Multiple Myeloma: Thomas' Story

With three transplants for multiple myeloma under his belt, Thomas Goode has a lot to say about beating myeloma.

It was something he had never thought much about. But when Thomas Goode was diagnosed in 2007 with multiple myeloma at age 34, he had a crash course in the value of support.

A Goode posse was orchestrated – 10 sisters and brothers from Texas, Virginia, Colorado and Maryland – by sister number five, to take care of their youngest brother after transplant.

As Thomas looked around during his recovery, he quickly understood that not everyone had the benefit of a family like his. And he started to get curious about what was available for support beyond family. When a quick Google search brought up BMT InfoNet, he eagerly consumed its information. It was then that his appreciation for support began to morph into a passion for advocacy.

“What I read that BMT InfoNet had published, gave me insight into what life might be life after transplant,” says Thomas. “It was a huge source of help because everything I found there turned out to be right and it prepared me for anything that came up as I was healing and not yet back to my regular self.”

He was accustomed to medical professionals supporting him, but he had not witnessed former patients helping patients.

He had been doing some things locally for his clinic in North Carolina, like talking to patients. Soon he started thinking bigger and co-founded the Triangle Area Myeloma Support Group, which he describes as "a small group, powerful in knowledge, that inspires, educates and supports members about myeloma and our journeys."

He supports his group in North Carolina through constant learning about issues patients and families face. He was recently one of 12 leaders of myeloma support groups invited to the American Society of Hematology's Annual Meeting featuring the best blood specialists in the world.

“I attend those conferences to learn about things that help me so I can help others,” he says.

Thomas has advice on how to live your best life with a diagnosis of multiple myeloma.
“Support others. Gather great people around you. Take care of your body,” he says.

On supporting others: Thomas offers solutions for aggravations that patients face, like losing their sense of taste. And he understands ongoing issues that caregivers encounter, offering resources like specialist speakers who talk to them without patients present so they can really unpack their experiences together with an expert.

“Caregivers often don’t want their patient to know about the things they feel,” he says.

On gathering wonderful people: Thomas became so close to 11 of his ex-coworkers at a North Carolina prison that they’ve committed to a yearly trip for rest, relaxation and fun with highlights like airboat riding, NFL games, college basketball games, and six-hour drives in search of the perfect BBQ. No talk of cancer or prisons allowed.

On care of his body: Thomas works out every day, doing weights and cardio. He eats a cleaner diet than he used to. “I try to make it a habit of passing up fast food and candy,” he says. “But I’m not perfect.”

Where does he find support and information?

“BMT InfoNet for information on transplants; my treatment team; my support group; and other support group leaders around the country, including a yearly summit where we meet to exchange ideas that help to keep my group innovating.”

He says that the website www.myeloma.org is abundant with information with resources like its #Ask Dr. Durie series that features posted questions and allows users to ask new ones, as is www.themmrf.org.

He urges patients and families to take help that’s offered, and to accept when people ask “Can I do anything?”

“Say ‘Yes, can you get me some Greek yogurt.’ And tell them the brand,” Thomas says. “People feel better when they can help.”

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