**From stigma to supermodel**

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I'll tell you a little bit about my story and who I am. I'm a fashion photographer based in New York City. I've worked for lots of different magazines in New York, I've worked for Elle and for Marie Claire, and for Interview and for GQ, and I got to work with some really beautiful people. My studio is in New York, but I also lived in Milan for about eight years, and in Paris as well, and worked for the house of Yves St. Laurent. I also did portraiture as well. I've worked for lots of different magazines, lots of great clients. But I was always told, every single day, who was beautiful. I was forced to work within certain parameters of the beauty standard. I was told, "This is the most amazing model of the moment, you've got to photograph her. She's incredible, you've got to. " And then the next season, it would change again, and I'd have to shift my ideas of beauty, and so we'd go to the next model, and it was kind of really crazy, because I'm an artist. I saw beauty everywhere. I didn't see beauty just on a magazine cover. I did a shoot with, of course, Cindy, for Revlon, and really fantastic, beautiful people. But I thought, someone's always telling me who's beautiful. And I was kind of frustrated. I left my studio one afternoon in New York, and I was walking down Park Avenue, and I saw, waiting for a bus at the corner of Park and 20th, this gorgeous kid. She had long, white, beautiful hair, and pale, pale skin. She had a genetic condition called albinism. I didn't know much about it, but she was stunning, and I'd never met a model like this before. And I went to grab her and say, "I have to take your photograph, you're amazing!" And the bus came, she got on, and then she took off, and I was really glad because she was 12, and I'd be in prison at the moment. (Laughter)But really, it was extraordinary to see this kid. So I continued right down to Union Square, to the huge Barnes and Noble, and started pulling any books, or any information I could about this genetic condition, albinism. And I found really kind of sad images. I didn't find images of this kid. I found images of people sitting in hospital beds, looking sad, looking downtrodden, just images of despair. I found images of a bright red eye, the albino eye. I'm thinking, this kid had beautiful blue eyes, she didn't have red eyes. And then I started seeing images from Africa, where kids were surrounded by tribes pointing spears at them or in cancer wards and clinics, or they're just in beds, and images of illness, of sadness, of sickness. And then, I started, of course, going through those same medical textbooks, and started finding these typical imagesof kids and adults in their underwear, against walls in doctor's offices, with the black bar across their eyes saying "disease. " This is a disease, defined by a disease. And I was like, this is crazy. And then I started going into it further, looking on the Internet, and all these different medical textbooks, and everything was so sad, and so negative. I then started finding images of the albino freak family in the circus, and then of course, all the movie references, from "Powder, " who had albinism because his mother was struck by lightning, to "The Princess Bride" and to "The Matrix Reloaded, "there were the ghost-like twins that came in and wreaked havoc, and destroyed things and then disappeared. Even most recently, "The Da Vinci Code, " there was like the evil albino driving around Paris at night, killing people, shooting at people. Well, I found out, through my research, that people with albinism have a visual impairment. There's always vision, but they're considered legally blind. So they certainly wouldn't be driving around Paris at night shooting at anybody and expect to hit anything. So I'm thinking, this is crazy. So I contact NOAH. Now, NOAH is the National Organization for Albinism and Hypopigmentation. It's a support group for people living with this condition, and their families. And I'm like, "Hey, I'm a fashion photographer. Let's show the world the beauty of albinism!" And they said, "Get lost. " And I'm pretty persistent. I'm like, "Won't you talk to me?" And they made it very clear to me about their fears of exploitation, that every time there was a magazine article that came out about a kid with albinism, it was a story about a victim. It was sad, or it was exploitative, or sensational — never positive, always negative. And I said, "Okay, well then, what do we do here?" So, let's form a nontraditional partnership — fashion photographer, genetic support group — and we'll work together. And you can keep an eye on me to make sure that we create something positive and powerful, showing the world the beauty of albinism. And they said okay. And I was like, fantastic, let's do this!So in walks the first person I'm about to photograph. Her name is Christine, and Christine is a knockout. Long white hair, really tall. She's stunning. She walks into my studio. The way that she walks in, though, instead of this gorgeous girl, she walks in like this, her head's down, shoulders hunched, one-word answers, she looks down, no eye contact. This kid has been teased her whole life because of her difference. And it was so apparent in the fact that it left her with zero self-esteem. And I'm thinking, oh, this kid is just so fragile. And just the day before, I was shooting Cindy on the same set, in my studio. I'm thinking well, I have to be so careful with her — no, out of respect for this gorgeous kid, I'm going to photograph her like I would anybody else. So the fan went on, the music went on, and I grabbed a mirror that was next to the set, and I held it up to her, and I said Christine, look at yourself. You're magnificent. And she looked in the mirror, and she got it. And she went from this to that. And that's our Christine, and she just exploded in front of the set. By the time she left the studio, she was kissing everybody on both cheeks, and saying, "Ciao!" and she was unbelievable. And I saw this transformation right in front of the lens, through photography, that she was now transformed, with a powerful and positive sense of who she is. The next day, she goes to school, she's going to change the way her community sees her difference. Instead of walking into that classroom like this, she's walking in like this. So it's all about ambassadors for change. It was extraordinary. And those first images, right after, we did a series of them, using several individuals with this condition, they were in Life magazine in 1998. So it was a while ago. It was a cover story, it was a five-page spread. It was really a fantastic editorial. It was great; I loved it. Then we used a lot of the images, though, from Life, and put them in other magazines, magazines worldwide. Magazines in the U. K. , in France, in Italy and Canada, and other magazines in the States. It was amazing. So this is from the U. K. , Christine again. Friends Jen and Ruthie are sisters, and Kristen. That's Lauren. We did a campaign for sunglasses. A lot of kids with this condition are photophobic, so they have a real strong light sensitivity. So we thought, perfect for a sunglass campaign. People magazine did a great story. So it was circulating, people were saying all this great stuff. It was fantastic. So I was getting calls, though. Getting calls from the U. K. , saying, well we just saw this spread, can you come photograph our kids with this condition?We have a support group here, can you come meet our families? People in Africa were calling in the same. New Zealand, can you help us start a support group? I'm like, fantastic! This is great! Let's do it! So I would travel in all these places, as I was shooting and doing my commercial work, I was at a local chapter conference in Philadelphia. Small family conference, about 40 families, did my presentation of kids with albinism, this mom came up to me, and she said, "My son Randy, when he was a little boy, he'd come home from school, and I could see the kids were teasing him, and he'd be in tears. And I'd buy him an ice-cream cone, or a toy truck, and he'd forget about it. " She said, "Now he's in high school. He comes home from school, I can see the pain, the anguish in his eyes. He walks in, he walks right past me, goes up to his room, slams the door, and I don't see him until the next day. He's not going to want to be photographed, he has zero self-esteem, this kid has such poor body image, and he's just so shy. But if you could just show him photographs of kids his own age, so that he knows he's not alone. " I'm like, "Of course. Where is he? Show me!" She points over to Randy. Now Randy's sitting there — his pants are hanging down to here, his underwear's hanging out, he has this long, great big shirt, he has ten earrings, he has a tattoo. He's amazing, this kid. I crawl over to Randy. I'm like, "Randy, I speak to moms and dads every single day, terrified about the future of their kids with albinism. All they have to do is take one look at you, and they're going to be fine. Please let me take a photo of you. Your mother said, she told me, that you didn't want to be photographed. " He said, "Rick, what do you mean? You have to understand, I'm 16 years old. I don't talk to my mother. " And then he said, "I want to be photographed. I want to show the world that who I am, with my albinism, but also other things about me —" You see how shy he was. Very, very shy, Randy. But Randy created, early days in this idea, of this nonprofit group Positive Exposure, the idea of networking stories, sharing experiences and the images around the world. I'll kind of quickly go through the album. I was very interested, at that point, getting calls from everybody in the world, to find out more about this idea, a message, about albinism, or perceptions of people in communities about this syndrome, albinism. So I started hearing about stigmas, and discrimination, so what I looked at is really trying to explore cultural perceptions and attitudes towards this condition. This is my friend [unclear], who's a Kuna Indian in the San Blas region of the world, the San Blas region of Panama. She's extraordinary. So the incidence of albinism is about one in 20, 000 worldwide. In the Kuna Indian, it's one in 125, the highest incidence in the world. We went to Fiji, actually, where we found out at the turn of the 19th century, a tribe could not hold their territory unless they had somebody with albinism in a powerful political position. My great friend Keke, I photographed in New Zealand, she's from India, from Delhi, but her family left Delhi because she was getting death threats. Now I'm thinking, this is horrible that they had to move, because she's eight years old. And we actually started a support group in Delhi, we found out that there are many kids that we worked with in their communities, after we started this group in India, that have had really positive experiences. So one of the things we want to make very clear is that we're not making generalizations about a community or a culture, and their reaction to people that are different. Keke's experiences were very different, but we've met many kids there that have been embraced by their communities throughout India. A great friend Sue Anna from Korea. Tom, who was just adopted by an American family, from China, This is my great friend Harry from Puerto Rico. And Natalia. She and I started the first albinism society in Russia. Maizan and her sister and mom in Malaysia. Ceara. All she ever wanted to do was be a dancer. She was told that because of her visual impairment, she'll never dance. She'll never be able to follow the choreography or the dance steps. She's like, they said, find another love, another passion. She's like, no. She's New Zealand's Celtic dance champion, and just started a school for dance for kids with visual impairment. I'm going to zip through this. Roz, from Australia. I spend a lot of time in Africa, where there's a high incidence of mortality associated with albinism, due to skin cancer. This is my friend Siri, who when she was born, the father's family put her out of the house, thinking she was cursed. and Mom, not knowing what to do, put Siri in the sun to get her dark like her brothers and sisters. So you can see, it's all sun damage. A lot of kids that I met throughout Africa were put in special schools, schools for the blind, not because the tools were better there for kids with visual impairment, but more importantly, because the teasing was so great, the discrimination is so great, these kids don't do well in mainstream schools. I started an albinism society in Kenya with my friend C. K. , who actually went to a mainstream school. I'm like, C. K. , how is it possible you went to a mainstream school? Nobody in Africa goes to mainstream schools. She said, "It's because of my twin sister, Delphine. " Fantastic. She said Delphine would get all the work off the board, the things I couldn't see, she'd help me with it. If the type was too small, she'd blow it up for me, she said. But more importantly, when kids would tease me, Delphine would beat them up. (Laughter)But on a sadder note, I was spending a lot of time in Tanzania, where witch doctors are saying, bring me the bones of an albino, and I'll make a potion that will make you rich. So we're working very closely with the government there, I've been there six times in the last two years, to create public awareness programs to save these kids. This is the dancer. This is in the Shinyanga region. This is one of the visuals that we created in East Africa, trying to fight and educate the public. I received the Art of Reporting award, from an organization called the Chromosome 18 Registry. The larger organization was the Genetic Alliance, which was a coalition of all the genetic support groups, and it was the award for the Life magazine piece. The president at the time said, I'm also the founder and director of the Chromosome 18 Research Society and Registry. I'm like, fantastic! That's great. What's that? She's like, well, if you have an anomaly on your 18th chromosome, then you have all kinds of problems and difficulties and challenges, and then we look after you, through this support group, like NOAH is. So I'm like, that's great. She said, I see there's a universal message here, about all kids with differences, so it's not just about albinism. Would you come and speak to our families in San Antonio with these chromosome 18 anomalies? I'm like, sure! I went back to them thinking, what the hell is a chromosome 18 anomaly? I was an art major at the school of visual arts, I had no idea. But I looked it up, these are the images that I saw. I'm thinking, albinism was so easy, this is going to be rough. But I went to San Antonio, walked down to the auditorium where the kids and young adults were, opened the door, and I was instantly surrounded by kids screaming with laughter. There were kids with cleft palates, kids with mobility issues, feeding tubes, trachs, but they were kids, first and foremost. That's Rebecca and Pauline. My great friend, that's Ellington. He's awesome. Remy. That's Emory. Byron. Taylor. Elizabeth. And my great friend Sean. So we decided at that point to involve other organizations to be part of this larger exhibition that was going to be sent out from the People's Genome Celebration in 2001. The National Human Genome Research Institute and the Genetic Alliance invited me to create an exhibition at the Smithsonian, commemorating the mapping of the human genome. So we actually invited other genetic support groups to be part of this exhibition, not just on albinism, but all groups, again illustrating the universal applicability. I saw these images from the Marfan Foundation, these kids grow very, very tall, at risk of an aortic dissection, but they're amazing kids, and I thought, how gorgeous. And I understood the importance of this image, how important it was to show how beautiful, and to show how the image presents itself. But isn't there another way to show it? Because nobody, and I've photographed thousands of kids now, with Marfan Syndrome, and nobody stands like this, with a portable black bar. It's extraordinary. So we decided to put them in a pool, show Billy swimming -- ["Bill with Marfan Syndrome"] -- show how it presents itself, but keep going, and keep presenting how these kids look, but put the humanity back in these gorgeous images. I only have a few seconds here, so I'm going to go through. Cool girls at the Costello Conference. These are great friends Danielle and Maggie, who actually met at the last Costello Conference. For both, the first time they ever met anybody with the same syndrome. They go to the same conferences every year and I go and photograph them. And this year, they were there again in Florida, but this time it's a little different. They're gangsters now. (Laughter) But they're pretty amazing kids. I just want to talk very briefly about this really great kid, to talk very briefly about a project that we're taking these images, and bringing them into high schools. I can photograph a great kid in my studio, and she's having a brilliant time, and she feels 10, 000 feet tall. By the time she leaves my studio and gets to Park Avenue, five people point at her, point at her birthmark, or at her white hair, or her wheelchair. So we have to make it relevant for all of us, for all these kids, to make people understand what the idea of celebrating diversity actually means. So we started a project called the PEARLS Project, where these photographs are going into high schools, and the kids that are in the images are blogging, and the students are following their blogs. And they all have these great video intros. I just want to give you this last one, and this is actually Byron, who is actually one of our bloggers. (Video) Byron: Hi, my name is Byron. I live in the D. C. area. I'm 14. When I was 10 months old, I had a left hemispherectomy. I had the left half of my brain removed, because I have something called Sturge-Weber Syndrome. I wear a brace on my right leg and right arm. I only see out of the right side of each eye, so sometimes it's harder for me to see things on the right side. So playing sports can be frustrating, because I might not see a ball coming. I didn't see that coming. Excuse me. Rick Guidotti: So we're using all the visual art to change public perceptions through these great kids. I feel as an artist, it's my responsibility. I know that when I was a kid, and I saw someone that was different walking down the street, If I stared, I got slapped by my mom. So the idea was if you don't stare, look away. And I think as an artist, it's my responsibility, and all of our responsibilities, to steady that gaze a little bit longer. Because you stand there, and you'll see a difference. You'll start seeing beauty in that difference. And you'll start seeing beautiful gorgeousness, and then this light just spreads, and once you're enlightened, it just changes your whole world. It's about seeing the beauty in all differences. Thank you so much, I'm sorry I ran over. Thank you guys, thank you.