

April 14, 2017

Chair Greenlick and Members of the Committee:

My name is Susan Daniel and I am an associate professor of philosophy at Western Oregon University. Medical Ethics is one of my areas of expertise. Among other things, I teach the medical ethics courses at WOU that are required of our pre-nursing students. I'm writing today to express my opposition to House Bill 3428. Hopefully the reasons for my opposition will become clearer if I tell you a little about myself. These are personal issues that I rarely discuss with anyone. However, it seems important that I do so now.

I have an extremely rare autoimmune disease called diffuse systemic scleroderma. This disease can be debilitating, as it has been for me in the past, and it is potentially fatal. There is no cure, so those of us who live with it must deal with it throughout our lives. Because the disease is so rare, few rheumatologists have the expertise needed to treat patients with this disease. For many years I had to travel to Seattle to Virginia Mason Hospital and Medical Center to be treated because no physicians in Oregon had the expertise necessary to provide me with the medical care that I needed. Fortunately, now Oregon Health and Science University has rheumatologists with the requisite expertise and so they are able to care for patients with diffuse systemic scleroderma. Also fortunately, the medical care that they provide is covered by my PEBB insurance. To my knowledge, and I have done a great deal of investigation, OHSU is the only medical facility in Oregon that has rheumatologists with the level of expertise needed to treat patients with diffuse systemic scleroderma. If I am unable to continue to see my physicians at OHSU because they are not covered by my medical insurance, it could cost me my health, my peace of mind, and indeed at some point my very life.

In addition, I developed cataracts at an unusually early age. My scleroderma places me in a higher risk group for cataract surgery. Furthermore, because of my extreme skin and tissue sensitivity due to the scleroderma, I opted for a new type of IOL, the "Symfony" lens. Only one surgeon at OHSU, Dr. Lorinna Lombardi, has been cleared to use this IOL because it is so new (it only received FDA approval last summer). It is my understanding that my surgeon is the first, and so far the only, surgeon in Oregon to use this type of IOL. I had my first surgery done last November. The surgery went well, however I have already developed posterior capsule opacification (secondary cataract) in the eye that was operated on. Hence, that eye will require further laser surgery or I will eventually lose vision in that eye altogether. Again, because of my scleroderma, I am a higher risk patient for this procedure as well and so this procedure also needs to be performed at OHSU. Because this is all rather expensive, particularly on a WOU associate professor's salary, even with PEBB insurance I cannot afford to pay for my next cataract surgery

until this coming November. It is important that the same kind of IOL be implanted in both eyes, that it is done by someone with the expertise necessary to deal with the potential complications posed by my scleroderma, and, again, that the follow up laser surgery to deal with the posterior capsule opacification also be performed by such a person. In Oregon, that means having these things done at OHSU. If I lose my current medical coverage as a result of HB 3428 such that I cannot continue as a patient at OHSU, I will not be able to complete the surgeries needed to restore my vision without facing an unnecessary, and hence unacceptable, level of risk.

Finally, as a philosophy professor, I travel abroad from time to time to present papers at international conferences. It is important to my work that I am able to continue to do this, and it is important to my health and peace of mind, that I am able to receive medical care while I am abroad should the need arise. If that is not possible as a result of the passage of HB 3428, I will not be able to continue to perform that part of my job.

I realize that I am just one person, but I am quite certain that many others are in situations that are similar to mine. I also realize that our state is facing economic pressures. However, as both an ethics professor and as a patient, I would argue that HB 3428, which potentially places the health and well being of Oregon's citizens in jeopardy, simply cannot be the way that we choose to deal with these economic pressures. We are Oregonians; we are better than that.

Please feel free to contact me at 503-838-8378 or daniels@wou.edu if you would like to discuss any of this further. Until then, please know how I strongly urge your opposition to HB 3428. Thank you for your time.

Sincerely,

Susan Daniel