

A Dedication in Memory of Michelle Mayer

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Michelle Mayer, PhD, died on October 11, 2008 at the far-too-young age of 39, but her contributions to patient advocacy live on. Dr. Mayer was a research assistant professor in health policy and management in the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill and a research fellow at the Cecil G. Sheps Center for Health Services Research.

Whether the subject was creating access to appropriate treatments, expanding research for particular diseases, removing the stigma of illness, improving patient-provider communication, opening a window into rare diseases, or exploring her own experience with illness in a way that opened the door for other patients, Michelle Mayer changed how we think about life and death. As a patient advocate, she reshaped how we think about and confront illnesses.

I came to know Michelle through the compelling blogs, newspaper, and journal articles she wrote during her illness and up until a couple days before her death. Her blog entries in *Diary of a Dying Mom*¹ were incredibly insightful if sometimes painful to read. She wrote with brutal honesty and compelling clarity about coping with a sometimes unbearable disease, scleroderma. In her introduction, she wrote: *I believe that, as a culture, we shy away from anything surrounding death and, consequently, deprive ourselves of all the lessons inherent in the dying and grieving process. This is not my version of "The Last Lecture." It is my heart, my thoughts, my joys, and my fears as they unfold along this journey. My hope is that you will find some of it useful on your own life's journey. I hope that sharing my experiences will help not only those struggling with terminal illnesses but also those who are blessedly healthy.* An estimated 115,000 people read and were touched by her website and print entries. She also wrote scholarly articles for professional audiences (for example, see "On being a 'difficult' patient").² A tribute to Dr. Mayer in Health Affairs highlighted her profound impact and contributions.³

Michelle taught us what it means to live with a catastrophic disease that attacks so much of the body. I read what would be her last blog entry a couple of days before her death, knowing

that the end was near, but willing her to live on. I returned to her blog two days later, hoping to find her words instead of silence. But there would be no more words. In a message sent after Michelle's death, her husband, Dr. William Steinbach wrote about how she dealt with the disease and almost constant pain: *Never to conceal it, but to not let it overtake her spirit. She taught us many things about living, and now taught us how to die with grace and dignity.* Michelle shared the lessons she learned from living with her illness with other patients, physicians, family members, friends, and many others. She showed us that we, too, could learn from her lessons and turn them into positive actions.

Michelle grew up in northeast Philadelphia and attended Nazareth Academy High School which has established a scholarship in her honor.⁴ She graduated summa cum laude from the University of Pennsylvania with a BSN in nursing. She earned an MPH in health behavior and health education and then a PhD in health policy and administration from the University of North Carolina at Chapel Hill School of Public Health. Active in a number of organizations, she founded the Elizabeth Ministry at St. Thomas More Catholic Church. The ministry supports women and their families during the childbearing years. Sister Mary Joan Jacobs, principal of Nazareth Academy High, says, *Michelle's greatest love was her family—her husband Bill, children Amelia and Aidan, her parents, her brothers, and her friends.* Our thoughts are with them all.

It is fitting that this issue is dedicated to Michelle Mayer. Throughout her adult life, and especially during her illness, Michelle was a remarkable advocate whose impact reached people all over the world. She wrote: *I suppose that in some ways I became a more calculating person. I did many things purposefully, knowing that my remaining time was short... In many ways, my illness has been my life's director, showing me how to play my part so that it was genuine and real. It taught me to listen to my heart rather than the brain that ruled my world during my healthy years.* Michelle's courageous advocacy lives on as a gift to all she left behind. As she wrote in her final post, *until we meet again, Godspeed.*

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REFERENCES

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- 2 Mayer ML. On being a 'difficult' patient. *Health Aff.* 2008;27(5):1416-1421.
- 3 Dentzer S. Eulogies: Allen Rosenfield, Raul Rogers, and Michelle Mayer. Health Affairs website. <http://healthaffairs.org/blog/2008/10/28/eulogies-allan-rosenfield-paul-rogers/>. Accessed March 3, 2009.
- 4 Alumnae memorials. Nazareth Academy High School website. <http://www.nazarethacademyhs.org/Alumnae/alummemorials.html>. Accessed March 3, 2009.

Health Reform: An Invitation to Contribute to the Discussion

The run up to the November election brought a lot of attention to health reform. Both major candidates presented relatively complete plans for major changes in the way we pay for health care and how we structure our health care delivery system. The appointments by President Obama point to a sustained effort to implement real change. This has prompted many experts and representatives of patients, providers, and payers to propose their own plans for reform. The *North Carolina Medical Journal* will be taking a part in this discussion with a section of the *Journal* devoted to articles and analyses that focus on reform. We would like to invite submissions that help the readership of the *Journal* understand why reform may be necessary, how the system should be changed, and how national reform will affect North Carolina. We invite scholarly discussions and analyses as well as commentaries that help illustrate the benefits as well as the problems that comprehensive change will bring to the costs, quality, and outcomes of health care and to the health of the people of North Carolina. The second installment of this new series starts on page 108 of this issue of the *Journal*.

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