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For Ethical Fundraising from Patients, Respect them as Partners

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For over 25 years, grateful patient donors and their families have financed breakthroughs in cancer immunotherapy at Providence's Earle A. Chiles Research Institute (EACRI) in Portland, Oregon. Patients and their families have given nearly \$200 million to our community hospital-based program—and, while our researchers compete successfully for NIH and other public funding, grateful patient giving currently makes up nearly 70% of our budget.

In my 20 years with EACRI, many of my own patients have become financial supporters of our research and volunteer to assist fellow patients in their cancer journey. One of them has contributed several hundred thousand dollars, spoken at events, and provided valuable advice as a member of one of Providence's foundations, which works to connect the community to our research team.

Never during my tenure with EACRI have I experienced medical ethical concerns about a grateful patient donor relationship. Foundation staff members have never asked me to invite a patient to an event or make any other fundraising "move" as part of a clinical visit, and none of my patients have suggested I give them access to a different treatment in exchange for a financial contribution. In fact, engaging patients in supporting our research has been remarkably uncomplicated and deeply rewarding, both professionally and personally.

This engagement is not contrived. It doesn't arise from any grateful patient fundraising training, which I've not received. It flows naturally out of my duty (and pleasure) to educate my patients about their disease and treatments, including research

options—and out of an understanding shared by everyone in our institute that anyone can contribute to ending cancer.

During clinical visits with my patients, my only role is to help them through what is probably the most difficult situation in their lives. But patients are naturally curious about cancer and its treatment, and, as a physician, I am both healer and teacher. Part of answering my patients' questions is to tell them that we have a research program and that I spend most of my time doing research, along with a large number of PhD scientists. I never volunteer that they can contribute financially or that we have a foundation; if they do ask how we pay for our research, I tell them the truth, that it's powered mostly by private philanthropy (including my own small gifts), peer-reviewed grants from places like the National Institutes of Health, American Cancer Society, the Susan B. Komen organization and pharmaceutical companies. If they ask how they can support the research, I let them know that there are brochures in the lobby or ask if they would like us to have a member of our foundation call them. (Our foundation has kindly provided us with stickers with its phone number on them for the backs of our cell phones!)

If a patient—any patient, expresses a strong interest in learning more about our research, I ask them if they would like to tour our laboratories. Typically, the foundation handles scheduling without first investigating the patient's giving capacity. I participate in tours whenever I can, again focusing on education. I talk about the history of the institute, how it came to be that we have world-class immunotherapy here, and some of the research underway. Frequently I tell the story of OX40, how it was derived from research spurred by a patient's challenging question and received support from private donors before it won NIH funding and developed into a company founded by one of our institute members. If the patient says, "We didn't know that cancer research was such an important part of the mission here to improve care for patients. How do we support it?" I smile and point to the foundation representative and she takes it from there.

To maintain my role as healer and teacher, I never participate in any solicitations or discussions

with donors about potential gifts—though I may participate in reporting out to donors the impact of their giving.

I do attend fundraising events with donors, some of whom are my patients. But I don't issue the appeal to them; I raise my own paddle alongside them. And this brings me to my second point; the ease and simplicity of our relationships with grateful patient donors flow from an organizational belief that curing cancer is a community endeavor to which anyone can contribute.

Compared to many others, EACRI is not a large cancer research program. We have been effective because we have been able to integrate clinical care, clinical research and basic research more closely than is possible in most places. Everyone is on the same team: physicians, patients, families, nurses, scheduling secretaries, volunteers, PhD scientists, and data managers. One of our project administrators captured this well: "The environment here at the EACRI is a highly collaborative one, where each person's contributions are valued and appreciated regardless of title or tenure."

Grateful patient donors are respected as part of the team because they provide essential funding that gives the rest of us the time and flexibility needed to sustain our bench-to-bedside collaboration. We could not do our work without them—and everyone at EACRI recognizes that. We also respect the many non-monetary ways our patients contribute by participating in clinical trials, serving as volunteer educators and advocates, and humbling us with questions that sometimes lead to important discoveries.

In exploring this culture of respect, I spoke with EACRI's founder, Walter J. Urba, Director of Cancer Research, EACRI and Physician Director of Research, Providence Health & Services—Oregon Region. According to Dr. Urba, a strong partnership with patients and the community has existed from the institute's beginning, when two philanthropists, Earle Chiles and Robert Franz, joined administrative leaders from Providence in recruiting him to lead it. "They convinced me that they would help bring the people we needed here," he said. "And they kept their word and supported

us throughout their lifetimes and through their estates."

In my time at EACRI I have observed Dr. Urba deliberately cultivate respect for grateful patients among the institute's physicians and researchers. Recruitment meetings frequently include donors. New recruits meet and learn the role of the foundation team as part of their orientation. Physicians and researchers present their work at meetings of the institute's volunteer leadership cabinet and philanthropic dollars are spread among researchers, so we all know where part of our salaries or lab support comes from.

Dr. Urba is clear with institute physicians that he never wants fundraising to come between them and their patients. He leads by example and as a mentor has helped me to appreciate that fundraising opportunities can be a natural outgrowth of the physician/patient relationship. He tells new members of the institute that he once had to explain to a patient that he could only see her on Wednesdays because he did research the rest of the week. "She said 'Gee, our family supports research. Tell me more,'" he recounted to me. "I didn't know who she was. It was just the friendly give-and-take of a relationship."



Grateful Patient Fundraising: Gratitude Matters

Leslie Matthews and Leah Murray

Editor's note: This narrative was written by Dr. Leslie Matthews MD, MBA, MS and his Philanthropy colleague, Leah Murray, MHA.

Leslie Matthews: A Collaborative Approach to Grateful Patient Fundraising

The concept of fundraising initiatives within a healthcare setting traditionally involves patient-focused fundraising. Most often, this is incredibly uncomfortable for providers. As an