

Not As I Pictured: A Pulitzer Prize-winning Photojournalist's Journey Through Cancer

Editor's Note: This is part of a series of Patient Advocate Guest Columns and Podcasts, launched as a forum for patient advocates to address a topic, issue, or trend within the cancer community through Cancer.Net, the patient information website of the American Society of Clinical Oncology (ASCO).

Not As I Pictured: A Pulitzer Prize-winning Photojournalist's Journey Through Cancer

A patient advocate guest column by: John Kaplan



As a well-known photojournalist, I was used to documenting life's challenges, even the worst that life could

offer a human being. In my more than 25-year career, I covered revolution in the Philippines, the worst tornadoes to hit the U.S. in a century, and many other devastating circumstances. Journalists who cover such real life drama can fall into an easy trap of believing we are invincible, that the life challenges faced by our subjects will not happen to us. Of course that is not true, but even at age 48, I had never truly faced my own vulnerability.

I was rarely ill, so when a routine CT scan revealed a kidney tumor and an eventual rare diagnosis of Non Hodgkin lymphoma growing inside me, picking up my camera was the last thing on my mind. Initially, as a way of coping with my fear, I began photographing and shooting video of myself through the treatment process. It was a distraction from the tough realities I faced. I soon realized that if I was able to go into remission -- and I hoped and prayed that I would -- my story could lend hope and courage to other families facing cancer.



The result is *Not As I Pictured*, a 54-minute feature length documentary film. Despite the serious topic, *Not As I*

Pictured is easy to watch and even humorous at times. Universally, cancer patients and their families tell us they feel better after watching it.

With the goal of giving away 10,000 free copies of *Not As I Pictured* for personal use to anyone touched by cancer (including medical professionals) I hope to share the message that so many cancers today, including some lymphomas, are beginning to be treated as chronic illnesses rather than death sentences, as in the past.

When suddenly faced with a life-threatening disease, I had no idea that so many positive things could come forth from such devastating news, and this has fortunately been at the core of my motivation to make the film.

As a professor at the University of Florida, I knew that for the medical community to embrace our humanitarian goals for the film, we first needed to do extensive focus group testing with oncologists, medical students, patients, caregivers, and survivors. The result has been universal, enthusiastic support. Hospitals, medical practices, and survivorship programs across the country are already using *Not As I Pictured* to help patients and others within the community. For medical humanities education, the film is generating tremendous interest as a teaching tool to impart a concept of growing importance, humanism in medicine. The movement seeks to understand the patient as a person, focusing on individual values, goals, and preferences with respect to clinical decisions.

We have also had great support within the music community. Well-known musicians have donated music for the film including Michael Stipe and R.E.M., Chris Martin of Coldplay, David Bowie, will.i.am of the Black Eyed Peas, Justin Timberlake, Pantera, and the Cowboy Junkies.

Having judged more than 200 competitions, including the Pulitzer, I know what a cliché many cancer stories can be. But, when you get cancer, you don't feel like a cliché, you just pray you can beat it. I believe that the film shares a powerful will to make it through the fear, balancing hardship with several serendipitous and surprisingly magical moments. Thus, *Not As I Pictured* does indeed confront the cliché, and hopefully takes the film to a

meaningful level for viewers.

As my oncologist in Gainesville, Florida says, with some cancers you never know. I don't spend time dwelling on that. I'm just glad to be in remission and here for my family, my students, and to see that *Not As I Pictured* is truly helping other people face the challenges of a cancer diagnosis.

One in three of us get cancer. That means almost every family deals with this disease. None of us ask for this. The dreaded news of cancer is certainly no fun, but you can make it through to the other side, back to health and the joy of every day.

Please visit www.NotAsIPictured.org [1] to view the two-minute film trailer, order a free copy for personal use, download a media kit, or inquire about screening the film in your community. At screening events, we often hold community-wide cancer coping roundtable discussions following the film, with survivorship experts and survivors. Although the film is free for personal use, organizations and libraries pay license fees that help support the long-term goals of our humanitarian program. The website also features extensive links to Cancer.Net.

If you are a patient advocate interested in authoring a future Patient Advocate Guest Column or Podcast, please contact patientadvocates@asco.org [2] or 571-483-1358.

The ideas and opinions expressed by the author and organization in this Patient Advocate Guest Column do not necessarily reflect those of the American Society of Clinical Oncology (ASCO). The mention of any product, service, organization, activity, or therapy in this column should not be construed as an ASCO endorsement. The information presented does not constitute medical or legal advice, and is not intended for use in the diagnosis or treatment of individual conditions or as a substitute for consultation with a licensed medical professional. ASCO assumes no responsibility for any injury or damage to persons or property arising out of or related to the information presented.

Last Updated: April 29, 2011

Links:

[1] <http://www.notasipictured.org/>

[2] <mailto:patientadvocates@asco.org>