Information empowers leukemia patients

Couple volunteers time to educate others and raise funds for chronic lymphocytic leukemia research

By Jacquelyn Johnson Gosse

Roy, 70, had never turned on a computer, but he wanted to learn more about chronic lymphocytic leukemia (CLL), the most common leukemia in adults. So he taught himself computer skills and how to search the Internet. He discovered CLLTopics.org and started corresponding with the Web site’s founders and Mayo Clinic patients and benefactors, Chaya Venkat, Ph.D., and her husband, P.C. Venkat.

After a year of correspondence, Dr. Venkat finally asked Roy about his cancer and when he was diagnosed. He responded that he didn’t have CLL. Roy’s 40-year-old son did — but was in denial. It was the father’s hope that when his son came to terms with his cancer, he could help him understand the disease and treatment options, which is exactly the intent of the Web site.

“We hope the discussions, article reviews and information on the Web site will bridge the gap between cancer researchers and practicing oncologists and patients and their families,” says Mr. Venkat.

The Venkats volunteer their time to answer 1,000 e-mails each month and spend more than 60 hours a week each reading, writing and maintaining the Web site. They constantly remind their readers that they are not medical professionals and do not provide medical advice or recommendations for treatment, but offer information, education, encouragement and patient advocacy.

Dr. Venkat is a scientist, engineer and educator who has 21 petrochemical process patents in her name. She received the Thomas Alva Edison Patent Award for industrial engineering in 2003. Mr. Venkat’s professional career included commercial and investment banking. They both retired in 2001, and Mr. Venkat was diagnosed soon after with CLL, a form of cancer neither of them knew anything about.

CLL diagnosis

According to Mr. Venkat, his diagnosis was fairly typical of a CLL patient. He discovered an enlarged lymph node and visited his primary care provider who referred him to an oncologist. He eventually came to Mayo Clinic.

After her husband was diagnosed with CLL, Dr. Venkat began to search the Internet to learn more. She started moderating a discussion group on the Internet which grew to 500 members in a few months. Interest continued, and when the discussion group became too large, they established the CLLTopics.org Web site in April 2003.

The Venkats agree that the Internet has transformed the way patients access medical information. Their Web site currently receives over 16,000 visits a month. They have also started an e-mail newsletter called Topics Alert that has added over 600 subscribers in six months. Recently, within 24 hours of a medication warning, CLLTopics.org sent out a Topics Alert that reached all the registered users worldwide in minutes.

In addition to the Web site and Topics Alerts, the Venkats recently registered CLL Topics, Inc., as a non-profit organization. CLL Topics, Inc., has raised thousands of dollars through the CLLTopics.org Web site from patients and their families. After a long and exhaustive process, the organization’s board of directors selected Mayo Clinic to receive the philanthropic funds and lead a clinical trial, which they named Project Alpha.

An innovative approach to a clinical trial

Project Alpha is a patient-sponsored and funded collaborative effort of Mayo Clinic Cancer Center Hematological Malignancies program and CLL Topics, Inc. Philanthropic support will provide funding for Neil Kay, M.D., a Mayo Clinic hematologist, and his research team to focus on two investigations.

Dr. Kay says, “The Venkats, along with their board of directors, are well-recognized in multiple CLL venues internationally. Importantly, their voice is heard and being heeded by all of us who take care of CLL patients.”

Dr. Venkat says, “Each of us receive the same salary and fringe benefits: $0 per month. That generous salary plus the knowledge that we are doing something worthwhile makes this the best job in the world.”

Chaya Venkat, Ph.D., and her husband, P.C. Venkat.