LETTER TO THE EDITOR

David Bailey is a patient here at Duke, with a glioblastoma multiforme. He has traveled the country over speaking to patient support groups and foundations and raising funds on behalf of brain tumor research. He approached Victor Levin, Henry Friedman, and me with the following letter. We believe David's message to neuro-oncologists is a timely one. Please read it with care and heed his recommendations.

—Darell D. Bigner, Editor

A Patient's Plea—Breaking the News

David M. Bailey

Dear Friends in Neuro-Science:

My name is David Bailey, and I am your biggest fan. The work you have done, and continue to do, is part of why I am here today. I have a brain tumor, a glioblastoma multiforme (GBM), which I have been fighting for over 3 years—actually, it's been 161 weeks. Yet when I was diagnosed, I was told I had perhaps 24 weeks to live, which to date means I have lived 6.83 times longer than predicted. For a normal person living to the ripe age of 70 that would be like living to the age of 478. In the brain tumor world, and in the GBM world, that is a long time. What is most remarkable about this, however, is that as long-term survivors go, I am still a rookie. I was on a panel with long-term survivors at a recent brain tumor conference, and the others sharing the table with me were 6, 8, and 12 years out from diagnosis. Conferences are a wonderful time for us to be together, and I discovered that, just as others have been inspired by my longevity, I am inspired by theirs.

It is about these [patient] conferences that I write to you with a plea. As a survivor and performing songwriter, I have had the privilege of attending a wide variety and number of conferences over the past 3 years, from children's to nurses' to pharmaceutical conferences. At the patient/caregiver conferences, I have heard many of you give presentations that begin exactly the same way: with a multicolor chart measuring the life of a patient in weeks and showing that therapy Z extends life an average of X number of weeks. The rest of your presentation may be brilliant. It may highlight new therapies and incredible technical progress in diagnostic

tools and surgical methods. It may detail definitive proof on how and why a cure is just around the corner. But it doesn't matter. For an audience of patients and caregivers, particularly for those who are, or care for, the newly diagnosed, your opening chart, statistics, and summaries have already made a first, indelible impression: a crushing message that says, "We're doing our very best, but if you have a tumor, you're sunk."

I am writing to you as one who has, on too many occasions, stood in the hallway and consoled fellow patients who emerge from your lectures in tears. I explain what it was you were really saying and why they must not let the numbers upset them. But it's a tough sell because your chart is now burned into their memories, and patients tend to believe things that doctors say, especially in color.

I know this probably surprises and upsets many of you. It strikes me that most presentations have been prepared for an audience of fellow scientists/doctors. I understand that in a conference environment, you depend on numbers, averages, and collected data to make judgements and to build a case for stating a position. But please understand that any patient who has pulled it together enough to make it to a brain tumor conference does NOT need a reminder of how bad it looks. We KNOW. We've been told several times by doctors and nurses; we've read the gloomy predictions in all the literature. We live with looks of helpless sympathy in the eyes of others around us. We come to conferences to meet each other and learn from you why we should keep hope alive. If you are presenting a talk to patients, I beg you, please take a look at your slides and

notes. If you do not create a separate set of slides for occasions when patients will be present, please at least eradicate the statistics and charts. Cut to the chase. Tell us why someday soon we are all going to be long-term survivors. Try talking without your notes, and just tell us what you know, what you are working on, and why you are excited about how much progress you have made in the last year. We will applaud and embrace and thank you like you cannot imagine.

Let me also ask, doctors, how do you drop the axe? How do you tell your patients the terrible news? Please consider the following two options. Option 1: "Hello, Mr. Jones. You have a brain tumor and may only have a year to live. We suggest you begin some type of therapy right away. You probably want to get some referrals for radiation and chemotherapy. Best of luck." Option 2: "Hello, Mr. Jones. You have a brain tumor and it is malignant. Some might tell you that you have less than 2 years to live because, historically, this tumor has been pretty nasty, but there are exceptions to every trend, and there is no reason you can't be one of them. In fact, I just returned from speaking at a conference where I met many other survivors who are more than 5 years out from diagnosis. One fellow, Bill Smith, has had this for 13 years! You'll need to pursue some fairly aggressive therapy, but you can do it. Odds are meant to be beaten,

and there are people and organizations across the country that can and will help you. Here is an information kit from the/association/foundation/society."

Specifics aside, the second example does two things that the first does not. It identifies a real living person as an example of someone who is making it—not just a laboratory theory. This gives the patient living proof that he or she can make it; it gives that person a goal to work toward and a reason to believe they can achieve it. The second example also ends with a tangible tool and a note of hope. The bare facts must be told, but the key to this delivery is that those facts are simultaneously presented with a tangible cause for hope, and the last word is one of hope and specific action.

Thank you for all you do. Please know that on behalf of all patients around the world, we believe in you. Don't stop.

Sincerely,
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