next frontier of representation conversation forward. We feel like disability awareness—we're in the throes of that conversation—so how can we utilize this program to help keep that moving forward?

Woodall: Can you tell me how SMA My Way got started?

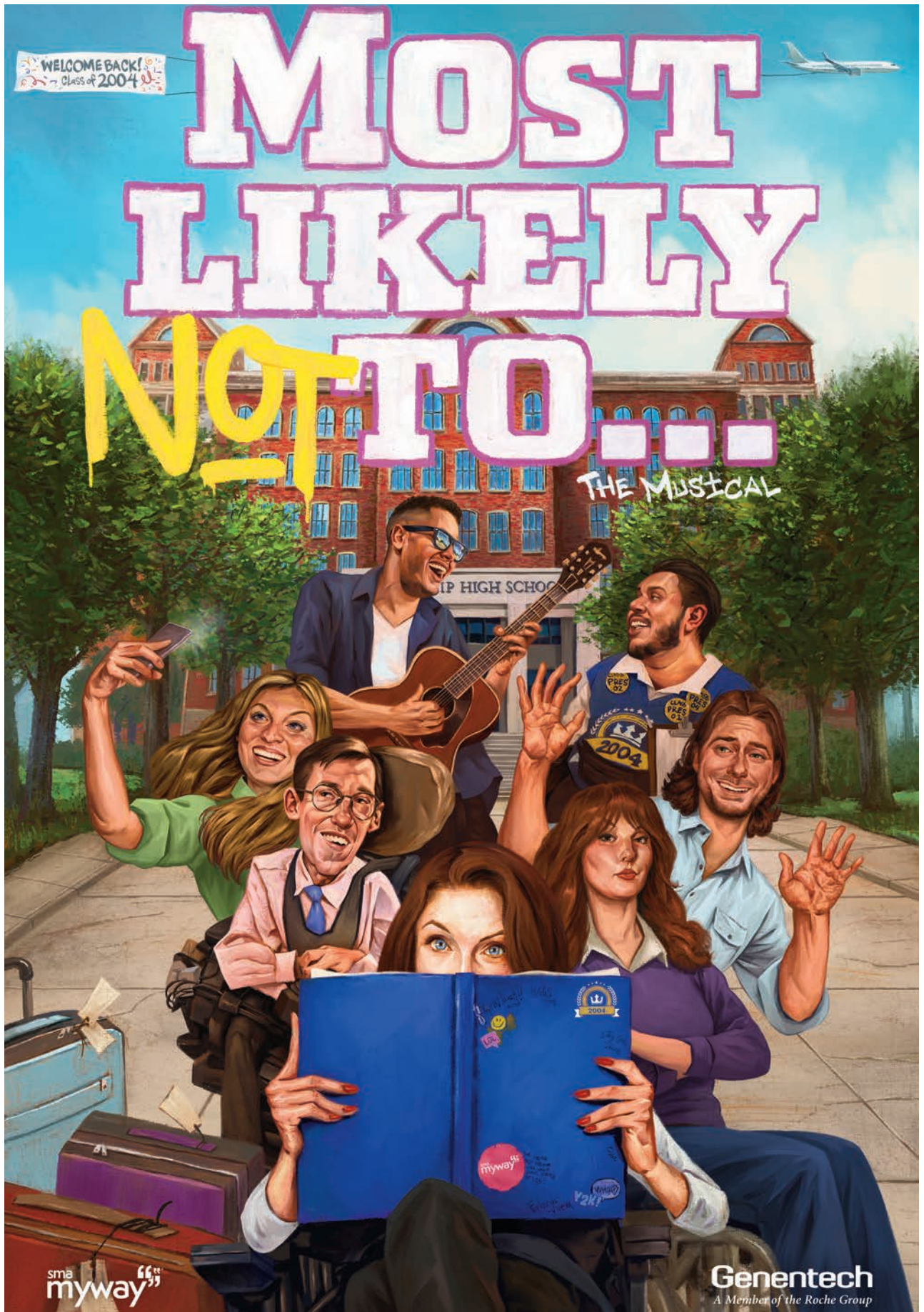
Pryor: So, SMA My Way lives on smamyway.com. It provides various types of resources to inspire and instruct the community, and portray them as multifaceted characters and provide real resources that are relevant to them. We were trying to figure out what would a program be in working with this community, and we went straight to the source and wanted this to be community led and community sourced, and this is what we heard—we want to have a one stop shop that represents who we are.

Woodall: James, can you tell me what it's like to prep for opening night, and what goes in to that? In addition, are there differences preparing for that when you have SMA versus when you don't?

Ian: Yeah, great question. So for part one of your question, in terms of just prepping for opening night, it's like heavy rehearsal. In a non-musical setting, like a dramatic theater experience, you're memorizing your lines and you're trying to bring the emotion and step into what the character is really feeling—what the character is really about. In the actual moments when the characters are interacting with dialog and other characters, you're trying to meet those moments authentically and honestly and really capture what someone's feeling and what they're trying to express. With the musical, there's an extra layer there of you want to sound good; you have lines, you have lyrics to memorize, you want to hit your notes. I feel like it's pretty daunting to act in a live setting because you can't do cuts and intakes. It's all right there, so there's not a lot of margin for error. Then you add a musical piece to it, too, so it gets even more precise.

I would say the prep is really intense. On top of lines and the emotions, you're trying to learn lyrics and hit your notes and then also convey the emotion of the song. It's really, really intense. I know me personally, I'm extremely thorough, and so I'm pretty meticulous. I'm going over everything with a fine-tooth comb, almost obsessively. To answer your second question, with SMA, we have to worry about our bodies. Fatigue with SMA is a very real thing. Weakness is a very real thing. My arms get tired. My legs get tired. So, for me personally, I know it's okay to have those things that SMA presents. I'm going to be cognizant of watching my steps and hoping that I don't trip and fall or if my arms get tired or weak, trying to account for that. It definitely adds another layer of physicality and protecting your energy and just being safe and making sure that you don't harm yourself. For the folks who use wheelchairs, hitting your marks with your wheelchair and trying to be accurate and precise with your stage marks, I think that's a very big factor, too.

Woodall: What is it like developing a show like this



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where you go from idea to putting pieces together?
What is that process like?

Pryor: It starts with bringing on the right team, making sure that all these functional experts are represented, then it just starts with an idea. In terms of the process that we like to implement when it comes to SMA My Way and how it's community led, it really starts with these group conversations with members of the SMA community to help inform everything that we're doing. So, it really was an open dialog and an open conversation with the SMA community about what is the story, what are these characters like, what is the look and feel of the creative, what are our songs addressing. I think that it's about pulling the right team and making sure we have our eyes set on what the purpose is.

Woodall: James, have you heard about abilityE?

Ian: I've definitely heard of *ABILITY Magazine*, but I've not heard of the entertainment piece.

Woodall: So abilityE is a free networking website where people within the entertainment industry that identify with having a disability can come together, and they're able to get casting from there, they can get in touch with people within the industry that are looking specifically to hire real life actors or real life singers that actually identify as having a disability. It's an awesome network. I like to tell the people that we talk to that are in the

entertainment sector about it because it's an awesome resource and it's not something that we really see in other places. We do this thing where we have reels that you could participate in if you wanted to, that we put on abilityE.org website and yeah, it would be just a great thing all around.

Ian: Thank you so much. I did not know about that, so I really appreciate that. Thanks, Jennifer. I'll for sure check that out.

Woodall: I really appreciate both of you guys taking the time to talk to me today. It's been awesome to hear more about this show and what you guys are doing with SMA My Way, and just bringing awareness.

Pryor: Well, thank you so much. Thanks for the interest. I'd like to say how excited we are about the musical, the creative, the songs, the script are just so good. I personally am just really grateful to get to do work like this. We will be debuting some of the songs before the show as well as some of the creatives. Thanks for your time, and James, thanks for everything—always.

Ian: Thanks for having me, and thanks, Jennifer. Really appreciate it. So cool to be a part of this project. So thank you, Adam as well. ■ **ABILITY**

smamyway.com/the-musical



Cultural Resistance — Tiro Association for Arts Lebanese Artist Kassem Istanbuli

Kassem Istanbuli is a passionate and renowned Lebanese artist who believes that art is for everyone. His conviction that artistic induction should be available everywhere, not just in metropolitan areas, led him to create the Tiro Association for Arts in Tripoli. Istanbuli's endeavors with Tiro have taken him around the world and into the heart of accessibility and inclusion efforts for people with disabilities.

Kassem Istanbuli met with *ABILITY Magazine's* Chet Cooper and Isabella Wisinger in a virtual interview to discuss his international career as an artist, winning the UNESCO-Sharjah Prize for Arab Culture, and the role of disability inclusion in the performing arts.

Isabella Wisinger: I would love to hear more about your career- how you got started as an artist and as a performer.

Kassem Istanbuli: I started as an actor in 2008 with Stanbury Theater Company. We started to do street performance. And we do different performances for Beckett, Arabal, international theaters. And we participate in

different festivals in the Arabic region, and in Europe and South America. In 2014, we started the project with Tiro Association for Arts. I had the idea about rehabilitating the old cinemas here in Lebanon. We rehabilitated four cinemas, three of them in the south of Lebanon, and one in the north. The idea is to link the south and north, and to create free cultural spaces. And that access to the arts becomes a right to everyone. From these ideas, we started different programs. We organize different festivals. Cinema, theater, contemporary dance, storytelling. We invite artists from all over the world to Lebanon. We do different training for kids and youth. And we started a program with women's handicrafts. We have community. We started a different program with special needs, to screen films to the deaf and also to the people who don't see.

This is new in Lebanon. This dream is from the people. And we all work together on this project to create free spaces for people and to art for everyone. In our space we have a library, we have coffee, we have a cinema. We also have a bus. It's called Peace Art Bus. I will send you a book about Tiro. We do different tours in areas





that have no culture. Our goal is to go to the people who have no opportunity to see art. And we work a lot with the community here. Lebanese, Syrian, and Palestinian people. We have many workers. They are coming from Bangladesh, from Ethiopia. They also participate in the festivals. For 15 years we've been doing a lot of activities. Till now, we've created like 61 festivals. I mean, a lot.

Wisinger: That's incredible. Can you tell me a how the festivals started?

Istanbouli: When we started to create festivals, we created this association. We invite people to come to stay in our houses. The families of the team cook. All the mothers cook for the guests. It's like we create a family festival. It's very personable. Artists come, they do training, they stay. We do a residency in Lebanon.

Wisinger: There's a live in residency program?

Istanbouli: Yeah. And this project is how we can believe



in our dream and make it fact. We are learning by doing. And everything's coming from community, from togetherness. We have the passion, we have the love. Imagine, we go from north to south. It's from the north, from the south to the north every day to create these old cinemas. Now the cinema in Tripoli is the oldest cinema in Lebanon, from 1932. The oldest cinema in Lebanon is open again after 30 years. Many of these independent cinemas closed because of the war in Lebanon. And now we created this space again to let people meet together again without fear. To meet people from different countries. We are lucky because this space is also our heritage. It's let us move between cultures and heritages. Also, we do cultural tourism. People move from place to place to see the festivals. This year, we will celebrate the 11th edition of the Tiro International Short Film Festival. We have the Tripoli International Theater Festival and Lebanon International Theater Festival for storytelling and contemporary dance. We do different performances with the students here, trainees from Tiro.

We do different plays for Dario, Lorca, Arabal, and

Beckett. And we do different performances like play-back theater. We also interact with the public in the street and open spaces with the bus when we move. Every day we have one movie screening, people can come without thinking about money because it's free. We work with the people who are poor, people of different cultures who come to watch movies, families, they all come to the cinema. You see different ages, different nationalities, different religions.

Wisinger: Are the screenings free to the public?

Istanbouli: Yes. All the activities, the training, the festivals, the spaces, anyone can access them for free. And the new name of the space is the Free Lebanese National Theater. It isn't linked to the government, the name means we are linked to the people. In most of Lebanon, it's difficult to access spaces because it costs money. All of this happened because this we started to do performance in the streets and open spaces. We do performances in different countries, more than 27 countries. They invite us, we invite them. Sometimes we invite them to stay in our home or in the cinema, sometimes we sleep in a hotel. Depends on the situation. Now that we have our partners, they believe in the project. We work with UNESCO and UNIFIL, here in the south of Lebanon. And the Institute in Lebanon gives us movies to screen.

Wisinger: I'm curious to know what inspired your love of film?

Istanbouli: When I was in school. One time the teacher asked, who wants to do the performance at the end of the year? All my friends raised their hands, and then I said, why I don't raise my hand? And I raised my hand, I didn't know that this rising of the hand would be a regular thing with me. And then I got on stage. And at that time, the stage had the person who sits on the stage with the text to tell you what to say. And now I visit the old theater all the time. It's near here, near the space we have in Tiro. I started to act every year in the school play. I remember one time I performed in a cinema Tiro later renewed, called Cinema Hamra. In the first memory I have of my brother, he took me to the cinema and it had no seats. I watched films at that cinema after we renewed it. It has been difficult, because we renewed four cinemas, but two of them, the owners got them back and they closed them.

This is a big problem. It's difficult to keep independent and to keep the spaces open. We have to include freedom in culture, because culture without freedom will not have the same results. At our cinemas, the first film we screen is always Cinema Paradiso, the Italian film. It speaks about the history of the cinema. I remember in Tripoli, the man who put on the projection cried. He said, this film is about me. I also have my roots, because my grandfather had his storytelling, he came from Turkey and he brought movies by boat from Greece and

Palestine. And they screen it here in Tiro on the wall. And my father, he also fixed problems in the projection. He's worked for us. Here in the south, there's no university to learn arts. So I went to Beirut. Now I am happy because we have the spaces to give opportunity to the people who live here in Tripoli, to learn arts and to see arts.

They don't need to go to Beirut. This is a problem about capitals that have all the centralized culture, and the goal of our project is to have balance, to have arts everywhere. Because we have many talented people everywhere. And anyone, if they have the opportunity and the access and the rights to watch art, they will go to watch arts. Because this is beauty, and this is the way that we are linked in all the world. It's by art. We can share human language, and we can understand each other. We can understand different cultures. When you sit with anyone to watch a film, you will share with him the pain, the happiness of that moment. And you clap together. You will not ask about any differences. You will always be with this person. And you see that we are all together, we are all human, we are all from this earth. We need same things. We need beauty and we need love.

Wisinger: I think that's beautiful. I love that you're bringing things back to your local community and inspiring people there. What are some of the most notable places that you've visited and organizations that you've partnered with?

Istanbouli: I mean, I traveled to Spain, for example, to the Barcelona Almagro Festival when we started. That was the first time I traveled, and then we traveled with the company. We asked the government to support. They didn't support. Then we went there, we had very little money, we rented a tent there to do our performance. And we enjoyed this experience, this festival. This first time, they selected Arabic companions to participate in this festival in Almagro in 2011. And then later we participated in Chile. I enjoy South America, we saw their culture and it's beautiful. I did a short film in Brazil, called "Back to Sao Paulo". It's a beautiful memory. In different Arabic regions, and in Spain, we usually participate a lot because we have many artists there. They're coming from South America, from Mexico, from Chile, from Venezuela, and Argentina. But we are lucky to meet them, because now during COVID we start to know that we all need each other, we are all connected. And to build culture, you need this. You cannot build alone, you need to build with the people.

We all need each other, we all support each other. And we can learn from each other, from different experiences. Because of this, we created the Arab Culture and Arts Network in 2020. And this network is how we can link all the world online, how we can exchange culture, how we can learn to speak and to open doors. We are lucky to have different platforms. This is the beauty of



technology. But yeah, I mean, it's difficult. And our experience these last five years has been very difficult. Because we face in Lebanon bad economic problems. To keep the cinema open, and to have the voice of the people. This is important. The people can say what they want on stage, to have social change, economic change, tourism change. This will help to change all the country. Because when people change their mind, they fight for rights. Especially when we work with special needs. We feel how much talent they have.

And it's not special needs, they are not in need, they have special power. When we screen films, the people who don't see, we see that they see by listening to how we can create films for them, how we can create movies with body language for the people who don't speak. And then we do performance with special needs. We have one member on the board of Tiro, who is also special needs. And we see they need space to create, they need to draw. The dream is that they feel like they give beautiful energy to the cinema and they are not alone. I

mean, we don't do separate training for them. No, we are all together. When we screen films, we let all the people come together, because this is what I mean, to be all together. This is important. It will not give any change if you do screening films only to them. You need to bring the people to see this experience.

Wisinger: Yes, you answered my next question before I could even ask it. I wanted to dive into your past experiences with disability equity and inclusion in the film space. And it sounds like you're already practicing that, which I think is wonderful. I was wondering, what are your thoughts on the state of disability inclusion in the film industry at the international level?

Istanbouli: We need the people, the production to start to think how we can put disabled characters in movies. You give them the space to speak about their stories, to speak about their problems, to build movies. This is the most important, to give them space, to give them voice. And this can be changed in theater. They can be beauti-



ful characters, they can draw, they can do different things. I mean, what the public needs to have a change, is to write stories, to speak about special needs, put them in a movies, give a job to the people with special needs. They can feel like they can be like anyone, they can do anything, they can work. This is the most important. But this is needed from every country to change, to give more opportunity and to think about how we can mix always.

They don't need to be separate. They need to be present for all the activities. It must be discussed how you can prepare theaters and cinemas for the special needs to enter these spaces, how you can have training in schools. For example, you can make one movie for the people who don't see. You can build a movie as voice, like storytelling. And this will bring in more of the public. If you only bring movies to the people who see, for example, then you will lose. This needs to be a big change. It needs to be thought about in the countries, in the law and the protection in theaters and cinema. It's

needed altogether to have the change.

I was curious to know if Tiro Arts is implementing any of this. What you were just mentioning—do you include voiceovers for people who are blind and low vision or sign language interpreters?

Istanbouli: You want to ask about the experience? I can send you different videos to see how they see the movies. They say first time they go to cinema, they say about how much they love the experience, how they enjoy seeing it and sharing and being in cinema, and how much they speak about it. I say we learn from them, they give a lot of energy. We speak with the schools here in Tripoli, and then we hear from them. I mean, they always love to come. And they tell the school, please, we need to go to the theater. And then we plan for them to come, we eat here, sometimes we cook together. It's not only watching the arts. And one of them, they said that they want to be an actor, someone said they want to go to the university. They have



Peace Art Bus

small dreams, and their dreams are very beautiful. They have different talents and I can say they give us power.

Wisinger: I wanted to ask you about your experience winning UNESCO-Sharjah Prize for Arab Culture.

Istanbouli: Any prize is good. UNESCO, they appreciate all the experience, all the work, and also that it's for the people, for all the ones who dream, who believe in this project, who support this project. No one can succeed alone. You need the support of the people to succeed. Maybe you are the image of this organization, or you are in the interview, for example. But yeah, when I go there, I had one member from Tiro, he's a refugee in Brussels. He's from Palestine and he's with us in the training. Before, when I invited him to go to Paris and then he went to the UNESCO office, he said how beautiful it was, how much all these people coming because of us made him feel proud. And we have also another student of Tiro. He's married now in Paris, and he has a job there, because after he finished here, he went to Paris, and he came to UNESCO. He was so proud. Yes, for me, I have a lot of beautiful memories. And also we spoke about the experience and we felt a lot of importance about what we did.

After we came to Lebanon, we enjoyed being with the group here in Tripoli. It's not successful because of the beautiful space, the different languages, or our professionalism. It's beautiful because of this sharing of beautiful emotion with the people. There's truth, love, passion, enjoyment. I remember one person in Tripoli who visited the cinema to see a film. When we turned off the lights, he slept, and we turned on the lights, he left. I

discovered that he came to the cinema because he needed to be warm, because he lived in the street.

Wisinger: It's incredible that it's doubling as shelter for people as well who need a little bit of reprieve.

Istanbouli: Yeah, I can say that this is a dream. It's become fact because of all the experiences, and it's important that the space stays open for the people in Tripoli. And when you come to Tiro- I hope one day you can visit us- you will see how important the space is for the people. It's a space for everyone. Children come to the cinema every day and wait outside because they want to learn, they want to come to the classes. Everyone has story, has a dream here. And many of them, they learn theater. We have students here who finish at the university. We have some of them that become an actor or actress or dancer. They go to Europe.

Wisinger: I'd love to hear a little bit more about the classes that you're offering. I think you mentioned earlier, there's a lot of diversity, especially in age.

Istanbouli: We start with six- or seven-year-olds. Sometimes they learn drawing, dancing, handicraft, theater. And with other ages, they learn photography, cinema, editing, traditional dance, dapki and storytelling. We work with schools and universities. They come to the space. Another part of our work is to protect the old movies in the archives, to scan all the old posters, because this is how we keep the memory alive. We do training in the villages too- we go by the bus and put on student performances in different areas. The group at Tiro travels sometimes to do performance outside. This

is what I meant earlier. During the festivals, people organize with us, and many of them become members of Tiro. They start when they six or seven, when they turn 17 and 18 and they're still in the cinema.

Chet Cooper: How did you find funding to restore these wonderful theaters?

Istanbouli: When we started, we didn't know what we would do. When we started to do street performance, we realized we needed to have different experiences too. We started to do rehabilitation of cinemas, and at the beginning, I started with my family. They supported me and I put all my money in. I had a shop where I sold movies before, and I put all my money into the new box outside of the theater at the entrance. Then people started to donate and then things went well and we had out start. I'll send you the book of Tiro so you can see more information. Later, we started to have organizations contact us. They started to work with us, and then we got donations, and then the people who become members of Tiro donated to the association. The public donates to cinema, and we create festivals. People pay for the tickets to come to Lebanon and then we host them. We ask people to volunteer.

And then after we met with different organizations, and started to work with the DROSOS organization. They are our partner and they helped us to renew the Tripoli cinema. After we renewed two cinemas at the beginning, we got partners and we worked with different groups around the world. They started to communicate with us. We have different agreements. Then we started an NGO, so we have a fund. We bought the bus by crowdfunding. People online that we don't know donate from all over the world. We bought a bus. We call it the Peace Art Bus. This is what I mean that now it's at a different level, especially with current economic problems in Lebanon. It's difficult, like when we started. When we started, it depended on volunteering and people donating. Now, people are tired and they're suffering from the war, from all the things in Lebanon. It's not easy to keep the place alive. And what I can say?

If everyone goes where we have light, who will come here? We have darkness. What we try to do is make the place alive by putting lights up so that people will come. I mean, when you do good things, something will return always.

Cooper: Have you been to Sharjah?

Istanbouli: Yes, I visited Sharjah one time. I was invited to Gulf Theater Festival and I participated in the festival. Just one time.

Cooper: Did you have a chance to meet his Highness Sheikh Dr. Sultan Bin Mohammed Al Qasimi?

Istanbouli: I'd love to meet him personally, but I didn't

have that chance to see him in Sharjah. But I hope I will meet him. For me, what he did for Arabic theater is very important, because it's important that someone who's empowered loves art. Imagine this person. He's writing text for theater. What he did is very important in the Arabic region, in culture, in arts, and I appreciate a lot what he did supporting Arabic artists.

Cooper: Right. And his sister created and runs, Sharjah City for Humanitarian Services for people with disabilities, which is doing such great work. We've met a couple of times in promotion of employment of PwDs and ABILITY Job Fair and abilityEntertainment platforms.

Istanbouli: Can you please send us the links?

Cooper: Sure, have you ever been to the UN?

Istanbouli: No, but one time I met the General Guterres. I met him at Tiro. Yeah, he's interesting, and I gave him a present, an old poster from the cinema. He put it in his collection.

Cooper: You mentioned electricity might cut off ?

Istanbouli: Yes, because we don't get electricity all the time. Yeah, it's a difficult life, because this is important for culture in this time. This is about cultural resistance, and it's important to keep the space open for people.

Cooper: Cultural resistance. I love that term. Are the electric issues in Lebanon or just the area you're in?

Istanbouli: In all of Lebanon, there's not a lot of electricity. It's 2 hours of electricity from the government. And then you pay to have an extra motor that's private. And then you need to put in a solar system. Sometimes we have no electricity at all. We hope that we keep our work alive, and keep the team. This is why we need to have different support from everywhere to keep our space open, so that we won't stop. And what we do is keep hope alive for people. ■ ABILITY

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Studio D

The Segerstrom Center for the Arts, located in Costa Mesa, California, is a renowned performing arts complex that opened in 1986. It offers a broad range of world-class performances and innovative education programs. Home to multiple performance and concert venues and schools like the American Ballet Theatre School, the Center broadened its community engagement in 2016 to include the School of Dance and Music for Children with Disabilities. The program continued to grow to include acting and all aspects of theatre. It is now known as Studio D.

Studio D's classes are inclusive, but specially designed for students with physical and cognitive disabilities such as Down syndrome, cerebral palsy, autism spectrum disorders, hearing and visual impairments and other complex needs. Classes can include siblings and children without disabilities. Studio D helps the students to explore their full physical, creative, and social potential through dance, creative movement, music and sensory tools.





Casey Reitz, President & CEO

ABILITY Magazine's Chet Cooper and photographer, Nancy Villere, visited The Segerstrom Center for the Arts to speak with President & CEO, Casey Reitz, about Studio D and its expansion, due in part to COVID. They also spoke with Studio D Manager, Chloe Saalsaa, about the classes and support offered to students as well as its community building benefits.

Chet Cooper: How did Studio D come about?

Casey Reitz: It predates me. I wasn't here for it. I arrived in December of 2019. But Studio D, which used to be called the School of Music and Dance for Children

with Disabilities, and they changed the name.—They had been thinking about changing the name when I arrived, and we did switch it to Studio D at that time.—It kind of came to be, along with the creation of our community engagement department, which started in 2017, and it also was aligned with the renovation and opening of the Argyros Plaza outside. So, the Argyros Plaza's mission is somewhat similar to Studio D in that it's trying to remove any and all barriers from participating in the performing arts.

Reitz: The barrier with the Plaza is by and large price. Because we do a lot of things that are free and low-cost

outside, and you just come and see it. Obviously with Studio D, it was trying to say that disability won't impede you from participating in the performing arts. Jason Holland, who ran the Department of Community Engagement at the time and a couple of board members and donors, Eileen Cirillo and Corey and Leslie Leyton, founded it with some of the seed money, and now it's serving 500 students a year and there's a faculty of about 19. But it started with mostly music and musical theater.

Cooper: Do you have virtual programs?

Reitz: The virtual started during the pandemic, when that was all we could do. We went out to try to connect with as many kids at home through the virtual as we could. And as we were promoting that, there were some families who arbitrarily started Googling resources and programs and came upon us. That's why we were able to start adding them to the virtual classes that we were doing during the pandemic. I think that has continued to this day.

The idea is that we prefer in-person instruction if we can do it. So, that's how we do it. And we try to make sure that each child has as much personal attention as we can (give). That's why we have in the room at any one time the instructor, plus usually, an accompanist. Plus, we have these middle school volunteers. They're usually assigned to, like, two kids at a time. Just so there's somebody always there to support them, helping them to understand what the instructor just said. Plus, we have a physical therapist, an occupational therapist and a number of people in the room who can help in any given situation.

The nice thing about the pandemic was—There were a few. —I was always looking for the silver lining in the pandemic because, otherwise, you would crawl up in the corner and just cry your eyes out and not function. But the good news about Studio D during the pandemic was we were able to do the classes virtually, and the kids could—And it was mostly kids at that time.—do the classes at home. With so many resources being cut off from kids at that time and this being one of the few programs that addresses the arts for children with disabilities, it was really encouraging and exciting to be able to serve the kids so they weren't lonely and sad and dealing with what so many kids were dealing with. But also, we were able to reach people outside of Orange County for the first time because there were some kids in South Carolina and Nebraska who signed up for the classes. I'm getting a little off-topic, but yeah, the program was created in 2017 with the idea of we're trying in every way we can to eliminate barriers to attend the performing arts, whether your issues are distance or money or disability. And that's just another one of the programs and tools that we have to address that.

What I think we learned during the pandemic, or at least

a goal that we achieved or identified during the pandemic, was that there were opportunities here to reach outside of, if not Orange County, at least off the campus. It started almost by necessity during the pandemic, with streaming the classes on Zoom so the kids could have them at home whether they lived in Orange County or elsewhere in the country. Now we've started partnerships with the Santa Ana public library system, with CHOC (Children's Hospital of Orange County), with the Santa Ana Unified System. So, we're able to do them at public libraries and at hospitals. So, we're starting to do it away from campus. That's even eliminating another barrier, being that you have to be physically here at the Center to be able to attend the class. That's no longer the case.

There's still room to grow, and we're looking at further partnerships and more ways to amplify it digitally. That's the other reason why, another barrier we got rid of. One of the reasons we changed it from the School of Music and Dance for Children with Disabilities was twofold. That name's a mouthful, and it's not very catchy and so on. But we wanted to expand beyond music and dance, so we now have classes in acting, we're planning on starting classes in visual arts. We were expanding beyond that. And then, we didn't want it to just be children any more. I think our oldest student right now is like—

Cooper: Get rid of him!

Reitz: (laughs) Yeah, get rid of him! This happens with a lot of our programs for young people. We start at a very young age in general at the Center. The ABT ballet school you can start at three years old. But so many of these kinds of programs that serve either kids with disabilities or kids in general stop cold after high school or maybe college. We recognized that there was no outlet for the kids who had grown up in the school. There's a little girl named Juliet who's been here since 2017.

Cooper: Great stage name.

Reitz: (laughs) Her name is perfect! She's just the cutest thing! We don't want to just send people on their way when they turn 18; we want to still be a home. We'll continue to serve an adult population as well.

It was time to change the name to allow us more flexibility in terms of what it can do and where we could take the program, so we changed it to Studio D.

Cooper: What are you doing off site?

Reitz: We have a lot of associations with Disney, we do a program called "Disney Musicals in Schools." We get the scripts and the instruction booklets from Disney. We send teaching artists into elementary schools, five schools a year, to perform "Jungle Book" or "Aladdin" or something. The idea is to create sustainable musical theater programs in schools.



Carly & Juliet

We focus on elementary schools because, as you look at public funding for the arts, it's been a problem for a very long time. If there is any public funding in the arts, it tends to be at the higher grade levels. You'll see it in high school, but it gets cut from elementary first. So, we try to address the elementary school population. This is separate from Studio D, but I bring it up to illustrate that we like to use known properties like "The Lion King" and "Beauty and the Beast" because the kids don't have to worry so much about learning the story or the characters. They are already familiar with them, so then you can focus on what it means to act or project or emote or feel a character or feel a line or pause for a joke. You can really focus on the acting.

What we did in the public share was the older student, the 36-year-old, was Gaston because he's a big strong

guy and could do it. And then, the other kids break up the roles. Some play the chorus; some play the smaller roles, but they do the show. That's how we taught them acting. You also teach them some prop work along the way. They have to make their own costumes, their own props for the show, a little sword or whatever it is.

We just started in the acting space. We started talking about it probably about a year or two ago, and I think in the last year we've started doing it in earnest with some pilot classes. The idea is to give the students options to pursue other things in the performing arts that aren't just singing or dancing. That's why we want to start doing the visual arts as well. It's a good time to do that because we just got the neighbor, the Orange County Museum of Arts, so it would ideally be a good collaboration with them.

Studio D

Chet Cooper: How did you get involved?

Chloe Saalsaa: It sort of all fell into place. I started working at the Center about seven and a half years ago as an admin and teaching assistant for ABT (American Ballet Theatre) plus the school, so the ballet program. Studio D was just being formed at that time. About a year or so in, they needed front-desk admin support. And I just kind of kept weaseling my way further into the program. I took on a full-time position as the coordinator in 2019 and then officially became manager in 2021.

Cooper: You're a dancer?

Saalsaa: Yeah, and that's what brought me to the Center and to the ABT program. I grew up dancing, ballet, predominantly. I went to UC Irvine and studied dance there as a dance major. I thought I wanted to dance on stage and go professional. But once I started working here my senior year, I learned more about arts admin and kind of found my groove better in that path than on stage. And I teach, I do teach a little bit, three classes a week for ABT. I'm still in the room leading the classes.

Cooper: Do you miss dancing?

Saalsaa: No, sometimes. I definitely get a sort of longing and sentimental feeling when I watch live dance.

Cooper: I noticed your foot started to twitch.

Saalsaa: (laughs) I know, the muscle reflexes, I guess. I don't know. But yeah, I think it was the better choice. But I do miss it. I miss the ritual of it and going to class daily and working on things. It's just such a different lifestyle than the average life. But no regrets. I'm much more stable. (laughs)

Cooper: Emotionally?

Saalsaa: Yeah, emotionally stable. I guess so. I think my passion in dance—I always thought it needed to be channeled through performance and my own discipline and art. But I think I find more fulfillment when it's either passing that on to my students or exposing students, who have less opportunity, to be involved in performing arts. Studio D being that new outlet for me to—I'm excited to bring dance to others. It's a good switch.

Cooper: You call everyone students?

Saalsaa: We call them students. We've settled on that label because they are learning from the program. We don't call them kids because we have adults in the program. We started at age four and have worked all the way up to senior age groups. They come to the program here. We also have classes off-site, but the majority of

our programming happens on campus, which is great.

Cooper: How often do students come out?

Saalsaa: Our students come typically once a week for an hour-long class. It's not so—You won't see the six-year-old turn 12 within the seven years we've been open, or turn 13, I guess, and see that they're completely a different artist or person based on Studio D, as if you would go to a conservatory-style school, where you're training every day and focusing so rigorously on this craft. But, I would say, the success for us is more building community and friendship with one another. We've really seen students who've come, once they've built those friendships, or they continue to come because their friends are involved. That community aspect is really big for us. That's success.

We've seen our curriculum grow from our students' interests, which is really important to us. We have always—Instead of, "Oh, we have a great pianist on faculty. Let's do a piano-focused music class," it's more so that our students have really expressed interest in acting and even voiceover acting. That sort of thing. Let's do a theater-based class that's focused on the art of acting. That's where we've invested our curriculum development energy.

Cooper: How many types of classes do you offer?

Saalsaa: We have three classes currently that we offer to our students. Each of the curriculums for the classes have been developed by our arts team. We started our original curriculum called Dance and Music; and our original faculty helped to develop it. Since then, we have also added Musical Theater and a Theater class, which is our newest.

Cooper: Are you talking about curriculum like school teachers have?

Saalsaa: No, it's not like a school-based structure. It just creates a structure and a guide for our faculty to execute certain goals.

Cooper: Your curriculum is a guide?

Saalsaa: Exactly, yes. These are our concepts of the week and the vocabulary associated. This is our class schedule.

We're still trying to get the word out there that we have this program for kids and adults who are curious about performing arts.

Cooper: It's inclusive?

Saalsaa: Yes, that's number one. It's always when we are talking with people who are trying to get to know the program more, it's always like, "Oh, interesting!"



That's the response to the fact that it's an inclusive program. There are certain organizations or schools or programs that serve the disability community, but rarely is it inclusive programming. There are dance classes for kids with Down syndrome, certain resources for people on the spectrum. But it's rare to find a program that is truly inclusive. I think it's becoming a little bit more common nowadays, but we enroll students truly of all abilities. One group of ten students in our Musical Theater teen class might have three kids with autism, a student in a wheelchair —

We have three teachers in every room, two artistic teachers and a therapist. We have OT (occupational therapist), CT (cognitive therapist), and a speech therapist on faculty. They're there to support the teaching artists and also to support the students and use their expertise to guide the teaching artists. Maybe, "Let's do large print font scripts!" These students have better access to the actual play material. Or let's bring in some noise-canceling headphones because we have one student who has a little bit of noise sensitivity. Little things like that. The therapists add a great extra layer.

Cooper: Every class has a therapist scheduled.

Saalsaa: Mm-hmm. Off-site, it depends, but we try to have them involved in all of the classes. Our most consistent off-site partnership, if you will, currently is with Alzheimer's Orange County. We basically deploy our teachers to one of their locations and they bring out Studio D material to their population. We've also worked with Easter Seals of Southern California, Unlimited Possibilities for more therapy-leaning orgs —

Some of the off-sites, like Easter Seals or Unlimited Possibilities, they have OTs on their staff who know the students, so it feels a little bit more natural to have their team a part of the classes versus ours.

Cooper: And these classes are inclusive?

Saalsaa: Yes. I would say 90% of the students do have a

disability. But we do have the occasional students who's just interested in some sort of performing arts class who have no experience in enrolling in something that's a little bit—I don't know, less beginner-level, less intimidating. We're kind of a welcoming space for that. We're also very low-cost. Our costs are highly subsidized. The cost is appealing to pretty much every family. And a lot of siblings. I would say any time we have someone who is non-disabled, they're typically a sibling or they heard about it from someone else in the program and they're friends with them. Here and there, not uncommon.

Yes, we call it inclusive. Open for everyone. It's interesting because some parents reach out, "Oh, this looks great, I want to sign up!" And then we do some extra steps in order to make sure our teachers are prepared before day one to know what the students would benefit from and engage with better. We send out a pretty hearty survey asking about communication style, any common behaviors we should be aware of, participation, any medical needs that we should be aware of as well. With that, some of the parents who don't have a disabled child, they're like, "Oh, is this the right program for us?" And we always reassure them, "Yes, it can be if you're open to it. We enroll everyone." But it's interesting what the response can be to that. But honestly, I think it's—I'm a little biased, but I think the program is so beautifully structured in that it is inclusive, and we would love to have— We specialize in instruction for kids with disabilities, and we want this to be their place, but we do find a lot of beauty in the integration. We see that a lot with our volunteers.

We bring on volunteers from the community, and some of them are high school students who need some community service hours or are trying to boost their college app. And we find a big switch in them as well. The empathy that they gain, the awareness of others, the care that they develop when working with the students is pretty big. ■ ABILITY

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Sue Ann PIEN

Most of us know Sue Ann Pien as the character “Violet,” on Amazon’s comedy-drama series, “As We See It,” that portrays three- 20-something adults on the autism spectrum who share an apartment in LA. For this role, Pien landed nominations for Best Lead Performance in a New Series at both the Film Independent’s Spirit Awards and the Gotham Awards.

ABILITY’s Chet Cooper met with Pien over Zoom where they chatted about Pien’s early life and how being on the autism spectrum led her to acting and, later, directing. They discussed Pien’s diverse array of interests, from the down-to-earth, authentic representation in entertainment, to the out-of-this-world space exploration, with a little zombie apocalypse thrown in for good measure.

Chet Cooper: We’ll start at the beginning. So, there are these gases that came together known as the Big Bang theory. Is that too far back?

Sue Ann Pien: Pien: Just a little. Let’s jump forward a little bit! (laughs)

Cooper: You’re already giggling. I did some homework. I usually don’t do too much homework I have a kind of adlib temperament. But I looked at some of your interviews, and one, in particular, was a talk with Google?





Pien: Yeah.

Cooper: In the interview, your peers on the TV show, “As we see it”, were all so funny! Rick is hysterical. I know he does stand-up. Even Albert — He seems to be more shy. — was right there with you. I wish more people could see you guys adlibbing and all cracking up. It was long, but really fun to watch.

Pien: Yeah. A lot of people pretty much imbibed the entire show in one sitting.

Cooper: Back to “As We See It,” was that filmed during COVID?

Pien: No. We had to pause production. I think we shot

the pilot in 2019. And then we paused all through 2020, and then I believe 2021, we started again. So, we were trying to get people in and out really fast. It was incredible with all the COVID protocols on set.

Cooper: Was this your first big show that you've done?

Pien: Yeah, this is the first series that I've been able to lead as a series regular on, absolutely. I've done co-stars, I've worked with Tom Hooper, I've done a ton of commercials, so I've been on pretty epic sets. I've been on the Warner Brothers back lot, where we shot "Night after Night" with David Nutter, the "Game of Thrones" award-winning director. We were doing all-night shoots, 12, 14 hours. You come in at 6 p.m. and then you wrap at 6 a.m., stuff like that. So, I've been on very big, big productions, absolutely. But by nature of I think the show and accounting for COVID, it was amazing to be on a sound stage. For a lot of the scenes, we did inside the apartment. And then we would go on location, we'd go to shoot at Arby's. One of my favorites, wow, was going to the Santa Monica pier. That was incredible because it was at the tail end of when everything started to open. For a while it was still pretty empty. And then when we went, we shut down the entire pier. And we got to have the whole night on the pier and the beach to ourselves, which was so magical. I've never seen that. Usually, it's packed out there. It was fantastic! I was like "What???"

Cooper: Did you go in the water?

Pien: Oh, yeah. We did some jumping and kicking and splashing on the ocean beach.

Cooper: Do you do any water sports, surf or anything?

Pien: I'm very particular about temperature. And also, I wear contact lenses, so I learn a lot of things the hard way. One, it's very uncomfortable to get salt water in your eye and worse if a contact falls out. Some of my favorite water sports I would have to do when it feels like bath water, like Hawaii. It's really fun to surf in Hawaii because if you fall off the board, and it's really strenuous, too, it's like falling into bath water. It's amazing.

Cooper: A good place to go is Bali.

Pien: Oh, I love Bali! I've been several times. I love it. Cynthia and I got married out there.

Cooper: That's why I said it, actually. (laughs)

Pien: Oh, cool! (laughs) Yeah, yeah! You've done some online stalking. Oh, my gosh, can we have some privacy in this household? (laughs)

Cooper: (laughs)

Pien: I have this tendency to overshare. I have to just not be on any social media.

Cooper: I also noticed that you were involved in "Mars One."

Pien: Oh, I loved Mars—yeah, I mean, space.

Cooper: Mars One had some controversy

Pien: Oh, yeah. I know that the press taped it—That's so funny you said that. That probably why they were trying to get us to do this documentary and my manager was like, "Oh, just don't worry about it, don't do it." (laughs) Because maybe there's a lot of, like—I mean, I don't care, people are going to say whatever they want.

What happened, if you go deep into that, I don't know what Bas Lansdorp did. —He was the CEO.— But the idea itself, I think, was an idea whose time had come.

My father worked in aerospace; he was an aerospace engineer. You're going to train people to be doctors, to be astrobiologists. That's what I applied for, to be the on-board astrobiologist. And in a 10-year span, you would train them as a team. In a 10-year span, anybody could get a Ph.D. in anything, right? Incredible.

And what was proposed by Mars One is no different than what Elon Musk is doing. He's always said he wants to create a city of a million people. And now, when I was doing this thing with Sony, I could see. And we had talked about this. Basically, NASA's finally catching up. And now you see that everyone's doing the same thing. They're doing simulations. They'll send people to Mars. People just didn't like that the first idea coming out of this wasn't theirs. MIT didn't like that it wasn't their idea. There was a paper they wrote that said that no, all the humans that you send to Mars will die within the first x amount of Mars days, right?

Yet here we are. We're doing exactly what Mars One had proposed. So, whatever happened financially, there were some strange choices. I'm curious. I don't know what happened. There was a stock exchange thing that made no sense to me. I know at one point—because there's also an entertainment element to that—Lion's Gate had approached Bas about creating an entire show, and he wouldn't do it because he didn't want to water down candidates. He really wanted and believed that the people who would be in this venture needed to really be Martian colonists.

Cooper: Basically you're saying that you want to go to Mars.

Pien: I think we have to. We could go into this conversation. I'm going to have a huge extended conversation with you. I think it's necessary. I think it's time. Why is there mass extinction of the animals? You're looking at



the carrying capacity of the earth. There's a problem. We're looking at overpopulation, a manmade extinction. Why are we still doing the same things? We have planned obsolescence. People don't even know what that is.

Cooper: I'm raising my hand. I know what it is.

Pien: You do?

Cooper: Sure. (laughs)

Pien: A lot of people don't know and don't care. I have a stove from the '60s that I never have to fix or exchange.

Cooper: But that was the economic model. The concept works because they'll have to buy it again in four to five years. It keeps that industry working. What it doesn't work for is the planet and our health. Toyota builds a vehicle, they have planned it not only to be for a long time, but it actually will go back to the earth, that the materials that they've used supposed are not only recyclable. But if you let the car sit there, Mother Earth would take it over and it would become part of the

ecosystem. At least that's what they've said. But the planned obsolescence, that's when you say the Japanese and the Germans take over vehicles for a long time. And then the Americans finally picked up and said, "OK, we can't keep having products that will fall apart," which is engineered.

Pien: Right. I do propose—us going off-planet is going to change not only the consciousness of how we run a civilization, what we consider. There's an astrobiologist named Dr. Charles Cockell, he's phenomenal. He ties environmentalism together hand in hand with off-planet exploration. The way that he writes about it, people have to read his books. Because some people are like, "Wait, why are we going off-planet when there are so many problems on earth?" It's not one or the other. It will change how we function as a society.

I've always loved things like the Venus Project. You look at technological advancements and what we can do, something called a resource-based economy. I'm sure there are many other types of models or prototypes we can also dive into. I found Jacques Fresco's particular passion and drive, what he did as a civil engineer with his life, was he in UNESCO? He got an award. The

cities he's designed are just phenomenal. This idea of a resource-based economy. You start to look at the entire planet system as all the resources as belonging not only to the planet but to future generations.

That's what I was using Mars for, to talk about that. (laughs) Like, what will I do with money on Mars with me and my 20 friends? Here's this Venus Society Project we could try out, what do you think about that?

Cooper: It's back to barter! Barter is the way it all started anyway.

Pien: (laughs) Mm-hmm!

Cooper: Two chickens. (laughs) That's what I wanted to talk to you about, I have these chickens...

(laughter)

Cooper: Do you play chess?

Pien: Yeah, I'm really good.

Cooper: Have you played recently?

Pien: I haven't played recently, but I play a lot of strategy-based games. My friends and I played the Game of Thrones game. It's about a nine-hour game. It's so fun. We've played it twice. It's so long and epic. I won both times.

Cooper: How did you get into acting?

Pien: (laughs) Well, from a very, very young age, it was really important that I show up a certain way, have certain mannerisms that were not myself. Now I look back and my mom was worried that I was very naïve and very idealistic. All traits now we know are on the autism spectrum, Asperger's, child-like. I was like a project. In first grade, she would teach me how to, "Look me in the eyes! Smile!" She would train me and coach me to do monologues. A bit of "Winnie the Pooh" monologue. How to behave in public, how to talk to people.

She was looking out for my future. As a Chinese mom, she was really worried, I don't think I was very verbal until I suddenly was. And then you couldn't shut me up. It was so funny because I was hyperlexic as a child. So, when I started to read—At first, they put me in ESL classes because I wasn't reading and I wasn't speaking. And then when I started to read, I was reading so above and beyond that at school gave me the principal's Most Improved award for the year. (laughs)

Cooper: (laughs)

Pien: They were like, "This kid is reading at a high school level." I had no idea what I was saying, though, but I was decoding words very quickly. I had no sense

of comprehension. That caught up with me after I skipped second grade. They said, "Oh, my gosh, she's so far advanced!" So, I skipped second grade and then in third grade, the teacher said, "Yeah, she reads really fast, and she has no idea what she's reading." (laughs) No idea what it was about. And then they tested me in fourth grade, and they were like, "She has a really high IQ, this kid. We don't know what to do with her. Either that or she's needing to be in a special class."

Cooper: Where was this?

Pien: This was all in southern California. I was born in LA, Torrance, to be exact. And then my mom and dad divorced when I was three, when I was sent to live with my dad's family in Taiwan. So, from three to five I grew up in Taiwan, and I retained my Mandarin Chinese skills from living there. And then when I was five, my mom had me back in California. We lived all over, from Monterey Park, Northridge, and then in high school, in four different high schools, that was brutal.

Cooper: Wow four different high schools. So, your acting came about from your mother working with you to make you appear more "normal", I think is the term you used.

Pien: Yeah. By the time I was in UCLA, I saw some friends and I was like, "What are they doing? They're traveling the world and doing all these really fun things." I was raised with a very rigid idea about what pathways are available to me in life. I have to get a Ph.D., become a lawyer, doctor, that's it. That's it.

I had no interest; I wasn't interested in any of that. I wanted to travel the world. I wanted to see and experience things that were so much different from what my mom told me was available. A friend became a model. He was traveling the world, and I was like, "That is so cool! I went to the same agency that he was signed with, and I said, I'm in, here I am."

I've become really good at mimicking, as a lot of females on the spectrum are. I could choose somebody, almost like a character study, and become them. I could take on their mannerisms, how they walk, how they talk. I would practice my facial features. I had one friend I thought was so cool and I wanted to be like her, and she always pouted. So everywhere I went I started to pout. And I took on the way she would talk. I was basically becoming the alpha females that I saw, and I loved it. It was a way to camouflage my differences.

It became an open doorway that one, nobody—I mean, I should have known. I think my mom knew. I think my mom should have been an actress. (laughs) She was dissuaded from it. She grew up on sets because she had a cousin who was a movie star in Hong Kong and Taiwan. It was so cool. I'm just starting to dive into this side of the family. She always had that sense of, how are you



seeing a set as a kid? How do you behave wherever you are? She was well aware of that. And she was very, very dramatic in her home life, where I think if she was on set and able to do that, she would have been more at peace at home. (laughs)

There was one point where they needed an older Asian woman, and my agents were like, “Does your mom want to come and try to audition?” And she did, and she booked it,” her first audition ever. I was shocked! She’s awesome. Why are we talking about my mom?

Cooper: We were talking about acting.

Pien: Then I was like, “This stuff’s easy! I’m going to do this!” (laughs) I was so excited! Actually, I really wanted to do good in the world. I wanted to join the Peace Corps at first, and they said, “You don’t have a college degree. Go get a college degree.” Social justice, environment, stuff like that had always been a calling throughout my life. You look at people like Greta Thunberg, it’s just part of the Asperger’s, the autism. There’s a strong sense of needing to do some type of social justice, of good in the world. My mom and I and my dad made a deal. I had to finish my college degree. “Just get

that undergraduate degree, and then we’ll let you do whatever you want to do with your life, OK?” I was like, “All right. I’m going to pursue acting full-time. That’s my game. I’m going to be like all the other kids in LA.”

At this point I’m meeting friends who really are, most of my friends were models, but in LA it’s the same because you’re doing commercial jobs. I started to realize one, I don’t really like posing as much because who knows what my face is doing? I just didn’t look as good as my friends when they modeled. They looked so good. They were really aware of their body and their face in a certain way. It seemed a lot harder for me to get that down. But two, I’d loved acting, because I was already doing it, over and over and over and over. I was basically a method actor without knowing it.

It was so natural for me to come in and pick up some dialogue and turn into this person, that person. That’s what it was. I’d been acting nearly half of my life now professionally. 2004 is when that job came in. For about 20-something years. It’s been a lot harder than I thought it would be. There were so many times I thought, “Oh, good, I’m going to have a big break.” But it was worth

it. It was fantastic. I can look back now and said, “Wow, look at how much I learned.” I mean, I just directed. That’s incredible. I wouldn’t have been able to be on set, to direct.

Cooper: What did you direct?

Pien: I directed a short film called “Once More Like Rain Man.” It’s about a young female autistic actress’s experiences through Hollywood written Bella Zoë Martinez. She’s on the spectrum. She just turned 18, and her family helped her out a ton, they work in the industry. We have Susanne Ellis, she’s the president of Beacon Pictures. They’ve done amazing things, created a series with Sharon Stone, Kevin Costner, Denzel Washington, “The Hurricane.” Darren Dean is one of our producers. He did “Tangerine: The Florida Project” with Sean Baker. These guys are really cool. And I’ve been directing for a while informally, with no budget. It was like an internship. They were like, “We’re going to build you out a legit team, department heads.” It was so fun, it was incredible. I put Sosie Bacon in there, we got Tracy Reiner in there, Joe Mantegna. We’re doing all the festival rounds. We’re bangin’ it out!

Cooper: Did you meet Joe’s daughter Mia?

Pien: Yes, yes, I did! She loves makeup.

Cooper: Yes, yes! I don’t know if they still have it, it was something like Mia’s Makeup Corner.

Pien: Yeah, yeah.

Cooper: Joe’s been on the cover of *ABILITY Magazine*.

Pien: He’s incredible. He makes me cry. He’s like the grandfather that everybody wants—he’s just such a beautiful kind-hearted human being.

Cooper: What did you think about the director.

Pien: (laughs) I thought she was great.

Cooper: (laughs)

Pien: And it turned out wonderful.

Cooper: Beyond that, do you have any other things you’re working on, planning to do?

Pien: There are things I can’t talk about. I feel really happy. I know I’m a lucky person.,

Cooper: You’re 86, right?

Pien: That’s right! I’m glad you did your homework! As are you! (laughs)

Cooper: (laughs)



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Pien: I remember those wars. It was hard. They were some of the harder times to live through. But we survived it, by golly. Where'd you serve? (laughs)

Cooper: (laughs) Boy Scouts. Front line. What were we talking about?

Pien: Why did we get to this point? What was I talking about?

Cooper: You said you were stalking me and that I should be concerned about—
I think you were saying something about, no matter how much I might practice beforehand, you're going to beat me at chess.

Pien: That's right. (laughs) Yes. No, I don't like doing that. I actually don't have that bone in me where I need to beat someone. Because I like to play for play's sake, and it just so happens I win, sometimes more often than not. But I don't have that sense of—if I lose, I lose, that's fine. But I'm going to play all out.

Cooper: But you're still angry at that two-year-old cutting in front of you for the water.

Pien: (laughs) That was a lack of integrity. Have you seen "The Peanut Butter Falcon"?

Cooper: Yes.

Pien: One of my best friends, Vanessa Halby, I knew her before she married Will Halby and they formed Zeno Mountain Farm, before that it was a Cheshire Project. It's a camp—

Cooper: I know them as well.

Pien: I grew up in those camps. That was my family for a long time. I was a camp counselor. I loved it. I fit right in, obviously. And I remember being on set one of those days at camp, way before Zack Gottsagen was in "Peanut Butter Falcon," I think was becoming bullet-proof, and he was playing the—he was like, "Hey, give me all your money!" He was like a bank robber. And he has Down syndrome. I couldn't look away from this kid. He was riveting. The charisma of this man. I was like, wow, that kid can act. It didn't matter that he had Down syndrome. So, I was not surprised years later when I saw him in that movie with Shia LaBeouf in "Peanut Butter Falcon".

Yes, a lot of people want to act and want to come indoors, but everyone knows it's a very competitive realm. There are only so many slots available for actors. So, you have to do the work. There's no getting around the work. And it's hard for anybody, no matter if you neurotypical, disabled, non-disabled. That's what Eileen Grubba was talking about. You've got to give actors who've been at this a long time to get out there and lead

the way, otherwise you'll give disabled talent a bad name.

You put a kid on a set who's never acted before and you call him autistic or whatever and they can't deliver their scenes or whatnot, they can't deal with the 10-, 12-, 14-hour days, then they're like, "Oh, we can't hire disabled people. They can't act." You cannot do that. That's what Eileen was talking about. Which makes a lot of sense. You've got to find people who have been doing this and who happen to have a disability. I have friends I've known who have had strokes. They're now disabled, but they've been acting for decades. That's very interesting to me. That will be a part of their persona and their character.

So yes, you'll find actors who are riveting and can bring so much. But what someone like Eileen, who's been doing this for 40, 50 years at the actors studio will bring to that role will be very different than someone who just happens to have a disability and you just want to place her in a role. She won't bring something that has craft. That's what we're talking about. She was saying that you also have to make sure you don't lose the acting in it, or you'll do disabled people a disservice. You can't just pull in some random kid off the street because they're in a wheelchair and go, "Do this role." Then they'll be like, "No, people in wheelchairs can't act." No, you've got to bring in people who have been doing this for a while. Nic Novicki, you have to be an actor. You have to know what you're doing.

Cooper: Yes, you have to have talent, without a doubt. But talent needs to be given opportunities.

Pien: You have to give people opportunities and open the doors. I just directed, I put Danielle Perez—I had to fill in some roles, Danielle is a wheelchair user. She's a very funny, very interesting actress, Spiderman, Spider-verse, all that. The role I gave her, you don't even see she's in a wheelchair. I did that on purpose because it doesn't matter. She's so funny. I want her to be able to be cast. So what? She just happens to be in a wheelchair, but she's going to play my casting director. And that's what we'll start looking at. Why can't someone who's at the bank teller have CP? She came from a different era, and I understand. Twenty, 30, 40 years ago actors had to be perfect. We had this idea of perfection. Now it's like, why can't the girl next door or the wife have a limp?

Cooper: Eileen has done a couple of video clips for us helping young people understand some of the benefits of having a disability in acting.

Pien: I do think that casting directors are way more open nowadays. I was looking at an old—they'd be afraid to type this into a casting breakdown. They called the character good-looking. Now everything's just open. "What have you got? Let us see it." If you can get the right

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That's the one thing Lolo and I were talking about. If I were going to create a character, I would have it that one of these guys survived the apocalypse, and they're bad-asses. Their wheelchair is tanked up, fire-spitting, machine guns! Come on! People love them. They're going to make sure their Down syndrome child had survived! Put 'em inside a van, keep 'em safe. I want to see that story line. The fact that we haven't seen that yet, we're missing out on a big audience. That's going to be a big draw. I would watch that. What's this girl in the wheelchair doing? Oh, my gosh, she's killin' zombies! How is she doin' that? Why? Come on! That's really cool. That's like *Mad Max*, but with a disability.

Cooper: Somebody did that. She tried to produce a movie.

Pien: Who did?

Cooper: I can't remember her name. It was years ago. She was a superhero of sorts. Her wheelchair was powered with machine guns and the whole thing.

Pien: And nobody wanted to see that?

Cooper: I don't know what happened to it. I know she was trying to find the funding and got something shot just as a trailer or a pitch for something. It didn't happen. As you know, to do that properly, you have to tie yourself to either someone who has a lot of money or a studio that has that idea, maybe from a comic book or something. It was called *Silver*—it was coming out of Syria as well. Before the Syrian war, before everything broke out in the Middle East. I don't know what happened to it. It was something like *Silver Scorpion*.

Pien: Whoa!

Cooper: I'm going to share my screen and see what happens when I search "autism" on the magazine website. (Shares screen) Have you ever heard about this? Autism-certified destinations? A friend of mine has a brother who has severe issues with—when something triggers him, he will destroy the place. This is a concept of making places accommodate somebody who needs that quiet space, but also that space can't be destroyed.

Pien: Awesome! A break room!

Cooper: (laughs) Yeah, a true break room.

Pien: You do motocross racing? That's amazing. I had a scooter. I took my scooter all the way to Joshua Tree because I thought I would take only a few hours more—

Cooper: You took a scooter from LA to Joshua Tree?

Pien: Yeah. Because I'd done the drive so many times in a car, I was like, "OK, I could do it through the backroads." I didn't realize it would take a lot longer. It took me six hours one way to get there.

Cooper: How did you go? Back into ___?

Pien: I went through Little Rock. I had to go through Angela's National Forest. At a certain point, I'm not even driving on the road, I'm driving on the shoulder. Big trucks go by. But I f**kin' made it. I took pictures and videos of it. It's so cool. And then I slept on a rock, and it was so hot that I had to stop and pour water on my head and put my helmet on. If I stopped riding I couldn't touch my brakes any more, so when I drove back home the next morning, I was like, "This is batshit crazy! I shouldn't have done that." I had to get up before the sun came up so I could get out of Joshua Tree before it was too hot. And then I would stop, pour water on my head. And you don't have GPS part of the way, so I had to count miles. I had to be like, "Oh, the next road get gas." But it was such an adventure, and doable.

Cooper: What size engine was that?

Pien: It was a 170 Buddy. I love my bike.

Cooper: That's enough to get you up to 50 miles an hour?

Pien: For sure, yeah. I'm a big scooter lover, best buds and all that. I was in Thailand, and this German guy, he brought his Ducati all the way from Germany and just rode all around in the jungles. It was really wild. I'd be scared on a motorcycle, just because I've crashed quite a few cars in my lifetime.

Cooper: I just went to a motocross track to meet with a nonprofit that adapts bikes called Moto Demption. I'm going to share my screen. [showing images of Fox Pala raceway]

Pien: Oh, dude!

Cooper: These guys all have ridden motocross in the past and injured themselves or lost a limb, so they modify these bikes, see the handle bar controls? That's modified. They strap themselves in.

Pien: Oh, my God! So they can still ride!

Cooper: Yes. Our friend and contributor Long Haul Paul has a doctor's prescription to ride called, MotoMedicine!

Pien: So cool! Remember that Nintendo motocross game? I love that game. It was a motocross racing game. What do you ride?

Cooper: I ride a 250 and a 450 CRF Honda. Even if the 450 was street legal it would be problematic to go to Joshua Tree.

Pien: I was halfway there, and by the time I was saying, "This was such a bad idea," I couldn't turn around, it had already been, like, three hours and I just had to keep going the whole way. You've got to finish the ride.

Cooper: A lot of people would have stopped. You have tenacity.

Pien: Perseverance? Hyperfocused. "We're going to make it happen." That was one thing as a kid, if I was going to do something, I was going to just do it. (laughs) Six hours each way and it's cool.

Cooper: Do you have the same bike now? A bigger one?

Pien: Oh, we had to get rid of it. At a certain point, Cynthia was riding around in LA and getting messages and calls that it was time to let it go. You can drive nice, but in LA it's not a scooter culture. They'll run you right over.

Cooper: I think street bikes are more dangerous, no matter if you've got a big bike or a small one. I think motocross, off-road is safer, you wear more protective

gear and a truck won't run you over.

Pien: When we actually got to Joshua Tree, it was magic. You're tearin' out inside the park. It's unbelievable once you're there. I love that feeling of just going so fast. I miss that.

Cooper: You could still get a bike and take the bike to a location.

Pien: We still do that any time we travel. When we were in Italy we got on a bike along the coast. We did that in Bali, that's a scooter culture. Certain towns and cities have that. I would love to have a bike and we'll just take it around to all the parks and just tear out.

Cooper: I hear that you climb mountains?

Pien: In fact, when I booked the pilot for "As We See It", my manager immediately was like, "You're not riding any scooters, you're not climbing any mountains, you're not going rock climbing." And it's fine because Violet wouldn't. She needs to be skinny. Otherwise, to have some crazy muscles, people would be like, "Wow, that's a really built autistic kid!" (laughs)

Cooper: So, you didn't?

Pien: Yeah, I didn't climb for a couple years.

Cooper: You did have that really strong grip at one point?

Pien: Oh, yeah. I used to be able to do one-finger pull-ups. I just auditioned for Mission Impossible—

Cooper: Wait... wait, what did you just say?

Pien: I used to do one-finger pull-ups.

Cooper: That's two fingers?

Pien: I guess two fingers, you're right. (laughs)

Cooper: Pull-up or just hanging?

Pien: This was in my twenties.

Cooper: I think I'll try.

Pien: Oh, I'd be impressed! You owe me a video! One-finger pull-ups right now. Don't hurt yourself.

Cooper: Ok I'll try to pull up a video.

Pien: Yeah! This was fun. I really enjoyed chatting with you about all kinds of weird and interesting things that I like to hide from the world. (laughs) ■ **ABILITY**

AMY PEDID

Whenever she's not tending to her duties as an art director for The Integer Group, web designer and accessibility advocate Amy Pedid devotes her time to building the Unibility. Undertaken as a passion project, the website will serve as a free, centralized database of digital resources for web designers, persons with disabilities and anyone else who wants to make the internet a more accessible place. "The world will be better when everyone embraces universal design," she said, "and when designers like myself realize the power we have to transform the lives of billions of people around the globe." Originally from Texas, Amy now lives with her husband and daughter in Lowell, Arkansas.

Itto Outini: You've served as an art director for several companies, most recently The Integer Group. What does being an art director mean?

Amy Pedid: I help our clients, who are mostly retailers, improve their design and marketing so their customers can access their products more easily. I've done physical designs for in-store signage as well as web design, and I've helped clients achieve compliance with the ADA (Americans with Disabilities Act) and WCAG (Web Content Accessibility Guidelines).

Lots of retailers don't realize the importance of digital accessibility and universal design, so I usually pitch it to them like this: different customers use different tools and strategies to navigate physical and digital spaces,







Amy Pedid

and if you don't take that into account, you'll lose customers. Sometimes, you might not even realize there's a problem because the barriers to entry are so high that the potential customers who're most affected can't even get through the door, literally or figuratively, to let you know about the issues they're experiencing. That's where I come in. I work to identify those problems, preemptively whenever possible, and develop solutions that my clients can use to improve their customers' experiences, and ultimately their own.

Itto: How did you first become aware of web accessibility and universal design? Is there a license or certification you have to get to prove that you're familiar with those concepts? Or is it a personal choice?

Amy: There's no mandatory certification for designers. WCAG does have a free comprehensive program (<https://www.w3.org/WAI/fundamentals/foundations-course/>) that anyone can take on their own, and you get a certificate for completing that. You can also find teachers and mentors online. A lot of very cool, accomplished people are working in this space.

As a designer, you can end up learning a lot about the ADA whether you set out to do so or not because every client has design rules for signage, websites, marketing materials, etc. that you have to learn, and while some of those rules are mostly there to differentiate the brands, others are derived from the ADA.

When I first got into marketing and web design, encoun-

tering all those different rules and guidelines got me thinking. I started wondering why they exist in the first place, whether they're actually benefiting anyone.

I started learning more about the ADA, and eventually it occurred to me that I have a few conditions that qualify as disabilities. For example, I have high myopia. I need really strong prescription lenses, and I'll very likely develop cataracts as I get older and maybe even lose my vision. I also had an experience with a short-term disability when I was pregnant. As soon as I realized that technology and design choices can improve these situations, I gained a deeper appreciation of universal design. I started seeking out knowledge, online and off, from people who've had direct experiences with both short- and long-term disabilities. I think that's how it goes for a lot of designers: we have some kind of personal experience, either ourselves or with a family member or a friend, and because of that we start to notice how different rules affect different people, and how universal design principles can benefit everyone.

Itto: Can you share some more examples of accessibility features you might build in for your clients?

Amy: Signage design and wording should be as high-contrast as possible so that as many people as possible can understand it. Rapid animations can trigger seizures for people with epilepsy. Videos should have audio description captions so that people who are deaf or hard of hearing or have sound sensitivity can access that content. Every button on a website should be labeled for screen reader users. Those are just some of the most common ones, but there's so much more--I could go on and on!

Itto: Which would you say is easier, in terms of accessibility: digital or physical design?

Amy: Probably digital. Most design software comes with accessibility options already built in, so it's just a matter of learning how, when and why to apply them. With digital materials, it doesn't take long to produce different options and let your client choose the one they like. With physical design, it's a longer, more complicated process.

On the other hand, web accessibility is a much newer concept than physical accessibility. Most people are already used to things like, for example, keeping large signage and displays out of the aisles so people with wheelchairs can get through, but with digital accessibility, it might take a lot longer to explain to retailers what needs to be done and why.

Itto: Is that something you encounter often? Retailers not appreciating the importance of accessibility?

Amy: It varies a lot from one to the next. They all have different rules when it comes to signage and website

design, and some are already doing a great job with accessibility. Dollar General, for instance: their customers skew a little older, so their guidelines are all about large type and high contrast, and they usually make their aisles wide enough for wheelchair users and keep their signage out of the way. Walmart changed their brand guidelines a few years ago to improve accessibility, too. That said, lots of retailers still don't get it and need someone to hold their hand.

Itto: How can retailers learn about universal design? Are there programs that target retailers and educate them about accessibility? Or do they just have to seek that knowledge on their own?

Amy: It's pretty much all driven by individual research from employees. Larger companies like Apple and Microsoft can maintain accessibility departments, but others need to outsource to third party vendors. Most retailers will research what's called "best in class"--that is, the best examples of what other retailers have done. Walmart changing their guidelines has pushed a lot of other retailers in the same direction. At the end of the day, though, it's up to the individual retailers to implement accessible practices. There's no ADA compliance police going around!

Itto: What motivates retailers to do that? Are they trying to attract more diverse customers? Head off lawsuits? Protect their reputations?

Amy: All of the above, to different degrees, depending on the company and the situation. There's been a lot of interesting stuff going on lately with lawsuits and digital accessibility, and I think that's motivating more retailers to ensure that their websites are WCAG-compliant, even if it's not strictly required by law.

The ADA prohibits discrimination on the basis of disability in places of public accommodation, but it was passed in 1990, before the internet counted as a place of public accommodation, so nothing in the law explicitly applies to web design. Recently, lots of legal decisions have been coming down, clarifying how web design fits into the ADA. For the most part, the law's getting interpreted to mean that if you have a physical retail location, then you have to make your website accessible, too. The Department of Justice even came out recently and confirmed that the ADA applies to websites.

That said, even if the ADA's applied to websites, it only explains rules to make federal sites accessible in Section 508. So for everyone else, the WCAG is the go-to for knowledge. So far, only federal agencies and their contractors are explicitly required to follow the WCAG, though it's widely considered the gold standard for anyone committed to web accessibility.

The problem is, all of that's based on a loose interpretation of the ADA, which technically only applies to pub-

lic-sector entities. That's why I think it's really important to focus on the business case for accessibility as well. If your store and website aren't accessible, it's going to hurt your reputation, period. You're going to lose customers. No matter how the law's interpreted, that should be sufficient motivation.

Itto: Why wouldn't clients want to comply with the WCAG?

Amy: There are some real challenges, but honestly, the biggest one is clients--or designers, sometimes--not realizing how important it is, or how easy, or both. If you go and read the WCAG, it can be kind of intimidating, but once you understand it, it's really not that hard to follow all the rules. Like I said, most design software comes with all the necessary tools built in.

Another problem I run into sometimes is when clients have websites that are already built, and then they want to go back and make them accessible. It's not hard to make a website WCAG-compliant when you're building it from the ground up, but it gets a lot harder when you're modifying something that's already there.

When you design a site, there's an organizational strategy involved. There's a specific pathway that you want users to follow, and hierarchies that make certain parts of the website more important than others. Every decision you make about accessibility and user safety has to be embedded somewhere in that hierarchy. When you start adding features to a website that's already built, you have to rethink the whole structure. There are a few things you can do without rebuilding it from scratch, like adding alt tags on images or labeling buttons for screen reader users, but there's a lot that can't be taken care of as an afterthought.

That said, even if you do have to rebuild everything from the ground up, it's 100 percent worth it. You'll be making things easier for yourself and anyone who visits your site in the long term.

Itto: Has the pandemic affected your work as a web designer?

Amy: Yes, definitely. Fewer people are going to the brick-and-mortar stores these days. There is a lot more online shopping, pickup and delivery, which means I'm doing a lot more with UX and UI—

Itto: What those are?

Amy: UX means “user experience” and UI stands for user “interface design.” UI only applies to digital products, and it's more about the visual aesthetic that makes the product easy or enjoyable to find and purchase. UX is more holistic. It applies to both digital and physical products and covers every aspect of user experience. Both are extremely important.

Lots of retailers have been reducing in-store signage and investing more online. I feel like that pivot is generally a good thing because it's opening up more opportunities to make retail accessible, but you still have to be careful because what works in physical spaces won't necessarily work online. You don't want to cram all the signage you'd find in a physical store into a single web page, for instance; you'll overload the shopper to the point where they get frustrated or distracted and can't find what they want. The design has to be simple, accessible and clear.

Honestly, because of the pandemic, I feel like this is an amazing time to be working in web design. It's all about solving problems in creative ways, and we have a lot of problems, but we also have a ton of tools and resources out there for anyone who looks for them. I hope more designers take this opportunity to educate themselves about the WCAG and the ADA.

Itto: Are you doing anything to promote universal design and WCAG-literacy within the design community?

Amy: I started a Facebook group in 2019 called Accessibility Advocates, where anyone can learn and share accessibility knowledge. We've grown to almost 500 members. I've met a lot of really passionate, creative people. It's one of the main reasons I'm building a site to consolidate accessible resources.

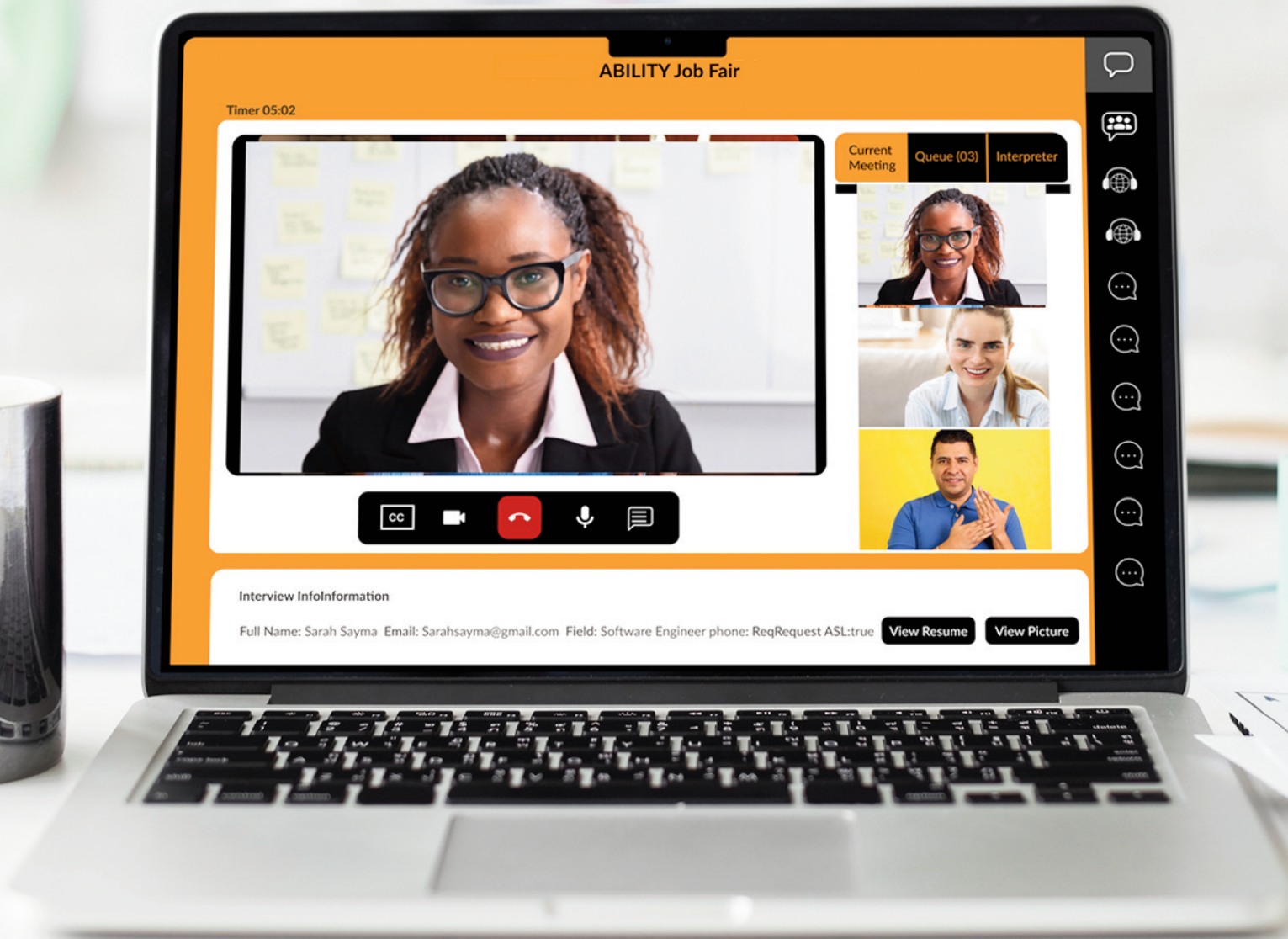
I also help locally. For a couple of years, I participated in Givecamp NWA, an event in Arkansas where NGOs from all around the state are paired with local volunteer designers and web developers that improve their sites for free. In 2019, I was assigned to a nonprofit called United We Dance NWA, and I did a demonstration on how to make their Wordpress websites accessible, and how to involve more people with disabilities in their organizations.

I'm currently working on a website for advocates, web designers, persons with disabilities--basically anyone who's interested in digital accessibility. It's going to be a central hub where people from all around the world can find a comprehensive database of resources related to digital and physical accessibility. There's no one-size-fits-all way to make things accessible: each solution has to be tailored to its context and balance lots of different, competing constraints and needs. There are tons of amazing resources out there, but right now, they're all scattered around. It would take years and years to sift through everything, and when you're trying to solve a problem in real time, you don't have years. The more we can pool our resources and crowd-source solutions to complex problems, the better the solutions are going to be. ■ **ABILITY**

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Christina Turczyn

Poet, visual artist and educator Christina Turczyn has been reflecting keenly on the world around her for most of her life. Water runs through her paintings—they're watercolors, after all—and through her poems, too, lending a fluid quality to her recurring themes: human endurance through violence, dislocation and disease; technology's capacity to link and sunder, efface and re-record; and the cool witness borne to it all by the natural world. A self-proclaimed "student of her students" and relentless observer of both natural and human phenomena, Christina lives in New Jersey, where she continues to serve her community by writing, painting, promoting the arts, poetry and championing inclusive education.

Poems by Christina Turczyn

Elsewhere

*I come for the deer—
this season, they kick up snow
in circles,
summoning clouds,
an ancient path of constellations
in the blood.*

*"Let your body remember," my Tai Chi
master reminds me, as scars
are a calligraphy of absence.*

*It is all in the breath:
Geography of skin.
What we know is on the other
side of bone.*

*Here, the pandemic creates silence,
prolongs the wait. I am
hurried out of the hospital, and still*

*am happy for the twentysomething,
who forgot to go to work, then arrived
after too much wine.*

*The nurses keep
laughing, but his friend comes to take
him home.*

*No one would do this for them,
as they
miss the secret—
undercurrent, stone.*

*Elsewhere in cages children go quietly to sleep,
without any knowledge of the depth
that being held up by a river brings.*

*Today, the deer summon a storm.
They thunder through the woods,
white water,
just listening.*





Virtual Water

Light climbs slowly up a vase—a ragged leaf, more solid than my surroundings. This is tangible light, not the kind that illumines my laptop at night with a bluish underwater glow. The universe. All stories bend, the farther away from us they travel.

A river runs away from a spring. Someone is filming the water, as a masked fisherman pulls up his catch. Trees move in the water of the sky, breathe.

People escaping their countries are drowning.

What would you do with virtual water? Virtual wars? Virtual salvation, virtual games, virtual rain, and virtual love?

Distance is safety, while in another country, a photo reaches a photo. My mother dies. Her sisters are gone. It is too late.

My student's father carries a portrait through Viet Nam. The portrait survives him.

When I was twenty, I drove to Sandy Hook, kicked off my red sneakers, and swam. Now, I paint a door to the sea. In the background, the water is rough. There is no chair to infinity, no sand—just a door through which I pass when I want to have a real conversation.

I am walking on an idyllic street lined with blossoms. I photograph the long, stretched shadows. Past the Wild Bird Emporium children play, while parents carefully tend their wings. The ice cream truck drives down the dead end—a melody wafts over grass. Too green. The street is empty. Stone bunnies on a lawn are outfitted with protective gear. Behind me, an ambulance breaks up the silence.

It was my letter that survived the flood in my friend's home. Only my letter survived. We are all just an inch about the flood. We are all just an inch above the deep, quiet water.



Holger Henke (Left) and Christina Turczyn

Much of it is hidden. From the outside, the building I live in is quaint. Inside, an old man tends an eagles' nest on his computer screen. All I see is a forest, yet I feel the presence of the hunter.

Is the nest everything this man has put away? He, as well, dived into the brook near the mill here, years ago. An avid painter of trains, he offers me his book.

I find a re-defined park not yet closed in the pandemic. Not a park, exactly, but an extension of the library.

I sit on the bench, watch the fisherman. Thirty-five years have passed. He casts his line. The friend of the letter calls. I am dancing to Rose Royce. "I Wish Upon A Star." This is before our friend dies, way too young. I would bring him water, books, seasons, records—anything, but the stream runs through my hands.

Every year, I have asked myself why he could not call. Why?

There are rooms in my body where constellations sleep.

He walks with my friend to school. They are children. Then, they are walking towards the dorm. They are still running, laughing. Today I am resting on my uncensored bench in Ho-Ho-Kus, letting the dust of light touch my shoulder. It has been traveling for a very long time to find me. Centuries, perhaps.

Renaming

What is love but language renewed daily? It is not the act of renaming, but rather, finding the hidden name in someone else, coaxing it out of them. What is language but belief, branches of sentences tending toward no conclusion, a single leaf turning in the windless sky? Renaming is an act of violence; peoples renamed are pried from their histories—unable to look in the mirror of the past, they do not recognize their beauty, but always look for affirmation elsewhere. This is a tragedy.

It happens to many women who "take one day at a





time” because they have been convinced that no future exists for them.

With Doors Wide Open

I have heard that in war-torn countries, people take brooms to their porches after a bombing, sweep away bits of debris during that millisecond before the bombs fall again.

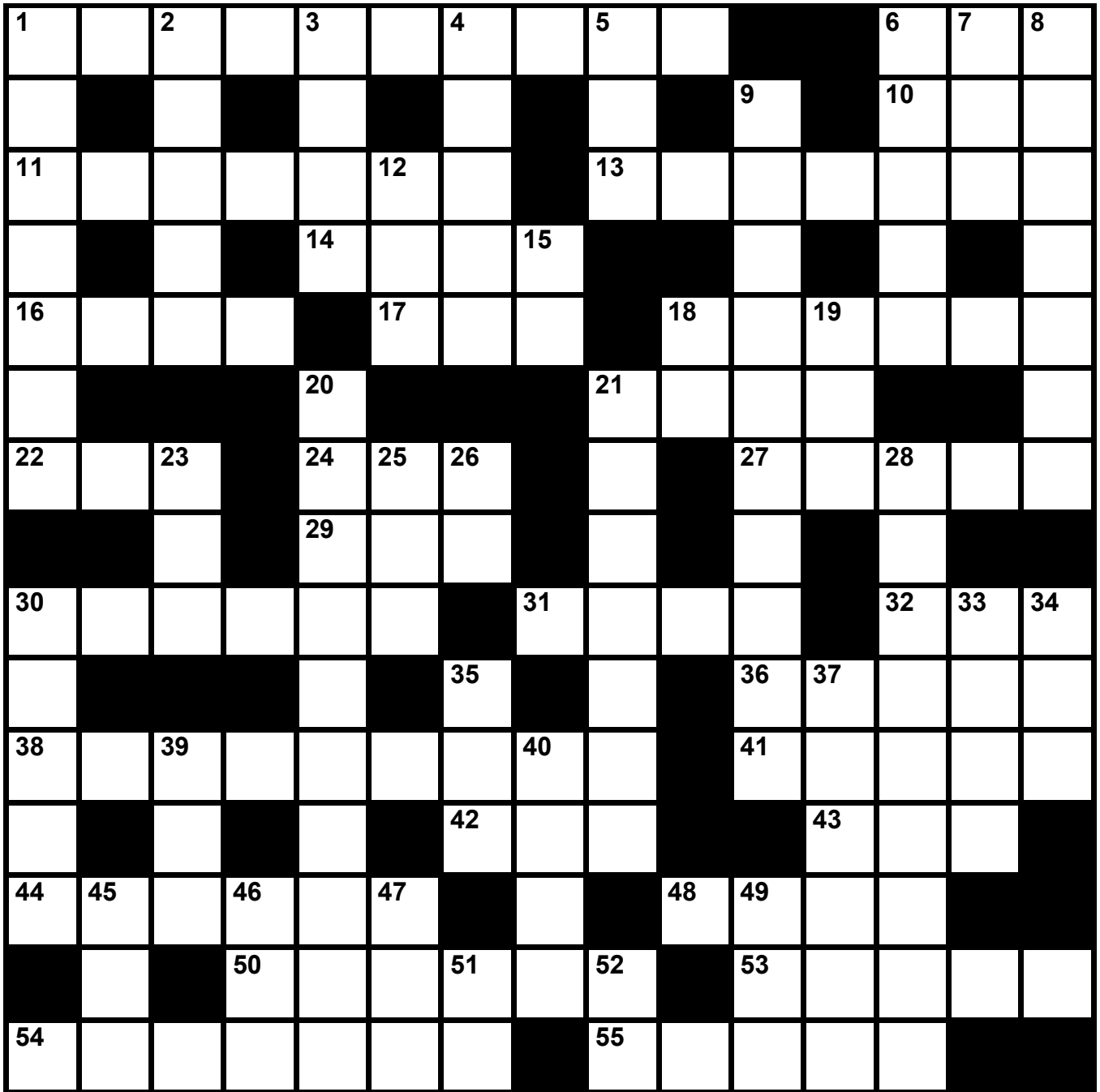
My mother knew the word for war. The language did not matter; once you had experienced devastation, you could never go to a tearjerker again. “Tragedy is for the young,” she says, as a challenge to what many people think. Her youth was spent in D.P. camps in barracks, and she associates tragedy with youth, questioning the existence of horror films when so much terror resides in real life. “It is no escape,” she tells me. “One needs an escape.” “You realize,” she says, “that we left our home with the doors wide open.”

Winter Coat

Leaving the camp,
a mother takes her daughter by the hand.
They walk along the path toward school.
A warm sleeve of wind envelops her,
until cold weather comes.
First the pain.
Then the numbness.
Then the education.
Walking past the distant hills, she feels
bread in the heart,
hunger in the heart of bread—
counts deer tracks, sees
galaxies of deer circling mountains,
life scaling stone. ■ **ABILITY**

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ABILITY'S



Crossword Puzzle



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ACROSS

- Ashley Fiolek's sport
- Coffee container
- NBC Universal network
- Putting out great love and joy
- Had good words for
- Take up a challenge
- Kind of cabbage
- Flower holder
- Save from danger
- Sea motion
- "The Big Bang Theory" character
- Employ
- Cardiff is its capital
- "No way"
- "Be disabled physically but not in spirit" - for example (quote from Stephen Hawking)
- Darling
- Bikini top
- She overcame a severe stroke but recovered doing a rehab program and founded BET Group Global, Emily ____
- Newly created device
- "The final frontier"
- First responding group, abbr.
- Poetic word for before
- Long Haul Paul's bike
- Small version
- Ed Sheeran song, "Bad ____"
- Requirements
- One who imagines a better future
- Patches up

DOWN

- First actor to use a wheelchair on a Broadway stage. Ali ____
- Bicycle mover
- "Abbey ____," Beatles album
- Dated but now trendy again
- Tree juice
- Shakespeare's "food of love" key to early childhood development
- Purpose
- Gizmos
- Founder band Saving Abel overcame addiction 2 words
- Short sleep
- Alien too good for earth
- Newport's state
- Salty water
- OT uses music in early childhood development, Kim ____
- Interlocking construction toy by Howard Romans for blind players
- Happiness
- NY village, ____ Harbor
- What, in Canada
- Sources for free reads
- Hot as food
- Asian food staple
- "____ you kidding?"
- Secure
- Unwrapped a present, say
- Energy
- Leave out
- Balloon filler
- Cry of discovery
- Pro civil rights Pres.
- B & B
- Injured reserve, in the NFL, abbr.
- Small, for short

answers on page 62

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45-65

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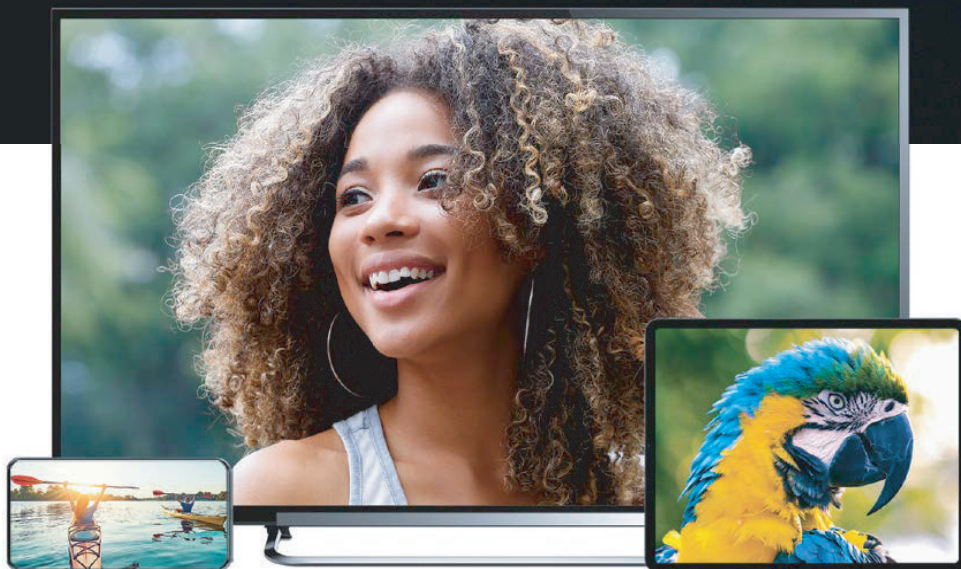
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Key Facts

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\$161.8B Market value of stock*

*Based on sales, profits, assets, and market value as of March 31, 2021.

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- For the tenth consecutive year, readers of **CAREERS & the disABLED** magazine recognized Wells Fargo as one of 2021's Top 50 Employers of people with disabilities.
- **Equal Opportunity** magazine ranks Wells Fargo No. 15 on the 30th Annual Top 50 Employers 2021 list.

Accommodations and accessibility assistance for team members and job seekers:
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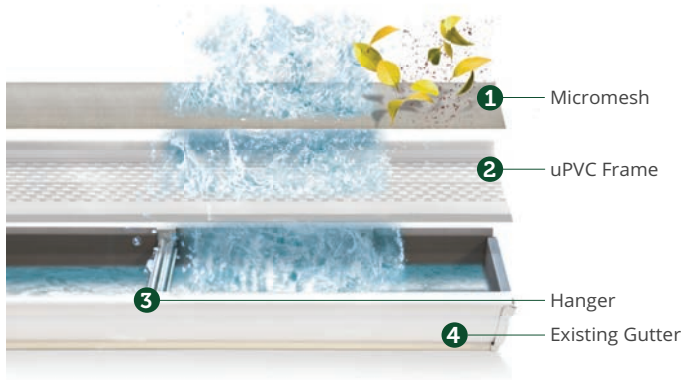
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