

Opening Session Facing the World “Head” On

By Deirdre Nero, Miami, Florida

I once had long, thick hair, curls down to here, and they would get knotted, and my sister Aria would bend me over the tub, and brush my hair, and I would cry and scream, because it hurt so bad. That was, probably, when I was about 10 years old. Who would think that now, at age 37, I would’ve cried so many tears—not over the pain of having my hair brushed, but over the fact that it’s not there. I still look back and see old pictures of myself and think, “Oh my God. Where did all that hair go?” And sometimes, I feel like crying. But more often when I look in the mirror and see my bald head, I don’t really feel like crying anymore. It’s more just, like I said, wondering where did all that hair go? I used to have so much, and I wonder why my body has chosen to attack itself in this way.

There must be some reason that I’ve been chosen to walk this path in my life. These are a lot of the thoughts that run through my head on a daily basis. And I know that all of you—and all of the millions of people out there with alopecia areata—can relate to this same kind of thought process. Meanwhile, there are the people that go about their daily lives and don’t really know anything about this and say things like, “Oh, it’s only hair” or “Oh, at least you don’t have a cancer.” Most of the time they’re well meaning, but I don’t think people realize how much comments like that really can hurt a person.

My name’s Deirdre Nero. I’m an attorney, I live in Miami, Florida, I’m 37 years old, and I’ve had alopecia areata since I was 21. And this disease has really changed my life; it has changed me deep down to my core. It’s made me weak and vulnerable, and it’s battered my self-esteem and heightened my insecurities—but, at the same time, it’s made me a stronger person. It’s made me a braver person. And I really think that it’s made me a better person. I know that that’s another sentiment that a lot of you can relate to; I heard a lot of people in the support groups saying similar things. It’s ironic, isn’t it, that losing a little thing like your hair could have such a profound effect.

I’ll tell you a little bit about my journey. I always fancied myself to be a real strong woman, kind of a badass. (Excuse my language.) I was always the confident, smart, pretty one. The one that always had her act together and knew what was going on with her life. Then one day, at 21, it seemed like all that turned on a dime. Well, it wasn’t really a dime; it was more like a quarter, or a 50 cent piece, because that was the size of the first bald spot that I found.

I was living in Spain at the time. I was studying abroad, having way more fun than anyone should be allowed to have when they’re supposed to be studying. And I was blow-drying my hair in the bathroom one day, and I flipped my head over the way I had done hundreds of times before up to that point, and I saw it—and it was huge and perfectly round, and I remember running my fingers over it, and it was completely smooth. And I just remember having this moment of instant panic, and thinking, “What is that? What the heck is that? What’s going on?” Sheer panic.

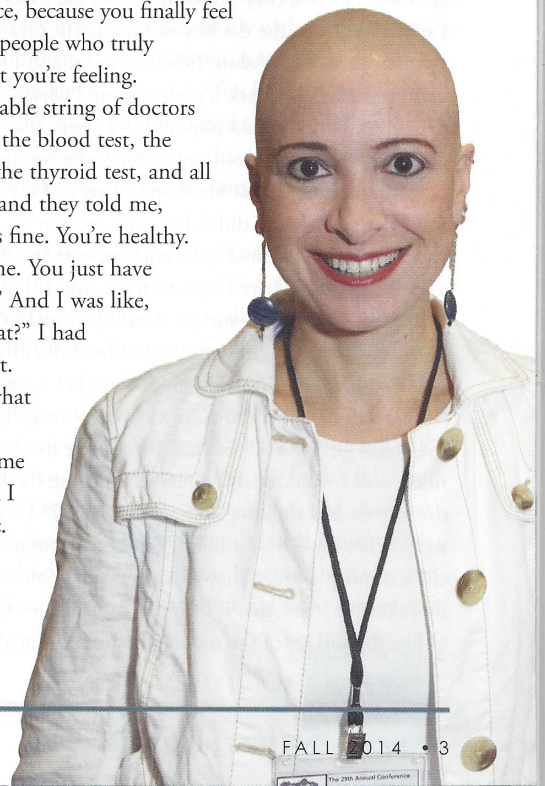
I called my mom on a transatlantic phone call, hysterically crying, and I don’t even know what I was saying. I was so upset! The only thing I really remember from that conversation is her saying to me, “Slow down. I can’t understand a word that you’re saying to me right now.” In hindsight, I think those words have come to be true in so many ways, because a lot of times I feel like nobody really understands what I’m saying, or feeling, when it comes to my alopecia areata.

They try, and they mean well, and they have really good intentions. But a lot of times I feel like they just don’t get it. That’s why I love being in this environment, at this conference, because you finally feel like you’re with people who truly understand what you’re feeling.

So the inevitable string of doctors followed. I had the blood test, the dermatologist, the thyroid test, and all the other tests, and they told me, “Your thyroid is fine. You’re healthy. You’re totally fine. You just have alopecia areata.” And I was like, “Alo-what? What?” I had never heard of it. I didn’t know what that was.

So they told me what it was, and I said, “Okay, doc. Fix me up.”

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Give me the pill. What do I have to do? Make it go away." At this point, it was still just one patch. And I thought, "Give me the magic cream, and let me be on my way." That's when they told me, "Sorry. There's no cure for this. We're not even really sure what causes it. But you must be really stressed." And I said, "You know over the years, I've been told by so many people how stressed out I must be. It's really stressing me out hearing this. I must really be stressed. Oh my goodness." So I remember then—this is back in 1998—going back to my parent's house in Miami, and on their enormous computer—getting on their internet and doing a search for alopecia areata.

I've always had this kind of lawyer mentality, and I needed to immediately know all the information. And what I found really kind of horrified me—more than their slow dial-up internet connection ever could horrify me. I was just reading, and seeing the pictures, and reading about alopecia areata, and I was like, "What do you mean, I could lose all my hair?" I remember telling my mom about what I found in the internet search, and she said, "Oh. I'm sure that's not gonna happen to you. You know that's not gonna happen to you. Don't worry." And for a long time it didn't.

It didn't happen to me. I lived for the next 10 years with just patchy alopecia areata. It was kind of degrees. Then I started to get more patches; they dotted my head like Swiss cheese. And I started going to the doctors and doing the creams—and the gels that irritated my skin. I did the shots, and I kind of felt like I was playing whack a mole. I would whack one spot, and then another one would pop up somewhere else. So, my part was always changing positions to try and cover the spots, and I managed to go like that for about 10 years. I even went through some periods where I didn't have any spots at all. That wasn't very often; I usually had at least a couple spots. But I did have a couple periods where I had no spots, and I thought, "Oh yay. I'm cured." But on the surface, I still managed to maintain the image of the pretty girl with the full head of curly hair.

At 28 I had already had alopecia areata for years, but I still had tons of hair. On the outside, I was portraying the image of the pretty girl with all the hair. But on the inside, I was really terrified, and I would spend hours scrutinizing the bald patches in the mirror, and thinking, "What if, what if?" I would just look at the patches until I went blind. But at that point, only my inner circle of people really knew what was going on with me. Only those people knew that if I flipped my head over, it looked kind of like the surface of the moon with all the craters.

I still met the man who is now my ex-husband, and he fell in love with me, he thought I was beautiful. He still was able to run his fingers through my hair; I still felt like a woman. You know? I was a woman with a secret, but a woman nonetheless. Towards the end of my marriage, the patches started to get really bad; they started to grow together, and get bigger. And I remember one day turning to my husband and saying to him, "Will you still love me, if I go bald?" And he said to me, "Oh, you're not gonna go bald, silly. That's not gonna happen."

I should've realized then, from that comment, that the end of our marriage was coming. I've always wished he would've just said, "Yes. Of course. I'll still love you. Doesn't matter." But that's not what he said. And you know what? I did end up going completely bald, but no, he did not end up still loving me. We're not married anymore. But actually, that's fine. Hindsight is 20-20. I'm much better without that guy.

I know from pictures that I still had hair when he left and when we got divorced. But, it's funny, because only from the pictures do I know that I still had hair at that point in time. When I think about it, in my brain, I was already bald at that point in time. I don't remember going bald; I think of myself as already bald in that moment. That's how I realized the mind is crazy, and it will play tricks on you. It's been a real process, over the years, trying to unlink those things, so that I can really try to find happiness and love without having those feelings of loss linked together.

That's been a work in progress. It's hard. We've talked about it at this conference—the rollercoaster ride of emotions that someone with alopecia areata goes through. One day you're angry, and the next day you're sad, and the next you're feeling acceptance—you're on this rollercoaster ride.

Not long after my ex-husband left, the patches start to get really bad, and I remember saying to my mom and sister, "Okay. I am not going to wear a wig. I refuse. No wigs for me. I won't buy one." But there I was, probably a week or two later, sitting in a wig shop. The wig store that had been recommended by a friend of a friend of a friend of my mom who had cancer, because we had no idea where to go to buy a wig. I had no clue where to start. So, I remember thinking, "Okay. This is it. I'm doing it." And then a couple of hours later, and a couple—several—hundred dollars later, I walked out with a wig. And I was just mortified. I kept saying to my mom, "What if people at work notice?" I mean, how is it possible that I went from having super thin hair yesterday, in one layer covering the spots, to now having this awesome bob, this full head of hair, in one day, overnight. It's like a miracle, right? So, obviously, people are gonna notice. And my mom said to me, "You know people don't really look at

you quite as closely as you look at yourself." I always remember that, and I think, "God. That's so true." You know? We're always much more critical of ourselves than other people are of us.

So, the hair kept falling out at an alarming rate, and before long, all I had was one little sad patch on the top of my head, and nothing else. So, then came the next life-of-an-alopecian milestone, which I know many of you have been through: the head shave.

My sister, bless her well-meaning heart, has never had a real knack for subtlety. I don't think that gene runs in our family, because I don't have that either. So she turned to me one day, and she was just like, "God, that thing looks ridiculous. Can we just shave it off? Just let me shave it off. Come on." And I said, "No. I still have this one little . . ." I had this one little patch of hair at the front that I used to try and pull out of the front of my wig. But then I looked in the mirror, and I thought, God, you know she's right. Who am I fooling? It's not like I have hair. I'm bald, and this little patch is not fooling anyone. So I turned to her and I said, "Okay. Let's do it. Let's do it." And the next thing I knew, I was sitting on the floor in the bathroom, and she was hovering over me with the razor, and I was just like, "Oh my God. Don't cut me."

And she said, "Don't worry, I won't." Quick. It was done. Two seconds later, I was really bald. Completely bald. That was it. I was a bald woman.

But I put my wig right back on when I went outside. When I left the house, my wig was my armor, it was my shield from having to face the world head on as the bald woman that I was. I wasn't ready for that, yet. I just wasn't.

All the hair on my head eventually stopped growing, or just grew a little bit and I would shave it clean. And I remember thinking through all of this time, as long as I don't lose my eyebrows and eyelashes, I'm gonna be fine. I'll be fine. As long as that doesn't happen, I'm cool. I can get through this.

Around the same time I attended my first NAAF Conference in Los Angeles. And I remember feeling so happy and so thankful to finally find a group of people that really understood what I was going through, that really understood what I was feeling on this journey. That conference really began my journey toward kind of identifying with myself as an alopecian.

That word makes me laugh. I know some people don't like the word alopecian. I don't mind it, but I think maybe it bothers

people because they think it sounds like martian. I think that that's a defense mechanism. Obviously alopecia areata has also turned me into a self-psychoanalyst, so if I ever have to give up my job as an attorney, I've got another gig. I don't know if it pays quite as well, but . . .

In the year between my first and second NAAF Conference, it finally happened—the thing that I had been dreading all along on this journey. My alopecia areata progressed from totalis to universalis. I lost my eyebrows, my eyelashes, and most of my body hair. In this weird twist, I never lost my underarm hair or some other hair that I would've liked to have gotten rid of—that I would have paid tons of money to get rid of. My brother was like, "That hair is the cockroach hair. It will live through nuclear war with you. That's the hair you'll never lose," And I'm think-

ing, "Great. Fabulous." But I did lose my leg hair. That's been one awesome thing—not having to shave my legs. The thing that struck me most around this time was that I wasn't only bald, but I was suddenly not recognizing my reflection in the mirror. Nothing can really compare to the feeling you get when you startle yourself when you look in the mirror. It's really kind of like feeling like a foreign invader has taken over the mirror image looking back at



you. I still don't really ever let people see me without eyebrows. I put them on, and then, I look at myself again. And I'm like, "Oh yeah. There you are. That's you." After losing the eyebrows and eyelashes, I went into a profound funk. I went back on that rollercoaster ride, back into depression. I started feeling uncomfortable in my own skin again, and for some reason, hiding behind the wigs.

My sister, who seems to have had her hand in a lot of my alopecia areata journey, is a really talented jewelry designer, and she had been saying to me for years, actually ever since I lost my head hair, "Wouldn't it be so cool for us to do a jewelry line, an earring line, and use your bald head as the display?" And I told her, "That's a great idea, but there's no way in hell I'm doing that. I am not ready to basically go out there and out myself as a bald woman. So, yeah, your idea's awesome. But no, I don't think so." Then around the time my eyebrows and eyelashes and all of my hair fell out, something inside of me changed, and I kind of felt like, oh, what the heck, people are gonna find out, now, anyway, so I might as well try to take this situation and make something

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good of out it—like the old proverbial turn lemons into lemonade type of thing.

So one day, when we were sitting in my mom's kitchen and my sister brought up the idea again, I said, "You know what? All right. Let's do it. Let's just do it." So, that day, in my mom's kitchen, the BALD jewelry line was born. It was a new jewelry line, with earrings only, and the acronym BALD stands for, excuse my French, BadAss Lawyer and Designer. I am the badass lawyer, my sister, the badass designer. So that's where we got the acronym from. We thought we were being so clever, you know? We decided to team up and try to do something together to create some awareness for alopecia areata, to empower women with hair loss, and to raise a little bit of money for charities like NAAF.

So we started selling jewelry at events. And I had to go without my wig at these events, right? That was the whole idea behind this jewelry line—to go out, bald head shining, big earrings on, and sell the jewelry. At that time, I was really nervous. I was really scared to let it all out there. But I figured, "Jump in. Feet first. Well, head first, at least in this case. And just kind of do it." And it was actually kind of fun being the center of attention. Everyone was really cool, and very supportive, and we even did a segment for the local news. I did a TV news interview that was shown on my local Fox affiliate.

Around this time, I decided that I was going to come out on Facebook. I did it for Alopecia Areata Awareness Month. I decided that for September, I was going to change my Facebook profile picture to one of the really awesome bald pictures from the jewelry photo shoot. It was to be just for the month of September, and then, I was going to change it back to my regular picture, with my wig on. But I've never changed it back—and that was about two years ago. I've kept the same picture up. I decided to never, ever take it down.

That was a big step for me, coming out on Facebook. And I think that everyone has to make that decision at their own pace. I remember thinking, okay, once you do this, there's no going back. That's it. Once you put it out there on Facebook, the world knows, it's official—and I was right. With one click of that mouse, I told, like, 600 people. I said, "Hey, look at me. Hey, guess what? I'm bald." I actually think that's what I wrote in the caption under one of the pictures. But it ended up being a positive experience. I don't think I had any negative comments. One friend from fifth grade, a guy, was like, "What happened to your hair? Where did all your hair go?" And I took it as an opportunity to educate him about alopecia areata. I wrote, "Hi, obviously you didn't read what

I wrote," and then, I took the opportunity to explain it to him again. Sometimes you've got to hammer it into people.

We didn't make a ton of money off the jewelry line. We didn't become famous. We're not in tons of stores, and we haven't been invited to be on the *Today* show or anything like that. But what it did do, for me, was force me to shed a mask and face the world as I am. It forced me to step out into my own reality, and I also hope that it helped me to empower some other people, even if it was just a little bit.

Through all of this process, I've become really active with NAAF. I've become one of the Legislative Liaisons, and I've traveled to DC. It was at the DC conference that I got pushed head first into the Legislative Liaison program when the guy that was supposed to lead our Florida-Georgia delegation on Capitol Hill visits didn't show up. NAAF Communication Director Gary Sherwood said, "You're a lawyer. Guess what? You're up at bat. This one's for you." And I stepped up to the plate, and I'm so glad I did, because it's been a really positive and amazing experience.

I've walked the hills and halls of the Capitol with no hair on, and I've sat in front of legislative aides and have shown them the face of this disease. I'm a lawyer, and I know how to be persuasive, I know how to talk, so, I figured, I would use that skill to try and bring some awareness, and, hopefully, do something positive for this organization. You don't have to be a lawyer or someone who likes to talk or someone who feels comfortable in front of crowds to get involved in this process. And I really encourage you to become one of the Legislative Liaisons, to visit with Gary and talk about how to get involved, because it's just an amazing experience. Recently, I took a picture with my hair on, then I went into the office of one of our congressional representatives and I sat down with her, and the first thing I did was take my wig off and put it on the table in front of me. She said, "Hi." And I told her, "Hi. Let me tell you about alopecia areata." She didn't even know what it was, I don't think, until that moment. That was an interesting experience I had very recently.

I've also gotten really involved with my local support group. I've sat outside with other girls with alopecia areata, who were wearing their wigs in the 90-degree Miami sun. I let them see me there, with my bald head, and I encourage them to feel safe enough to take their wigs off—especially, in the support group, which is a safe space for them to be able to do that. But some of them aren't comfortable with that, they really want to keep their wigs on, and I can understand that. Everyone has to walk this path their own way. Not everyone is ready to do it—or even wants to do it—the way that you do it or I do it. I just

encourage them to feel safe enough to do it, if they want to.

We did a local fundraising event, we did a Zumba-thon for alopecia areata awareness, and it was funny because my sister was there, and she looked around, and she said to me, "Why are you the only bald woman here? This is an alopecia areata fundraiser." And I said, "I'm not the only bald woman here; I'm the only bald woman here without a wig—and there's a difference." So, even at this event, most of the people with alopecia areata did not choose to uncover their heads. I did, and I became the token bald person at the event; everyone at the Zumba-thon wanted to take pictures with me. It was really kind of funny.

So is it easy for me? No. It's not easy for me to go out without my wig on. And yes, I do feel strange sometimes when I walk out of the house without my wig on and I get the stares or people ask me how my chemotherapy is going. Of course, that's hard! But I just suck it up, I just do it, because I feel like it's one little thing that I can do—not only for myself, but for our community as a whole, to build awareness. I take a deep breath, and I suck it up, and I just do it.

I do still wear wigs. I'm a lawyer, and I really feel that to maintain my professional image, to be successful in my career, I need to wear hair. Maybe that's a social construct that I should be trying to lead the fight against, but actually, I'm okay with it. My hair—my wig—has become part of the uniform. It's part of the outfit, an accessory. It's one of the things that I put on, along with my suit, and my high heels. That's how I've chosen to use it, and I'm okay with that.

The most important thing, I think, is that I don't hide my alopecia areata, anymore. That's the difference, to me. I will readily tell someone, even in a professional setting, that my hair's a wig. I get this all the time: "Oh my God. Your hair is so great. How do you keep it so straight in the Miami humidity?" I'm like, "Oh, you like my hair? It's a wig. For \$600, you can have the exact same hair." And they ask, "It's a wig?" And I say, "Yes, it's a wig. I'm bald. I have alopecia areata. Oh, you don't know what that is? Let me tell you about it." I've had the same conversation more times than I can count, and in every setting—professional, social—and I don't mind. I think that's part of what this is all about.

I'm part of a networking group called BNI, which stands for Business Networking International, and we meet weekly. We do it to pass referrals to each other. There are about 50 professionals in my group, and I'm there as a lawyer. Every month the group supports a charity, and for the longest time I wanted to suggest NAAF, but I was scared because I knew I would have to explain to everyone what it was, and I was "up to here" with the whole process, with the jewelry, with coming out. But I finally decided

that I would suggest NAAF as a charity, and I had two meetings to give the NAAF pitch and try to raise money.

At the first one, I just gave the pitch—I talked about NAAF, about how great it is, what alopecia areata is—and I told them that I had it, and then I collected a few meager little donations. So the next week, to make an impact, I knew I had to do something. As I went up to give my pitch, I took my hair off and put it on the table right in front of me, and then I gave the exact same pitch that I had given the week before—and this time I raised \$1,500. What I'm learning is that showing people your vulnerability goes a long way, and being vulnerable is actually, ironically, a show of incredible strength. It's funny how that works.

So, now, I'm at the point where my hairs have started to come back. I'm on the rollercoaster ride, again. I finally—kind of—came to terms with being bald, and then, the hair started to grow back—in spots, kind of like Swiss cheese—and then it started to fall out again.

That's been an interesting rollercoaster.

I became a spinning instructor, and I think, "Okay. I'm going to get up in front of a room of 20 people and teach a spinning class"—and obviously, I'm not going to wear a wig, so I'll do it with a head scarf, or bald. And that's been really fun for me. So my advice is to find things that empower you, that make you feel stronger. Try and see yourself through the eyes of the people that love you. Sometimes this is hard. We can be our own harshest critics, but those people that love us—they just love us. They don't care if we have hair, or not. So trying to see ourselves through their eyes can be an awesome thing.

Try to have fun too. Really try to maintain your sense of humor about all this. I have a photo of my niece putting temporary tattoos on my bald spots during Christmas—tattoos that she got in her stocking. I will never miss an opportunity to have some fun with my alopecia.

Try to maintain the ability to laugh at yourself, and just believe in yourself, and be yourself.

If any of you would like to contact me, I invite you to email me anytime you want. The NAAF office can provide you with my contact information. I'm really here to be one of you, and I hope that you enjoyed this talk. ■

