

The Inspiration Behind The MetaCancer Foundation

Remarks by Michael Lundblad at the Elizabeth Anne Prostic Room Dedication at Turning Point: The Center for Hope and Healing

November 25, 2006

I want to express my deep gratitude to all of you for supporting MetaCancer, for enabling us to establish a great new program at Turning Point, and for helping us honor Lizzie by dedicating a room here today in her memory. With your help we are empowered to provide the kinds of resources and support that were lacking when Lizzie and I first learned of her diagnosis. Many of you are familiar with the details of that diagnosis and how it eventually led to the establishment of The MetaCancer Foundation, but I want to emphasize a few parts of our story, not only to honor Lizzie, but also to give you a better sense of how our grants and initiatives address the unique mission of The MetaCancer Foundation.

Lizzie was diagnosed with stage IV, metastatic breast cancer on October 15, 2004. Our daughter Harper was only four months old. I remember hearing the diagnosis on the phone and thinking, "Thank God it's not lymphoma," since that's what was originally suspected. I had no idea at the time how serious metastatic breast cancer was. I just assumed that any kind of breast cancer must be better than lymphoma. As I hit the Internet to find out more about it, though, I quickly realized just how serious it was. One of the first statistics I found was a 16% five-year survival rate. That means only 16% of those diagnosed with stage IV, metastatic breast cancer survive for five years or more from the time of diagnosis. I subsequently found odds that were slightly better, but Lizzie never wanted to know the statistics. From the very beginning she just assumed she would beat her diagnosis, whatever the odds. She refused to accept a statistic as a prophecy. She tapped into the same drive and spirit that made her so successful as a professional woman and as an amazing wife and mother, sister and daughter, relative and friend. Lance Armstrong said, "Live Strong," and that's exactly what Lizzie did. But the cancer eventually metastasized or spread to the fluid surrounding her brain, and there was nothing we could do about it, no matter how strong we tried to be. When Lizzie passed away on March 31, 2005, she left us with a tidal wave of grief and an ocean of tears. The challenge of staying afloat has seemed impossible at times, but what we are doing here today suggests one way, at least, of resisting utter despair by channeling our energies toward helping others facing similar situations.

We created The MetaCancer Foundation first and foremost to honor Lizzie's phenomenal spirit. Our specific mission, though, is to provide resources and support for survivors and caregivers living with metastatic cancers. We define a survivor as anyone diagnosed with cancer, whether they are currently receiving treatment or not. But we are committed to addressing the emotional and psychological issues that are unique to metastatic cancers. Many people do not realize how dramatically different a diagnosis of metastatic cancer can be from a diagnosis of early-stage cancer, which means it is localized to a specific part of the body. The assumption is that survivors with localized and metastatic breast cancer, for example, would have more in common with each other than those with metastatic breast cancer and metastatic prostate cancer. If breast cancer has *not* metastasized to other parts of the body, the five-year survival rate is 98%. For skin cancer it's 99%, and for prostate cancer it's 100%. But if the cancer *metastasizes* to distant parts of the body, the five-year survival rate for breast cancer drops to 26%. Skin cancer drops to 16%, and prostate cancer drops to 33%. Other kinds of cancer such as urinary/bladder, cervical, colorectal, and kidney or renal have survival rates over 90% if localized, but less than 15% if metastasized. If you look these cancers up on medical websites, you might see them labeled as incurable, or terminal. You might find information about clinical trials for drugs in development. But you won't find much in terms of helping you deal with the potentially paralyzing realization that you probably have very little time left to live. That kind of realization is radically different than worrying about whether your hair will grow back the same way or what your life might be like *after* you're done with treatment. These might be the short-term concerns of those with localized or early-stage cancer. Those concerns can be very real and very frightening as well, but you can begin to see that those with metastatic cancer, regardless of where it started, might find it more helpful to communicate with others facing similar situations, rather than those with the same type of cancer at an earlier stage.

The name MetaCancer reflects this commonality among all those facing metastatic cancers, and distinguishes us from other nonprofit cancer organizations that focus either on specific cancer types or cancer in general, regardless of stage. The other reason we are called The MetaCancer Foundation is to indicate our approach to metastatic cancers: we encourage people to "go meta," to think about how they are living with their diagnosis, to be aware of how they are thinking and how they are approaching their experience. "Meta" means going beyond, as in the word metastatic itself, which means beyond a stable condition or beyond the original tumor, or in the word metaphysical, which means beyond the physical. While none of us knows when we will die, we all have the ability to choose how we will live. At The MetaCancer Foundation we believe that positive thinking can profoundly affect how well we live, and perhaps even how long we live. As one of the essays on our website explains, "Thinking positively doesn't necessarily mean being happy all the time or putting on a brave face. It might mean turning the statistics around: Why can't you be one of those who lives beyond expectations? Your five-year survival rate is not zero. That means some people survive. Some people survive for decades. Why not you?" Or, it might mean preparing yourself for the end of life but feeling empowered by the ability to focus on and celebrate the things most important to you. There is not a single right way to approach a diagnosis of metastatic cancer. But thinking about your own approach on a meta-level can help you feel in control of your own experience, your own life, for as long as you might live it. We suggest that someone living with cancer is much more than just a cancer patient. Even metastatic cancer survivors and their caregivers can focus on living beyond cancer. That means not only beating it at some point down the road, but also refusing to let it consume you right now: rising above it on a daily basis, no matter how often you might be engaged with treatments, therapies, and the everyday ups and downs of metastatic cancers.

We launched our website www.metacancer.org on March 31, 2006, the first anniversary of Lizzie's death, to advocate for this approach. If you browse through our web pages you will see the range of ways we encourage people to think about their experience with cancer on a meta level. We offer articles and resources, for example, for those interested in reading about how to communicate with doctors more effectively, or how to get creative with nutrition and exercise in the midst of chemotherapy, or how to maintain hope in the face of overwhelming odds. For those interested in communicating directly with others in similar situations, we offer a message board, where registered users can post messages, ask and respond to questions, or simply read through the messages of others. The message board also includes a Hall of Fame, which is based upon one of the very first ideas Lizzie and I talked about, where survivors of metastatic cancer can post their stats to indicate how long they have been living with metastatic disease and how well they are doing. We wanted to read about people outliving the odds, and living well. Many people do, of course, but it can be very difficult to find their stories on other websites that are not devoted to metastatic cancer. The message board on our website also contains a forum for sharing memories of Lizzie and organizing teams for fundraising events in her honor. I encourage you all to visit that section in particular, at least to sign our virtual guestbook. You will also notice that much of the artwork and aesthetic design of the site is inspired by the work of Rita Blitt, who has generously and lovingly supported our efforts from the beginning. In the future we plan to incorporate even more artwork and music of various kinds from various artists in order to suggest other perspectives on living with metastatic cancer.

In addition to our website we have already funded several unique initiatives. Our grant to Turning Point: The Center for Hope and Healing in Kansas City will help create an innovative new program that will address the unique psychosocial issues of living with advanced-stage cancers. Another grant to the Truman Medical Center at Hospital Hill enables this key safety-net hospital to purchase equipment and materials for the benefit of cancer patients, including metastatic cancer patients, in Truman's Oncology Clinic and Patient Navigator program. A resource room named in honor of Lizzie contains a computer workstation for survivors and caregivers to conduct their own Internet research, and CDs and DVDs are available for survivors while they receive chemotherapy in the Oncology Clinic. When two or three patients share a single room and a single television, and reading skills are sometimes limited or it is difficult to concentrate, audio and visual materials that focus on guided imagery, meditation, biofeedback, or simple entertainment will make the chemotherapy time more tolerable and useful.

Outside the Kansas City area we are developing two new grants, both of which focus specifically on metastatic cancer issues. The first is a research grant for graduate students at the University of Pennsylvania from the schools of Nursing, Social Policy and Practice, and the program in Public Health in the Medical School. The recipient of this grant will use MetaCancer funds to conduct original research on the psychosocial issues unique to metastatic cancers. Another grant we are making in early 2007 will be to The Wellness Community, which is a leading nonprofit cancer organization that provides essential support services in communities all over the country, as well as online support groups. Currently these support groups are focused either on specific cancer types or cancer in general. Our grant will establish a new group specifically designed for metastatic cancer survivors: it will allow people to join an online community and receive professional support while remaining in the comfort of their own homes. These grants correspond with the categories we have established for future grants as well: resource rooms and research grants in memory of Lizzie, and professional counseling and support for metastatic cancer survivors and caregivers.

The MetaCancer Foundation will continue to address the unique needs and concerns of metastatic cancer patients and caregivers through our website and future grants and initiatives. More information on our current projects is available at www.metacancer.org.

The MetaCancer Foundation is a 501(c)(3) public charity. Tax-deductible donations can be mailed to The MetaCancer Foundation, Inc., 11 North Washington Street, Suite 600, Rockville, MD 20850.