

Master's thesis is foundation for film that shatters old myths of Down syndrome

July 9 2014, by Janet Showalter



Leigh Ann Kaman with her family, including Benjamin, who has Down syndrome

Leigh Ann Kaman fell to the floor when doctors told her that her newborn son, Benjamin, had Down syndrome. She and her husband, Brian, felt totally alone.

"It's not the diagnosis you want to hear," she said. "I felt scared, anxious and sad. I had to grieve the loss of the expectations I had for my first-born child."

Now 12, Benjamin is enrolled in mainstream classes at school, loves to play sports, read, swim and go hiking with his parents and younger siblings, Samuel and Gracie. A far cry from what his parents feared.

"Quite frankly, we didn't know what to expect," Leigh Ann Kaman said. "There wasn't a lot out there to help us figure it all out."

That's why the Kamans are ecstatic to be working with the Virginia Commonwealth University genetics and film departments on a project to help raise awareness about Down syndrome. Along with about a dozen other local families, the Kamans will be featured in a documentary that will illustrate the needs and aspirations of people with Down syndrome and bring about improvements in knowledge and access to community resources.

"We are just delighted about this," said Colleen Jackson-Cook, Ph.D., director of the Cytogenetic Diagnostic Lab and professor of pathology in the School of Medicine. "What is so exciting is how many people have pulled together to make this happen. That is so gratifying."

The VCU Council for Community Engagement, in partnership with the Down Syndrome Association of Greater Richmond, awarded the project \$17,000. Jackson-Cook submitted the grant and is helping to develop the film. But her involvement is just the beginning.

As part of her thesis for her master's degree in [genetic counseling](#), Kayla Claxton developed a survey to assess the educational and service needs of parents who have children with Down syndrome. She distributed the 39-question survey to parents and service providers, analyzed the results, wrote a detailed thesis and presented her conclusions during an event at the Down Syndrome Association of Greater Richmond.

VCU is the only school in the state to offer an accredited master's degree

program in genetic counseling. It is part of the School of Medicine's Department of Human and Molecular Genetics.

"I feel so proud to be part of the program and part of this project," Claxton said. "This was not just my thesis project, but it's something that will help the entire community. It is a great way to help people understand what Down syndrome is and to help parents realize they are not alone."

Claxton provided her conclusions and survey results to Sasha Waters Freyer, the chair of the Department of Photography and Film in the School of the Arts. Freyer is producing the film with help from 15 of her advanced documentary students. They are using the survey results to focus the content of the film.

"This is a great opportunity for the students," Freyer said. "It's working with a real world client, and it also serves the needs of the community. It's nice to work on a project that you know will benefit a large audience."

Freyer and her students began filming in March and now are in the editing stage. They hope to have a rough cut to show to Jackson-Cook and the Down Syndrome Association by the end of July. After some fine-tuning, the 20- to 30-minute film will be distributed to parents, [health care providers](#) and medical and education students. The National Down Syndrome Association has also expressed interest in showing it at its annual conference. In addition, plans call for a Spanish translation of the film by Eugenia Munoz, Ph.D., associate professor of Spanish in the School of World Studies, part of the College of Humanities and Sciences.

The documentary will replace an outdated 1980s version. The new film will provide more updated information on a number of topics for

parents, including insurance, medical advances and research, respite care and support. For medical students, it offers guidance on appropriate ways to deliver the diagnosis and interact with patients and [parents](#). The film shatters the old myths of Down syndrome and shows how children can lead healthy, productive lives.

"I really wish something like this had been available when we were facing Benjamin's diagnosis," Leigh Ann Kaman said. "I am so happy to be part of this project, to be a ministry to someone who is hurting and facing a challenge."

Provided by Virginia Commonwealth University

Citation: Master's thesis is foundation for film that shatters old myths of Down syndrome (2014, July 9) retrieved 27 April 2024 from <https://medicalxpress.com/news/2014-07-master-thesis-foundation-shatters-myths.html>

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