

The Patient Eye

by Elizabeth Grant

Senator John McCain was recently quoted as saying that “the plight of the Irish is not alcohol but fair skin.” And this was certainly never more true than in my case.

Every summer of my young life was spent in the sun. My family had a summer house by the ocean and every year, as soon as school finished, my family (all nine of us) packed up our summer things and took off for the house on the New Jersey shore just across the street from the beach. And there we stayed until Labor Day.

Needless to say, in those days, the only protection we ever used was zinc oxide on our noses, which my dad had left over from his Navy days. It will come as no surprise to anyone today that in my mid-forties, skin problems started to appear which required attention – some serious, and others just a nuisance. I remember asking my dermatologist when we first met if she minded that I called her by her first name, because I had a feeling we were going to see a great deal of each another.

Seven years ago I had a basal cell carcinoma just millimeters from the corner of my eye. There was a possibility that it may have infiltrated the tear duct because of the proximity, but I was lucky and it had not. In the procedure to remove the tumor, the surgeon uses a surgical instrument called a Mohs that takes microscopic sections of tissue. The idea is to take as little tissue as possible and

still get clean margins around the growth, thus preventing a recurrence.

The procedure is performed under deep sedation. The surgeon removes a small section of tissue, and while I remain on the operating table, he looks microscopically to see if all the tumor cells have been removed. If there are still cells remaining, he returns to remove more tissue until the cells are normal. Because of the precarious location of the lesion, its close proximity to the eye, the repair had to be performed by an ophthalmic reconstructive surgeon who was located elsewhere.

The Mohs surgeon bandaged the lesion and sent me off to the ophthalmic surgeon in a cab. The area had been anesthetized, so there was no pain beyond a little discomfort. The repair was performed in the operating room in a hospital by grafting skin from behind my ear. When this occurred seven years ago I never dreamed that I would ever have to repeat the procedure, but I was wrong.

Several months ago I detected what looked suspiciously like another basal cell on the lower eyelid of the same eye. It was located directly on top of the tear duct opening, so there was little doubt that it had, this time, infiltrated the tear duct, which meant reconstruction of the duct would be required. It was a little less frightening this time because I was familiar with the procedure. I was, however, more concerned about the disfigurement because I knew that I would lose eyelashes, among other things, and no one would know how many, until the

Mohs surgeon could see how extensive the growth was.

I was to report to the Mohs surgeon's office at 9 a.m. and expect to be there until noon, at least. And that's pretty much the way it happened. I was ready to depart for the hospital at 12:30. I asked the surgeon if he would make sure that the area around my eye was sufficiently anesthetized so that it would stay numb until I went into the operating room at the hospital. There had been a significant piece of tissue removed, and all that remained was a hole. He assured me that I would be OK and that he didn't want to inject any more anesthetic and cause swelling, thus making the repair more difficult.

So my husband and I were off to the hospital in a taxi and in a very short time we reached the area in the hospital where we were to wait for me to be taken to the operating room for the repair phase of this ordeal. When I arrived and checked in at the desk I informed the receptionist that the anesthetic was beginning to wear off and I was in considerable – and increasing – discomfort. She went into the operating suite and returned, informing me that

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Thank you Karen Martinac

We in the health advocacy program wish to thank longtime HAP Bulletin co-editor Karen Martinac. Karen recently decided to step down as co-editor of the Bulletin, the better to attend to her own health and pursue other goals. (Karen detailed her journey as a patient in the Spring 2000 issue of the HAP Bulletin.)

Karen has been a tireless voice for patients and their advocates for many years. She truly understands the problems of the U.S. health care system from both sides of the bed. She worked hard to make the HAP Bulletin a quality publication of value to practicing health advocates. We look forward to her occasional contributions to the Bulletin, and thank her most sincerely for her years of dedicated service.

Best wishes Karen!

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someone would be right with me.

We sat and ten minutes went by. Then fifteen, twenty minutes, and the pain was getting more and more intense. I stood and walked to the desk again. I asked the receptionist to go back into the operating suite and send someone out to speak to me, reminding her that my anesthetic was wearing off and I needed to be tended to as soon as possible. She started to tell me that she had already gone in before and I told her that I was aware of that and I wanted her to go in there again. She reluctantly got up, walked in and in a matter of seconds a nurse came out and informed me that my surgeon was ready for me and whisked me off to prepare for the last lap in a long and grueling day. I lay in a room with other patients who were also being prepped for surgery.

My surgeon came in briefly and before long someone was beginning to start an IV in my hand. She was involved in a conversation with someone else in the room and stuck my hand several times before she was able to start the IV, all the while having a completely unrelated conversation with her coworker. Each time she stuck the back of my hand it felt like burning hot coals. After a two-and-a-half hour repair procedure I was in the recovery room eager to go home and put an end to an excruciatingly long and tedious process. The doctor gave my husband a prescription for pain for me and at 5:30 p.m. we were on our way home.

I was surprised at how foggy I was as compared to my previous experience in 1993. My throat was very sore and only then did I realize that I had been given general anesthesia. My understanding had been that I would have deep sedation for the repair just as I had for the Mohs surgery. I was wrong. At home I settled down to try to sleep but found that I was in too much discomfort. I took the pain medicine the surgeon had prescribed and found no relief. At 4:30 in the morning I finally read the label on the prescription to find that it was little more than Tylenol. Fortunately I had pain medication left over from a prior procedure that allowed me to go to sleep in some comfort.

The following morning when I woke I was puzzled by intense tenderness on one side of my nose. Neither the sutures behind my ear nor ones around my eye caused me any significant discomfort. I could not figure why my nose was too sore to touch, let alone blow or even wear my glasses. The plastic surgeon had casually mentioned that they would "go through the nose" at some point, but he never elaborated. There was one long bruise that ran from just below my eye to my chin. Apparently there was a small tube inserted from my lower eye lid into my nose in order for a new tear duct to form. The tube is to stay in place for about a year and then be removed, leaving a newly formed tear duct.

When I went for my first postoperative visit a week later the surgeon en-

tered the room and in a jocular fashion asked me, "So, which hurt more, your ear or your eye?" I answered him that neither hurt but my nose was extremely tender. He answered by saying "Gee, we barely worked on the nose." Period. No further discussion.

The point of describing this whole experience is to illustrate how a patient's pain seems, at least in my experience, to have been given a very low priority. Although precision is crucial, health care providers need to remember that what they are working with is a whole being, not just a vein on a hand or a rebuilt tear duct. When a patient is in pain all their energy goes toward dealing with the pain, not healing.

Last year I did field work in a shelter for battered women and the staff attended a meeting with a Family Court judge to discuss how domestic violence is handled in the court system. The judge said that she had attended a conference of judges recently and was floored by what she described as "gross indifference" on the part of the judges when it came to really understanding what being beaten by someone twice your size actually feels like. She asked the group of judges to stop for one minute and try to imagine what it feels like to actually be dragged by your hair. They all agreed that they had never thought about it in those terms before. The message is the same for health care providers, who should all be required, at some time in their training, to put on a hospital gown, with the back open, and actually experience some of the procedures that they perform. Perhaps next time they won't be so casual about starting an IV. Perhaps, when a patient says that she is in pain they will respond a little more promptly. Maybe they will think twice about sending someone home with little more than Tylenol for pain after a complicated surgical procedure. ■

Elizabeth Grant will graduate from Sarah Lawrence in May 2001 with a B.A. in Liberal Arts and a solid foundation in psychology. She will enter the SLC master's program in Health Advocacy in Fall 2002. Elizabeth, a New Yorker who formerly volunteered in the Child Life Program at New York Hospital, is especially interested in bioethics and the teaching of humanizing medicine to medical students.

Professional Development Series Debuts

Spring 2001 saw the inauguration of a series of free professional development workshops with guest faculty, jointly sponsored by the Health Advocacy Program and the Human Genetics Program. The workshops were kept small to take advantage of Sarah Lawrence's trademark seminar format.

In February, the series featured SLC psychology professor Linwood Lewis, Ph.D., on the challenges facing researchers who work with vulnerable populations, as well as what IRBs look for in assessing ethical research with vulnerable populations.

The March program brought Gabor

Keitner, M.D., of Brown University Medical School and the Rhode Island Hospital, to speak on the ethical complexities of running clinical trials.

In April, Arthur Frank, Ph.D., professor of sociology at the University of Calgary and author of *The Wounded Storyteller: Body, Illness and Ethics* (University of Chicago Press 1995), returned to his native northeast to lead program participants in a discussion of illness narratives. Dr. Frank's current work involves learning how and why people who have been seriously ill turn this experience into advocacy, art or other public expression.