

American Indian Cancer Foundation Survivor Interview

Conducted February 2021

INTERVIEWEE: Michaela Marchi (Isleta Pueblo), Lynch Syndrome Carrier & Colorectal Cancer Survivor

INTERVIEWER: Misha Loeffler (Bay Mills Ojibwe), AICAF Cancer Equity Coordinator

MISHA LOEFFLER: In February 2021, I sat down with Michaela Marchi to discuss her experience with Lynch Syndrome, colorectal cancer, and the things that bring her life. Throughout this interview, Michaela beautifully invites us in to learn more about CRC and offers us ways to lovingly engage with ourselves, our own health, and our community. This is a sacred story.

MISHA LOEFFLER: So this is just the introduction part. Can you tell me more about yourself?

MICHAELA MARCHI: I'm quarter blood Isleta Pueblo. My mom's mom was from there and my mom was raised there until she was about six. I'm multi-ethnic, so I'm also a quarter Filipina and I have to include my dad too, my dad was from Italy. Came over on a boat.

I am, first and foremost, a mother of two children, a 9-year-old daughter, and a 12-year-old son who keep me very busy. I'm also an artist. I'm a singer/songwriter. I am multi-ethnic as I have mentioned, I try to incorporate my multi-ethnic background into just about everything I've done. I've done a lot of diversity in education work in my life. I feel like bridge building is very important in our society and communities. I try to stay in touch with multiple communities around me and across the country because of my family and even across the globe, I've done a lot of traveling. I have a master's in elementary education. I play piano. I love to be in nature and to make sure that my kids connect with nature and the arts and I have a wonderful husband who's also an artist, a visual artist actually.

I was diagnosed with stage 4 colorectal cancer in March of 2016 as a result of having Lynch Syndrome and I'm very interested in my health and figuring out how to live my best life because I've had a lot of cancer in my family and knowing that I have Lynch Syndrome and all the risks that it brings into my current and future life. I have to be very diligent about how I take care of myself and for my kids sake too. I do a lot of research. I also think it's important to pass it on. What brings me joy is sharing the love, sharing the education, sharing whatever I can from my experience and the fact that I'm the first in three generations to survive stage 4 colon cancer, so far, I think is a real gift, something that I have to treasure and honor and do something with to help others if I can. Because I didn't get here by myself and it wasn't easy and I'd like to preserve as much of this good life that I can so that brings me joy right now.

MISHA LOEFFLER: Thank you. That was a beautiful answer. So you talked a little bit about Lynch Syndrome and how cancer has run in your family. Can you tell me more about your family history and how that relates to your diagnosis?

MICHAELA MARCHI: My mother was diagnosed with ovarian cancer at 42 and she died from it at 45. I was 13. Her mother had gastric or stomach cancer and died in her late 50s, which is still pretty young. We also have, as I found out later, many cousins, aunts and uncles on that side, which is from Isleta Pueblo [in New Mexico], who have Lynch and all different kinds of cancers associated with Lynch. Then on my father's side, my father had squamous cell [cancer] base of the tongue in his early 70s cancer and his brother had urothelial cancer [also in his early 70s]. His mother had breast cancer. They were all potential genetic risks that I needed to be aware of. But the cancer that I ended up with as it relates to Lynch Syndrome, [which was] colon cancer. My Lynch Syndrome is a genetic mutation of two of the four [correction: five] genes [associated with Lynch Syndrome]. I have MLH1 and PMS2 mutations which means that I have an 85 percent lifetime risk of developing colon cancer, and then 40-60 percent lifetime risk greater than the general population of developing, especially endometrial cancer but pretty much any of the reproductive organs. Then something like 20, 25 percent greater lifetime risk of several of the different organs in the abdomen like bile duct, stomach, small intestine, and several others. There's like a 4-6 percent chance of developing brain and certain types of skin cancer. It's a whole family of many different cancers that this puts you at risk for. It all depends on what type of genetic mutation you get and if you have a combination of different ones. Then because of my family history, it can skew that even further. I went in for genetic counseling at 40 and they tested me for 11 different possible genetic mutations. I ended up with Lynch. It also presents typically young, can be [present] in your 20's so my kids have to be tested when they're of age. Then probably if either one of them have it, they have a 50-50 chance of having it, each of them, they have to start getting monitored

right away with regular colonoscopies, etc.

MISHA LOEFFLER: You've talked a little bit about how you were diagnosed with cancer. Do you want to talk a little bit maybe about your current diagnosis?

MICHAELA MARCHI: Oh, okay. So my current diagnosis, I'm actually what they call NED or "dancing with NED", "No Evidence of Disease" as of April of 2019, which is awesome and precious. I was diagnosed with stage 4 in March of 2016. Actually, I was diagnosed with colon cancer. They found a tumor in my colon in March of 2016. May of 2016, they did exploratory surgery. They were going to take everything out but then found that it had spread all over in my omentum and lymph system, staged me, and then wanted to start chemotherapy, and with some help, I ended up finding a website, IHaveLynchSyndrome.com, run by this woman who was doing everything by herself, and she told me that I needed to contact a doctor, Luis Diaz, at Johns Hopkins about a clinical trial for just my kind of cancer that was using immunotherapy. I did, and he called me back right away and he said, "Let's get your genetic profiling done, and see if you're eligible." I was and was able to start a clinical trial at University of Chicago, phase III, which meant they were comparing immunotherapy to traditional forms of treatment which would have been chemotherapy. I happened to get selected for the immunotherapy arm. Did that for a year before I had some rough side effects. But a year turned out to be enough, and all my tumor sites started to shrink and then disappear except for one pesky little lymph node that was near my colon, and so we decided to take it out, which meant that we had to take a part of my colon out [too] I had a hemicolectomy in April of 2019, and since then I have had regular CT scans and no evidence of disease since then. They want to monitor me every six months, five years out, and make sure that it doesn't come back. In the meantime, I'm looking at my other organs now and considering a hysterectomy and other things to prevent my other risks. But right now I feel good. My scans are coming out clean and there's no new growths, no new tumors, no new sites of any disease, so I'm very lucky.

MISHA LOEFFLER: Yeah, I'm really happy to hear that for you. So I just want to bring in the family piece a little bit. Can you discuss how your friends and family reacted to your diagnosis and then maybe a bit about what they did to help you?

MICHAELA MARCHI: Sure. So my family - I have one younger brother, he's just a year younger than me, so we're very close. I think when I was first diagnosed, it was very difficult for him because we've been through so much cancer diagnoses with mom, dad, uncle, aunt, and we were the caregivers for all of them. It was very tough. But he's also been a great support. He and his wife, and of course my husband has been a rock, both nurturing and solid, and wonderful. I think because I've lost family pretty young, I don't know if everybody who's lost a parent early on does this, but I've collected family members as I go along and I sort of make my own tribe in the world. I'm also far away from my family in New Mexico. I was born here in Chicago and I have family in Isleta Pueblo, which is in New Mexico, and I have an aunt there as well, one last aunt in my nuclear family, my mom's sister who's surviving. Then several other aunts mostly, and lots of cousins but one close aunt. I try and keep in touch with everybody, especially since my mom passed, I'm probably closer to them than my brother is. But it's hard being so far away from them. I also have family and friends in Italy actually, and I speak the language there, so my brother and I both keep in touch with them a lot and we've gone there a lot, and they've been really supportive from Italy. Then, my friends, I have a wonderful network of support. When I was first diagnosed and going through that first surgery and starting treatment, my circle of friends here started a meal train and took turns taking our kids and made sure that they were taken care of and supported and kept busy, and fulfilled in all sorts of ways. I've been really blessed with a lot of support and love, and compassion in all those ways. I just recently discovered these survivor support groups and didn't realize that I never sought out support groups during my treatment, and maybe that's because I had such a strong support network that really lifted me, and gave me so much love during all those really rough times. My in-laws too, who actually live in Puerto Rico. They would come for months at a time, and especially my mother-in-law, and just take over and do everything you could imagine. Yeah, a lot of support and that makes a huge difference.

MISHA LOEFFLER: Yeah, that's really special. I'm really happy to hear too about all of your family and your loved ones that were really able to step out and be there for you in all of the ways that they were.

MICHAELA MARCHI: Yeah.

MISHA LOEFFLER: I'm going to switch it back to more of your treatment and your cancer journey. Can you tell me about what was going on when you guys were first discussing treatment and then how you ended up using immunotherapy and maybe more about what your thoughts are around that?

MICHAELA MARCHI: So treatment - Everything happened so fast to be honest. I recently found my journal from

those days and re-read through it, and I was shocked about how fast it went really. I knew that from my research the cancer that I have, then the genetic profile that I have, that chemotherapy isn't very effective. I had also watched all of my family go through chemotherapy and I'd seen how difficult it can be on the body and how much damage it can also do. It doesn't work for every kind of cancer. Obviously they're trying to find different ways to treat cancer because it doesn't work for every kind of cancer. It can do some good, but it also does a good deal of damage in some cases. I knew from my research that my particular cancer, there weren't good outcome results, so I was not on board with doing chemotherapy at all. When they staged me, I remember coming out of surgery and the oncologist coming to my bedside and saying that I was stage 4 and basically let's get you healed and ready to start chemotherapy. I was like "No, why? What for? That doesn't seem like a good option, there has to be something else." I called on my friends, I called on my support system, and I had a little team of researchers just scouring the Internet for alternative options. I have some really smart friends who know how to look into research journals, and that's how we ended up finding that there was this clinical trial for immunotherapy specifically for my kind of cancer. Lynch syndrome, stage 4 colon cancer with a genetic profile of MSI high, which means microsatellite instable. Which basically means that within the tumor site, instead of there being a few 100 mutations, like there would be in a typical cancer that isn't genetically related. In an MSI high tumor, you have thousands and thousands of mutations happening, and also my genetic profile includes it being dMMR, which means mismatch repair deficient, which has to do with the way that the tumor cells repair themselves, fix themselves, go on. The way that immunotherapy works in a simple explanation, it switches on your immune system to recognize the proteins that the cancer cells emit. The more mutations that you have, the better your immune system can recognize where the tumor site is and the more responsive you will be to that therapy, and that's what happened with me. When I heard about the clinical trial, some people might be afraid to try something like that because you might have an assumption that you're being treated like a guinea pig and that who knows what's going to happen? Are you're going to get a placebo, where first of all, you can ask questions. You can find out information if you have any [questions]. If you feel uncertain about any part of the trial, that's really important. It's really important to speak up for yourself and to find out all the details about the trial. I happened to be the only one in Chicago who was on this trial at the time, but I did know that there were a couple thousand people who had tried this before, so I knew that I wasn't the only one in the world. I did ask lots of questions, but I also asked "what if I don't do this?" I'm also very pro-science, I am pro-research. I believe in getting information on more than one peer reviewed article, which we also did so I was very much into getting into that clinical trial and seeing that it would help.

MISHA LOEFFLER: Your story is really powerful because you, not only are you such an amazing advocate for yourself, you also know when to call on other people, which I have heard can be really difficult at times to kind of face the reality that these - that you want people around, and that you want some support so I just think it's really significant and powerful that you were told by your oncologist these are the next steps, and that you were like no, that's not going to work for me, and that you actually went out there and figured it out for yourself so I guess can you kind of discuss that experience more?

MICHAELA MARCHI: So my father was a doctor and my mother was an artist and I really think that that combination and the love that they had between each other really set the stage for me to be able to have a rich conversation in the world with people who have really different worldviews. My father was in awe of my mother's ability to believe in the spiritual world and to see all the intricacies and I don't want to use [the word] magic, but it is the magic of Mother Nature. The intellect of Mother Nature, I think. He was born and raised in Italy, and he was always quoting Plato, and Aristotle, and Dante, which I also studied. He was very much about civic duty and giving back to the community. He was also raised in a church. It's very Catholic in Italy. At a certain point, he became an agnostic because well, the church was not so just in certain ways in his experience. Anyway, I think the two of them and the love that they had for each other and the way that they saw the world and how they melded that together to raise us gave me certain tools to navigate my life on this plane. He was not someone who said no politics at the dinner table. We always talked about politics. We always talked about difficult things at the dinner table and had debates and had tough conversations and my mom was all about compassion and patience. When she died at the memorial, I remember every person coming to me and whispering in my ear, "she made me feel like she was my best friend; I was her best friend." Connection to one another, connection to nature. Always finding ways to be creative. These were all gifts that they gave me and to question, and to be curious, and to learn. That's what they gave me to walk on this Earth with. When that doctor said, let's get you ready for chemo, I was like, "Wait, we need to talk. This is where I come from. This is my experience and this is what I'm reading and I don't agree. There has to be something else. Either help me find it or help me find the time so I can find it and then let's talk again." Doctors are people. We all have the agency to question them. We have to remind ourselves of that. We all have a part to play and we have to be our own advocates in our self-care because things can go wrong. Things went wrong with her treatment and care, things went wrong even with my father's treatment and care. Things that I've had to overlook. We have to ask questions. We have to be critical thinkers. I mean, look at what's going on in the world right now. There's so much that we haven't talked about in so long and so much that we could be doing more to be taking care of ourselves and each other so that we could be living better lives and be more connected to one another. Did I answer

your question?

MISHA LOEFFLER: Yes, you did. In the most insightful and just like beautifully layered way. I love that you use the word magic and then also to hear about the love between your parents and how it sounds like they were very inspired by one another and how that greatly impacted you. Now, how you are using that to also equip people with the internal understanding that they too can advocate for themselves. That you can be creative with your treatment.

MICHAELA MARCHI: Yeah, actually, I want to share about something else that I did when I was first diagnosed.

MISHA LOEFFLER: Sure, of course.

MICHAELA MARCHI: When I was preparing for my first surgery which I thought was going to be a surgery, I got diagnosed with having this tumor in my colon. I was diagnosed with colon cancer but I didn't know what stage it was or the extent of it. The surgery was supposed to be a full hysterectomy, and they were going to take my large colon out, the whole thing. The diagnosis was early in March and the surgery was going to be in May. It all felt very fast. I decided to reach out to as many people as I could who were around, even people who were far away, and hold a "Letting Go Ceremony." Reciprocal, not just for me but for all of us. It was late March around the spring equinox. I thought that was a good time. So here in Chicago it was still pretty cold. It was a cold, windy, wet day, and I picked this spot on the lake here, Lighthouse Beach, and I didn't know how many people were going to come. But at the time when I was first diagnosed, I was teaching early childhood music and movement, and I had this center and I was teaching in several different places. I've always had lots of different instruments, and I love making music with little kids. I brought a couple baskets of my rattles and bells, and little drums, and invited a bunch of people. It was on a late Sunday afternoon, and it started to rain a little bit, and we went to this beach...and about 50 or 60 people showed up with their kids. There was a shelter with picnic tables, so we did have some shelter from the rain, but it wasn't enclosed, so we still got hit with the winds. But we decided to go to the water and pick up all these rocks, and we brought them back to the shelter and everybody took two rocks, and the kids also had their rattles and bells. I lit some sage, and we brought in the ancestors, and I brought a bunch of my mom's sacred items and laid them out on the table. I said a couple of prayers that I thought were appropriate, things that I had written. We went around the circle and everybody gave a prayer for me, but they also were thinking about things that they wanted to let go. In one hand they held a rock and they were putting all that energy into that rock to let go of what they wanted to get rid of, and they were done with, that was on one side, and on the other side the other rock was all their hopes and wishes and dreams of things they wanted to ask for in abundance for the future. And I also sang. I sang a couple of songs after everybody had said something and did their own self prayers. As I was singing, I had to move the sage from the middle of the circle to behind me because the way the wind was blowing, it was blowing the smoke too much in my mother in law's face, and so I moved it behind me, and I started to sing, maybe I put too much sage in there, I don't know now, but my friend across the circle started to walk. I saw he left the circle and he started to walk around outside the circle to me. I wasn't sure why but I had to keep singing - I was in the moment, and then at a certain point, I guess he turned back. I find out later that as I was singing with the sage in the shell, the flames had blown up. I think my mom was there, I really do. I think that we called her in and she was with us. It was such an intense, powerful gathering. There was so much good energy, and I'm sharing this just to prove that. When I finished singing the flame went down, we actually left a mark in one of the picnic tables, but nobody got hurt. But it was so beautiful. It was so beautiful. I'm sharing this because when you put it out there, I really believe when you reach out, and I know it can be hard, but when you do reach out people respond. People respond [I've found] because they also want that connection, and they want that sense of community and they want that love. We all do, and no matter where you come from, what tribe you come from or if you're in a tribe or not, I've been displaced by different factors, so my, my tribal connection is creatively manifested and then some. But it does come about in the most beautiful way if the intention is good and nature responds, the universe responds. I really think that that set me up for this really impactful, not to say that there weren't difficulties in this journey, but ultimately, I'm still here and I'm okay right now. Today I feel good, and I have hope. I think it's so important to set up that foundation and to try and master that courage to reach out, grab somebody's hand, and share that love, share that fear. That's how we survive. So at the end we took our rocks with that energy that we wanted to let go and we went down to the to the shore, and we said our last goodbyes and we threw those rocks into the water and just watched the waves come in, and go out, and matched our breath to the rhythm of the waves and stood there for a while together and held each other, and that was it, and it was a beautiful, rainy, wet, cold afternoon. Then I went on with this whole story.

MISHA LOEFFLER: Wow. That is a really remarkable ceremony to have with all of your loved ones. And then for your mom and your ancestors to show up like that, that's really incredible and that's miraculous.

MICHAELA MARCHI: It was, it really was. I'm thinking, I'm thinking, so that was 2016, I'm thinking, like, it's time to do another one because now I'm coming back full circle to actually do the hysterectomy now, and it's been five years. We've

had such a crazy year all of us. I'm sure I know that people would want to have some things to let go. I'm thinking now it's a good time to do it again in March.

MISHA LOEFFLER: Yeah, I love that imagery of the circle too. I'm just really amazed, and inspired, and thankful to hear your story in many ways because not only are you working on healing for yourself, but you also invite others in such a supportive way, including our AICAF community now with the story that you're sharing. Yeah, my heart is feeling a lot there, so I'm really thankful. We only have a few minutes left, so I guess my final question to you for now, for now, is - all right, I have two kind of: What did cancer teach you about yourself? And then, what would you like to be the main takeaway of your story?

MICHAELA MARCHI: What did cancer teach me about myself? Well, I can do hard things. I guess, I knew that, but I know it deeper now, I think, and that I am so connected to this body and so grateful for this body. I've also struggled with my weight all my life. Sometimes I think I disconnect myself from that. I think that this has centered me into honoring my body in a different way, and how beautiful, and how powerful, and how much my body can do to heal itself if I don't get in my own way. I think once I let all the channels of energy be open and I take care of myself in the best way that I can, I think that my mind, body, and spirit work together in a really beautiful way. I knew that to some extent before, but this journey has really imprinted that in a more profound way, I think. The main takeaway from my story, I guess, I want to share this story because I'm here, because I'm alive, because I'm a survivor now today. That could change. I don't take that lightly, I don't take that for granted. I don't put my energy into that, not being true, but right now, today, I'm here and I am grateful for that. I didn't get here by myself. I want people to know that this cancer wasn't found because I had some crazy symptoms and I had to go in to get checked, or I had a pain in my side or my belly or blood in my stool, nothing like that. I had no symptoms. But I knew my family medical history. I knew from experience what had happened. I knew from conversations with my family how pervasive this cancer was throughout my family. So when I thought it was the right time, at 40, I went to see a genetic counselor. It was my birthday gift to myself, like it's time, it's time to do this. I went and I got maybe not the answer that I wanted, but the answer that empowered me to take control, and make some decisions about my life and ultimately save myself by having the knowledge of what was going on in my body. So it's so important to have the channels of communication open, even if you are having symptoms, to not be afraid to talk about them with your family, to be up on your doctor visits when you have to go - you got to go, to talk to your doctors, to question them, to ask questions. Beyond first parents, grandparents, who else might have had something? Sometimes that can be difficult because we don't have all the information. But work with what you've got and try the best you can. Genetic counseling is really informative and is a powerful tool for helping us understand what kinds of things can be going on in our body and what we can do about it. That's the main takeaway. I hope it helps somebody.

MISHA LOEFFLER: I imagine that a lot of the community members, myself included, who are listening to your story are going to feel very inspired by things that you share. I am just so thankful to have heard your story in this hour or perhaps less than an hour that we've been recording.

MICHAELA MARCHI: Yeah.

MISHA LOEFFLER: One thing also that I wanted to say is that I so appreciate the ways that you weave your story together. You are a true artist and it was just so remarkable and just really marvelous to get the imagery that you've shared with us throughout this whole interview about your journey related to your ceremony on the beach, related to that warm, loving environment with your parents and then the people around you. I - yeah, I just feel really touched by everything that you've shared today and so I'm just really thankful that you are bringing your advocacy to our community and that you care so deeply. We are better people for the ways that you show up in our community.

MICHAELA MARCHI: Oh, I'm so glad, I'm honored as well. I feel really grateful and I'm so glad that we could talk and that we connected like this and anything I can do, I am here to share and to give whatever I can.

The American Indian Cancer Foundation is deeply grateful to Michaela for the wonderful and sacred advocacy, support, and love she shares with the community.