Myeloma Survivors launch www.MyelomaCrowd.org

to Help Navigate Treatments & Side Effects

MULTIPLE MYELOMA IS THE SECOND MOST COMMON BLOOD CANCER.

Multiple myeloma survivors Jenny Ahlstrom and Lizzy Smith, met via Twitter. After realizing that they both received treatment at the Huntsman Cancer Institute, they met for lunch and discovered they had much in common: they were the same age, had the same disease, were diagnosed just a year apart, endured the same treatment protocol and were both mothers of young children. They also shared a passion for finding treatments and cures for myeloma.

"As you can imagine, a cancer diagnosis is terrifying," said Jenny. "But what adds to the fear is that few of us have ever heard of the disease. We naturally wanted to start fighting immediately but with myeloma, there are countless ways to treat it. It was hard to know where to turn and where to get information to make decisions about our care."

Multiple myeloma is the second most common blood cancer yet it's often difficult to detect because symptoms can resemble other common ailments including bone pain, low blood counts, nervous system symptoms, kidney problems and other infections.

"Diagnosing myeloma is often tricky," shares Lizzy. "Many general doctors are unaware of the signs and symptoms and therefore patients are left untreated for years. By the time they are diagnosed they can be in failing health making treatment options for difficult to endure. Jenny's symptoms included bone pain that wouldn't go away. My symptoms were the inability to run (I was dangerously anemic), night sweats, and ribs that frequently ached."

After seeing that much of the information found on the Internet was alarming, outdated, and confusing, Jenny and Liz began building a website that would provide the myeloma community a place to connect, learn how to navigate the disease, find doctors and facilities, select treatments and find clinical trials right for them. In January 2014 they launched www.MyelomaCrowd.org.

"Once a person is diagnosed with myeloma," states Jenny, "it is a lifetime process, so staying informed and updated is essential." Staying on top of your health is part of surviving this disease."

Another component of living with myeloma is managing side effects. "One of the worst side effects is chemo brain," says Lizzy. "Trying to remember anything is hard. I really struggled at my doctor appointments. Even though my mom accompanied me to every visit, we often left with conflicting information as we both remembered something differently, or we had a list of meds yet needed a follow up with a nurse to ensure we got it all correct. It was a mess. Plus, we were often so busy trying to write down our notes that we often forgot half of our questions."

Jenny, who also had a tough time remembering her doctor visits, decided by provide a solution for those struggling with 'chemo brain' by creating the My Doc Notes app, a free smart phone iOS and Android app that can be used during office visits to record important information.

"The app isn't just for cancer patients. It really is for anyone who needs it and it's really simple," said Jenny. "I use it at almost all of my appointments and we have excellent reviews from other users."

Dr. Jatin Shah, a cancer expert at MD Anderson, stated that coming prepared with written questions and a tool to take notes is an important way for patients to get the most out of their doctor's visit. "Write all of your questions down when you come in," he advises. "Bring a caregiver with an extra set of ears that can listen and remember and recall what we've talked about, and then write down some of those answers that we talked about or have the physician write down some of those answers. That way you can really maximize your time and really feel comfortable leaving and thinking about it over the next few days as you mull over your options."

The My Doc Notes app provides a simple way to follow Dr. Shah's instructions and with an in-app purchase, users can record memos and email them to a caregiver, themselves, or anyone else they want to share it with.

Navigating the cancer world requires tenacity, patience, prayers, hope and a lot of help. Jenny and Liz are on a quest to make that journey just a bit easier.

"The more myeloma patients understand their disease and their treatment options," adds Lizzy, "the better they can be in helping make decisions that are in their best interest." ■

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