SarcomaUpdate

For Patients with Sarcoma & Their Families

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Spin4Survival Challenges Mind, Body and Soul to Defeat Sarcoma

JENNIFER LINN

he Second Annual Spin4Survival (www.spin4survival.org) was held on January 27, 2008, at Equinox Fitness at Columbus Circle in New York City. The event, an eight-hour indoor cycling event, raised more than \$630,000 to fund orphan cancers (cancers that are underfunded and/or less prominent) and survivorship programs at Memorial Sloan-Kettering Cancer Center.

Spin4Survival was launched in 2007 by Jennifer Goodman Linn and her husband, Dave. Ms. Linn has been treated at MSKCC for MFH sarcoma, which was diagnosed in December 2004 when she was just 33. "During my three-year ordeal, which continues to this day (including three major surgeries and countless doses of chemotherapy), I have never stopped exercising. It is the one thing that makes me feel empowered, alive, and willing to keep on fighting against this dreadful disease. I fell in love with an activity that enabled me to push myself to the best of my ability every day." The Equinox in Columbus Circle, Ms. Linn's gym for the years she has battled cancer, agreed to host the event.



From left: Katie Kotkins, Zeena Abdoulahad, Amy Carpenter, Nancy G. Houlihan, Jennifer Goodman Linn, David Linn, and Dr. Robert Maki

The Linns created Spin4Survival as a way to give back to MKSCC. "I vowed that I would create an entity that would thank my 'extended family' at MSKCC for all of the time, effort, and concern they invested in me. I am so grateful that I can make good on that promise," she said.

The first Spin4Survival event, held in January 2007, attracted more than 250 participants and raised more than \$200,000. The 2008 event tripled the dollars raised and the Linns presented a check for \$630,000 (and counting) to MSKCC sarcoma expert Robert Maki and other MSKCC representatives on January 27.

More than 120 teams (550-plus riders) participated in New York City and around the world. "We wanted to allow people to get involved no matter where they lived so we created the idea of satellite teams," Ms. Linn explained. "We had teams cycling in Hawaii, Chicago, London, and even Israel."

Planning for the 2009 event is already underway. If you'd like to participate in New York City or organize a satellite team in your hometown, please contact Jennifer Goodman Linn (jen@spin4survival.org) or Katie Kotkins (kotkinsk@mskcc.org). You can read more about the event at www.spin4survival.org.

A Nurse's Perspective Working on the Sarcoma Service

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the tools for self-management. After nearly seven years of working in outpatient gastrointestinal oncology, I thought I knew how to do my job well. I was a nurse. I assessed, intervened, reevaluated, and then revised plans accordingly.

Then I transferred to a research nurse position in the sarcoma service. I found this rare disease to be complicated, involving many different pathology subtypes and mutations. How could I ever get it straight and teach the patients? What I didn't realize, and soon learned, was that in sarcoma, the collaborative

model is not just between the physician and the nurse, but includes the patient as well. I realized you, the patients, not only did your homework, you contributed the chapters! What a humbling experience to have you test my knowledge and often tell me the new lines of therapy coming down the pipeline.

You have inspired me in so many ways: the strength that you show in the face of such adversity, your drive to arm yourselves with knowledge of the latest research, and the spirit that keeps you from giving up. Instead of accepting that there is lack of funding for sarcoma, you rallied for the Spin4Survival fundraiser and raised more than \$600,000 under the direction of Jennifer Linn, a patient. Amazing! It is with heartfelt gratitude that I write this letter to you. You may turn to the clinical team for direction with your medical care, but please know that we get our inspiration and strength from you.

Gloria Wasilewski is a former oncology nurse who used to work on the sarcoma service at Memorial Sloan-Kettering Cancer Center.