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New book details local mother's life with disability

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Morgantown native and current Bowling Green resident Kimberly Parsley stands with her husband, Michael Parsley, and their children Ian and Sayer.

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Like for any mother, weekday mornings for Kimberly Parsley are focused on the mad dash of getting her two children out the door to school.

Her husband, Michael Parsley, works alongside his wife to make sure their kids, Ian and Sayer, are fed and fully prepared for the day.

It's not until the children have left the house that Kimberly Parsley's everyday life begins to differ from that of most parents.

For the Morgantown native and current Bowling Green resident, many days are filled with doctor's appointments, physical therapy and using special technology to do life's everyday tasks.

Kimberly Parsley has a genetic condition called von Hippel-Landau (VHL) disease, which is characterized by blood vessel tumors in up to 10 areas of the body. These tumors can be benign or cancerous.

The condition has left her blind in both eyes since she was 14.

In 2016, a tumor on her spinal cord caused her to lose control of her left arm, and in 2019 another tumor removed from her brain stem left her with severe balance issues.

Despite these bumps in the road, Kimberly Parsley has authored a handful of fantasy novels, but more importantly, she has successfully raised a family with her husband.

She recently described her life's journey in the new book "A Celebration of Family: Stories of Parents with Disabilities" published by the Center For Accessible Living.

"I am always thrilled when people's unique experiences get to be talked about," Kimberly Parsley said. "So many times, we think we are alone, and then you read these stories. One story can make someone realize they aren't alone.

"It's very important to help you get through a struggle that other people have been there and gotten through it," she said. "Representation is important. There is so much in this book, and there is so much about the disability movement."

Not too long after becoming blind, Kimberly Parsley graduated from Western Kentucky University, where she earned a degree in public relations in 1997 and met her eventual husband.

The couple continued to live in Bowling Green, where she worked in WKU's university relations department. She eventually decided to quit her job and stay at home to take care of her children. Her son Ian is now 13 and her daughter Sayer is 10.

“It’s fortunate my kids are older now and they can do more things for their selves,” Kimberly Parsley said with a laugh. “Being blind and having little children is exhausting. My daughter was a climber so there was a lot of worrying about that.”

She said her full-time job now is managing her chronic illness and going about her daily life from her physical therapy sessions and doctor’s appointments to reading books and playing with her three pets.

Thanks to different braille and audio programs on her iPhone, Kimberly Parsley can still read many books and enjoys watching TV.

However, she said the technology she uses each day is an expensive necessity. The issue of health insurance casts a long shadow.

“Insurance will elicit a groan from anyone who reads or hears that word,” Kimberly Parsley said. “We have all struggled with the pain that is dealing with an insurance company, and it shouldn’t be that way. We should all contact our local officials about this issue and fight for better coverage. I feel very strongly about this.”

After the children return home for school, Michael Parsley will usually cook dinner for the family while Sayer sometimes helps with the cooking.

Then, she will make up stories to tell her children or she will come up with new games to play with them.

Due to her multiple disabilities, she can no longer write her fantasy novels. She now refocuses that imagination to spend quality time with her kids.

Unfortunately, she says one of her children has VHL as well, and the family is soon leaving town for a VHL-related procedure in Houston.

Center for Accessible Living Program Coordinator Dave Matheis said it's not uncommon for some genetic conditions to be passed down.

Matheis came up with the idea for "A Celebration of Family: Stories of Parents with Disabilities" and is the book's editor.

He has known Kimberly Parsley for more than 25 years.

"It's a decision some folks have to make if the disorder is inheritable," Matheis said. "Two people in my book decided to have children, and another one didn't. It's a personal decision.

"I've known her since she was a teenager," he said of Kimberly Parsley. "She was just going blind then. Kim is a very sharp lady. She is very determined, and she has been through a lot of difficulties with her disability."

She commended Matheis for his hard work putting the book together and spoke to the importance of dozens of stories detailed.

“I feel like people think if you are disabled, you can’t have kids,” Kimberly Parsley said. “And that’s not the case. I was thrilled to take part in this project. I want people to know that there are people out there doing it, and it can be done. It is scary, but it absolutely can be done.”

The book can be purchased on Amazon.com, and further information on VHL can be found at www.vhl.org.

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