

TESTIMONY IN SUPPORT OF H-141
FEBRUARY 11, 2015

My name is Michael Scollins. I'm a retired internist and Professor of Medicine and Pharmacology at the UVM College of Medicine, a board member of the Vermont Kidney Association (VKA), a member of VMS (Vermont Medical Society), a member along with my wife, who has kidney failure, of the Transplant Donor Network (TDN), and have also been part, since its inception 3 years ago, of the Governor's Advisory Council on Organ Donation and Transplantation. At that time the legislation was introduced, I believe, by Reps Topper McFaun and Patsy French, and prompted by Art Magnaghi (a prior heart recipient) and Matt Boger (state relations representative), both from the NEOB (New England Organ Bank). The proposal was based on positive experience of NEOB with similar groups formed in other New England states, including Maine and NH.

As it happened, a patchwork Vermont-based group of delegates from VKA, TDN, and the transplant team from FAHC (now UVMMC) were also trying to introduce some organ procurement legislation at the same time—and the fact that the one group didn't know about the other, was itself a compelling indication for the need of some overriding, coordinating group. When the Vermont group learned of the NEOB proposed legislation, we abandoned our own agenda and joined forces, achieving passage of the Advisory Council legislation.

The original group was empowered for one year, at the end of which time our report was submitted to the legislature. This report included the strong request that our group be continued, and I remember vividly testifying two years ago that I hoped we wouldn't need to keep coming back every few years to plead for our group's continuance. I'm here again, to do just that: unless the legislature agrees to give us further life, our group sunsets at this time.

The reasons to keep us going are compelling—in non-legislative parlance this decision should be a “no-brainer”. Until 3 years ago, the various entities serving our state's interests in organ procurement and donation, shared only limited communication and coordination. This included the two OPO's (Organ Procurement Organizations) covering Vermont—NEOB based in Boston which serves the eastern half of the state, and CDT (Center for Donation and Transplant) based in Albany and serving our western half, both dealing only with deceased organs, the VKA (which mainly focuses on supportive care for dialysis patients, such as helping with medicine and transportation costs), the TDN, a support group for potential and past donors and recipients, based in and serving mainly northwestern Vermont, the transplant team at UVMMC, funeral directors, who play a key role in organ procurement, and the DMV, which offers by far the best means of reaching and registering potential organ donors. The members volunteer their time, and thus far have functioned without any state funding, but have been resourceful in meeting their limited expenditures.

The Advisory Council, under the able leadership of Commissioner Harry Chen, has proved to be a remarkably effective and vibrant means of coordination among all these

groups. I'll spare you a detailed list of all the issues we've addressed—these are nicely enumerated in Dawn Philibert's reports submitted to the legislature in January 2013, and again last month (Act 32). I'll just highlight a few examples:

- 1) When this group first convened, only 7% of Vermont adults were registered as deceased organ donors. Through a prolonged, productive dialogue, the DMV in January 2013 finally put into place a very effective work-around process, that is now consistently registering about 45% of all drivers as deceased organ donors. By January 2017 all drivers will have been cycled through the renewal process, so likely at least 45% of all our drivers will have registered as donors. The legislature had charged the DMV to implement such a program 5 years earlier, but it happened only after the persistent involvement of the Advisory Council.
- 2) Despite the success of this project, it does not address LIVE organ donation, nor are any of the individual entities comprising the Advisory Council charged with that mission. Live kidney donation, for example, offers the promise of avoiding kidney dialysis altogether, and longer transplanted organ survival (about 10 vs 6 years, on average). The Advisory Council CAN tackle that issue, and has been working on ways to heighten awareness for the need of live organ donation, including PSA's, newsletters, and possible legislation offering tax benefits and defrayed costs to donors. Increasing deceased organ donations cannot, by itself, meet the full need for transplanted organs.
- 3) Rep. Barbara Rachelson's recently introduced H-37, proposing presumed consent, i.e. regarding each of us as a deceased organ donor unless we specifically indicate otherwise, undoubtedly well-intentioned, would likely never have been introduced had she known about the existence of our group and thought to consult us first. There is ample data that this approach doesn't have the desired effect—but this is not the time for that discussion.

The Advisory Group include the foremost experts in the region to address these problems. They have been so effective, that I have no doubt they will continue to operate, even if for some unforeseen reason the legislature doesn't choose to re-appoint them. We have developed a very collegial and efficient communications process through meetings and E-mail, and see the continuation of the Council as being vital to the state's ability to formulate and respond to organ procurement and transplantation issues as the discipline evolves. Certainly we can function best with the State's approval and with the leadership of our Commissioner of Health, so I urge you enthusiastically to extend our existence for as long as legislative wisdom will allow!

Respectfully,
Michael J. Scollins, M.D.