Sitting Down With the Filmmakers of Invisible

by KATE TURNER

How the Team of *Invisible* Is Bringing About Change for Fibro

It's the first day of editing for the film she's featured in and producing, and Megan Densmore is choked up. Her passion for change in the fibromyalgia community is clear in her voice, strong between cracks of emotion.

For many years Densmore kept her fibromyalgia hidden — she was "passing as fine" to the people around her, she says. But, growing tired of being "the only unicorn in the room," she decided chronic, invisible illnesses like hers needed to be talked about.

"I wasn't involved in the fibro community, and I still kind of struggle to be," Densmore explains.

Bringing the Invisible to Light

So Densmore and a small team of filmmakers, including director Nick Demos, set out to tell the stories of people living with fibromyalgia — aptly named *Invisible.*

"[We wanted to] bring visibility to something that is seemingly invisible to the rest of the world," Demos says.

For both Densmore and Demos, it's a cause that's close to their hearts.

Densmore was diagnosed with fibromyalgia at the age of 13, right at the time in her life when she should have been excelling in the athletics she loved so much. She was sent to a rheumatologist after coaches grew concerned about her worsening ability and received a conclusive diagnosis.

"I did not have the mystery diagnosis experience that many people have with the illness. I know now that I could be grateful for that — at the time I wasn't very grateful for that."

The doctor prescribed her with a couple of medications and matter-of-factly told her she would be in pain for the rest of her life.

"To which I probably responded with, 'F you! That's not the way my life is gonna go,' " Densmore laughs.

For Demos, it was his mother's fibromyalgia and his own concerns and questions over developing the condition that piqued his interest in *Invisible.*

"Questions always lead to, 'I have to do something about this,' " he explains.

> #WCW? this week goes to our two amazing producers Pallavi Sastry and MeganMasterFit! Here they are wearing our awesome t-shirts which brings us to a huge new ?#?InvisibleFilm?

development: T-Shirts! From now until September 16th, if you buy an #InvisibleFilm ?#?Tshirt?, you can have the chance of winning a free coaching session with renowned Fibromyalgia Coach, Tami Stackelhouse! And for everyone who buys a shirt, you can get a credit in the film! Click the link in our bio, and don't wait, this deal ends in one month!

A photo posted by Invisible: The Film (@invisible_film) on Aug 17, 2016 at 3:19pm PDT

A Learning Process

Despite their ties to fibromyalgia, even Demos and Densmore had a lot to take away from the year they followed their subjects.

“When I was told [about my mother’s fibro], I was told basically over the phone,” Demos explains. “She had just gone through a bout with breast cancer, and I think we were so relieved that she was alive that when it became, ‘Oh this is manageable — phew!’ it sort of took a back seat.”

She didn’t speak of her fibro to anyone but his father. Once he realized his mom’s fibro was so disabling she had to stop working, he began to gain understanding of just how serious the illness’ grasp can be. And his understanding has only grown since starting work on the film.

“This film has brought us closer together because I’ve gotten to actually sit with her and ask her [about her condition].”

For Densmore, *Invisible* has brought her new sense of connectedness to the fibro community — something she hadn’t experienced previously.

“I haven’t been really involved because I was living in the closet for so long,” she says.

“A lot of my goal in wanting to do this film and connect with the other people in this film was to maybe find my place in the community. Find a place where my story can be inspiring and not derisive.”

Next page: a unified community.

A Unified Community

The connection and support in the tight-knit fibromyalgia community is something Demos has found beautiful to witness throughout the course of making the film. The community, he says, has been very supportive of them, as well.

“I really am so passionate and excited about how the environment and the world around these people who have fibromyalgia is going to change,” Densmore adds.

Those outside of the fibro community, however, still aren’t quite sure what it is they’re making their film about.

“There are still so many misconceptions about what fibromyalgia is, and honestly a lack of education about fibromyalgia,” he explains. “And I am the perfect example of this; here I am with somebody in my own family has fibro, and I didn’t really even understand what it was.”

“My hope is that it will bridge those communities together in a way. If we can shine the light in a large enough way

that the outer community can see what the inner community is looking at and dealing with."

> Last day of shooting!! We are set up at the NYC Caterpillar Walk #oneyearlater. #invisible #fibromyalgia #producer #documentary
>
> A photo posted by Invisible: The Film (@invisible_film) on May 7, 2016 at 6:27am PDT

'There Is Hope'

When asked what his hopes for what people will take away from the film, Demos says, "That there is hope."

"That we as the community can come together, and the more that we band together, the more visible that we become, that the more likely change can occur for us."

With more visibility comes more money in the direction of fibromyalgia treatment, he says.

"Particularly from the insurance companies, alternatives — like massage, like nutrition counseling, like a Pilates class, like yoga — those things need to be covered under insurance. For a lot of people and a lot of insurance, alternative treatments … are not covered."

Densmore and Demos both echoed the importance of people with fibromyalgia being their own advocates and finding what works best for them.

"Whether that's changing a job or not taking a medication, or taking a medication, or trying a new treatment — empower yourself to discover what it is that feels like the right choice for you in that moment," Densmore says.

They hope, too, that with more visibility the fibro community will finally be able to stop explaining themselves and convincing others their disease is not in their heads.

"Instead of taking the approach of, 'I'm going to convince this person that my disease is real,' it's purely like, 'No — I can't do that today,' " Densmere says.

"Stand true to who you know you are, and what you know to be true," Demos adds.