

The Role of Nonprofit Organizations in Pain Medicine

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Philanthropy and involvement in nonprofit organizations can rekindle a sense of purpose and satisfaction in a physician's professional life. Following is a description of my travels through a philanthropic journey.

In the Beginning

The "private world" in which I have practiced for nearly 20 years has offered a remarkable and rich diversity of professional avenues to explore. The autonomy to establish the unique mission of the practice, the very personal relationships established with long-term patients and the cultivation of capable staff are deeply satisfying.

Unfortunately, the grind of private practice can easily separate us from the sense of public service and work for the greater good that is the hallmark of the institutions in which most of us trained. Philanthropy and public service, however, can be found in abundance in the world of private practice.

In 1994, acting on the interest to add a public service dimension to my practice, I asked my accountant if it would be possible to set up a nonprofit corporation. My hope was to establish a vehicle that could collect funds from community members, patients and industry partners and distribute them for the greater good of our community and to less fortunate patients. With a relatively small investment (but many forms from the Internal Revenue Service), we successfully received approval for a 501(c)(3) not-for-profit organization called Napa Pain Resources. 501(c) is a provision of the United States Internal Revenue Code (26 U.S.C. § 501(c)), listing types of nonprofit organizations exempt from some federal income taxes.

Activities of Napa Pain Resources

Our original mission was to support research, education and patient care in pain management in our community. Our foundation has accomplished this in a number of simple ways.

First of all, we have tried to help with transportation. We all recognize that many patients with chronic illness (especially chronic pain) have severe financial stress. Our nonprofit has addressed this by providing cab fare and transportation funds for patients so they can keep their appointments. This seems simple, but in the business of prescribing controlled substances for pain, failure to keep appointments might be viewed as a "red flag" by prescribing doctors. It is sad when patients are considered noncompliant and dismissed from well-intentioned practices because they simply could not afford to get there.

We have also been able to provide medications, in special situations, for patients with implanted infusion pumps. Patients with chronic illness often have lapses in insurance coverage due to lost jobs or during the delay between private insurance and obtaining Medicare coverage. Our ability to supplement our patients in this way has undoubtedly prevented the necessity of explants for some of our patients. Even the co-pay for expensive medications is out of the reach of some patients with financial hardship.

The Napa Pain Conference

I founded the Napa Pain Conference in the early 1990s to bring first-quality pain education to our community. Shortly after inception, the conference has been the principal educational effort of our foundation.

The 14th Napa Pain Conference, held this year in Yountville, Napa Valley, last October 5-7, has been a great success in community building and fund raising for our nonprofit. We have been fortunate to have many of the icons and leaders of our field speak and attend over the years, and we have a dedicated following of clinicians.

The 2008 version of the Napa Pain Conference will offer participants unique exposure to community service. In addition to an excellent clinical program, we will offer a day-long workshop on nonprofits and community philanthropy for participants. Several internationally known foundations have tentatively committed to the event, held each year during the first week of October.

Renaming the Organization — The Margaret Dunn Grigsby Foundation

My mother, Margaret Grigsby, was my model for philanthropy. Born before the Great Depression in a small Tennessee community in Appalachia, she had no money and little opportunity for education. However, as so many in her generation, she found remarkable ways to manage our family and contribute, even while suffering from her own serious and chronic illness.

Of course she would have thought the term “philanthropy” was for rich people. She would have described her tireless help for the needy as just helping out her friends in the community. She showed me that community service does not take money as much as the instinct to look beyond ourselves. When my mom passed on in 2004, we renamed the organization the Margaret Dunn Grigsby Foundation.

Our Newest Commitment — Palliative Care in Malawi, Eastern Africa

We have by no means solved the problem of access to adequate pain services in Napa, California. Nevertheless, we are compelled by my recent experiences in Malawi, in eastern Africa, to contribute something to the immense suffering of these people from the AIDS pandemic, which is still in full swing.

Malawi is a small, land-locked country of 12 million people in southeast Africa. English is the official language, as it was once a British protectorate. There exists a long history of missionary work and philanthropy aimed at health care and community improvement.

Despite these efforts, Malawi depends nearly entirely on donations from Europe, the United States and developed countries for its economy. The society is traditional and agrarian, with more than 90 percent of the population living without electricity or running water.

Like many third-world countries, the public health challenges in Malawi are immense. Dirty water, cholera in the rainy season and malaria are endemic. The health system is primarily funded by the government, which operates on a very limited budget. Other than the excellent work of church-sponsored hospitals, no meaningful private sector exists. HIV/AIDS has been devastating to the people of Malawi. It is estimated that as many as 2 million of the 12 million total population are HIV-positive. Of course with few testing centers and laboratories, and with most patients living in the countryside with no transportation, that estimate is probably low. Incomprehensibly, more than 1 million children in Malawi have been orphaned by AIDS.

Treatment for AIDS is very limited, with only 5 percent of those infected receiving anti-retroviral medications (ARVs). Medical decisions in Malawi are very functional and practical in the face of limited medications. For example, HIV-positive patients do not receive ARVs until they develop AIDS. Those with AIDS, also sick with tuberculosis or cancer, do not receive ARVs as they are deemed too sick to benefit.

Palliative care in Malawi and throughout sub-Saharan Africa is in its infancy. The use of very limited resources of medications such as morphine to make dying patients more comfortable has not been seen as a practical.

Our nonprofit is working with the Health Ministry in Lilongwe, the capital of Malawi, to begin a three-part educational process for palliative care. Working with the fledgling Palliative Care Association of Malawi, or PACAM, we are helping to write a curriculum in palliative care for the small medical school and the school of nursing.

In cooperation with the Global AIDS Interfaith Alliance (GAIA) in San Francisco, we are exploring a pilot project in pain relief. GAIA has a relationship with 37 villages in Malawi and provides orphan care, AIDS support and community development. We are exploring ways to get analgesics (morphine is the cheapest and easiest to handle) to communities and to educate communities in their use.

Of course the challenges in pain management in Malawi parallel our experiences here in some ways. Clinicians receive little or no education regarding pain management or the concept of palliative care. Some even view palliative care as a waste of resources on the hopelessly sick. "Opiophobia" is alive and well, as patients requesting morphine are still viewed with suspicion. The problems of diversion are amplified in an impoverished economy, as morphine has a tangible street value in real currency.

Unlike in the United States, however, morphine is simply physically unavailable. By my informal calculation, the amount of morphine available in an entire year in Malawi is used in a year by a single small community hospital in the United States. Dosing is

dissimilar as well. In home visits for palliative care, I have seen patients and families who describe dramatic pain relief with 5 to 10 milligrams of morphine in 24 hours orally.

The challenges are large and our abilities are small. But each life changed for the better is important, and so we are determined and inspired by the opportunities.

Future Opportunities

It is no news that physicians are under something of a relentless assault in our country. Autonomy in clinical decision-making, financial compensation and our sense of place in society have eroded to the point of discouragement. Anesthesiology, in many ways, is on the ragged, leading edge of these trends.

Recapturing some of the joy and satisfaction lost from our careers may be difficult, but one place to look is in the world of nonprofits. This realm is populated by generous people with passion, spirit and community purpose, which were alive in us all in the early days. I encourage you to explore the possibilities, as the needs are as great as your vision to contribute.

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