

[From Forbes Magazine, Nov. 1, 1999]

THE ORGAN KING

(By Brigid McMenamin)

Ever since Forbes exposed the federal monopoly that's chilling the supply of transplantable organs and letting Americans who need them die needlessly (Forbes, Mar. 11, 1996), Health & Human Services Secretary Donna Shalala has been trying to challenge the way United Network for Organ Sharing operates.

But the Richmond, Va.-based cartel will have none of it. Using a heavy-handed mix of litigation, lobbying and bullying of its opponents, UNOS has solidified its position as the federal contractor in charge of deciding which people get new kidneys, livers or hearts.

Under the UNOS system, most organs are shared only within 62 regional territories. A potential recipient in, say, New York, where donations are low, can expect to wait months for an organ to show up, even though there may be so many donors across the river in New Jersey that New Jersey patients are getting transplants after short waits or when they are far from desperate.

Though UNOS has begun to relax the locals-first policy, still, last year 4,855 Americans died while waiting for transplants. (This doesn't even count people pulled off the list after they became too sick to handle a transplant.) It is a matter of debate how much lower the number of deaths would be if the system for obtaining and allocating organs were more rational. But Consad, a research outfit in Pittsburgh, estimates that at least 1,000 people die needlessly each year.

When Shalala urged that organs be shared over wider regions, UNOS Executive Director Walter K. Graham refused. He decreed, in a memo to his member hospitals and organ banks, that UNOS doesn't have to take direction from the federal government on this point.

UNOS' main source of funding is the \$375 registration fee potential organ recipients must pay to get on the waiting list. That amounts to some \$13 million a year, money that is supposed to be spent mostly to match organs with suitable recipients. In reality, at best half of the money goes to that.

What about the rest? Graham and his 40 board members spend some \$1 million each year on jetting around and on meetings and conferences. A new \$7 million headquarters building is planned. In 1997, some \$1.6 million went for items network officials refuse to explain. "They really never tell you what they're spending money on," says veteran board member John Fung, a liver surgeon at the University of Pittsburgh.

When Shalala tried to exert more control over the rising registration fees, Graham challenged her in a proceeding before the U.S. General Accounting Office, claiming she had no right even to know how he spent the fees. The suit was settled; Shalala backed down.

Why not simply bring in another contractor to ration organs? Good luck. The congressional committee in charge of such matters is headed by Representative Thomas Bliley, from UNOS' home city of Richmond. His cousin Paul S. Bliley is a law partner of UNOS lawyer Malcolm E. (Dick) Ritsch. Last fall, then-Louisiana Congressman Robert Livingston, whose home state includes eight profitable transplant centers, pushed through a bill halting further attempts by Shalala to control the contractor.

After the Senate rejected this moratorium, Livingston got it tacked onto another bill behind closed doors by threatening to hold

up funding for the International Monetary Fund. The moratorium ends Oct. 21. But UNOS has already had Wisconsin Congressman David Obey tack another one-year extension onto a bill that was set to go to the full House for a vote in October. His state's four transplant centers stand to lose organs if UNOS loses its grip.

Craig Howe, executive director of the National Marrow Donor Program, recently expressed interest in having his organization bid on the organ contract. After UNOS found out he was interested, his board members, who include 14 physicians, axed him. Although some powerful and prominent surgeons like Fung are an exception, most doctors involved in the business fear offending UNOS lest their organ supply be affected.

In another instance FORBES is aware of, UNOS threatened to retaliate against an outfit it perceived as a rival bidder for the organ allocation job.

Tax-exempt groups like UNOS are supposed to make their financial statements available for public perusal. But UNOS hides significant activity behind two little-known affiliates that aren't required to disclose anything.

The first is the UNOS Foundation, a six-year-old shadow organization run by UNOS staffers. Spokesman Robert Spieldenner claims the foundation doesn't have to file tax returns because it brings in less than \$25,000 a year. The UNOS Foundation owns something called the Transplant Informatics Institute, a for-profit company run by organ network staffers. Transplants Informatics is so secret that even some UNOS board members are unaware that it exists.

What does the institute do? The government thinks it markets UNOS-developed software to organ network members. In an audit looking into the use of registration fees for lobbying, the Office of the Inspector General got just that impression. What the institute really does is analyze and sell organ network data to profit-making companies like Fujisawa, the Japanese firm that sells drugs for transplant patients. When the institute has not been able to cover its costs with such sales, UNOS has used its registration fee income to make up the difference. Prospective organ recipients are therefore effectively funding this hidden business.

You'd think someone on UNOS' board would scream bloody murder about all this. After all, the 40-person board is almost half doctors, dedicated to saving lives. But the directors have little idea what's going on. "The board is kind of in the dark," sighs patient advocate Charles Fiske, a former board member.

"We received an annual financial report and pretty much accepted it as written," says University of Oklahoma transplant doctor Larry R. Pennington, a board member from 1996 to 1998. They really don't know how to interpret the data. "All I'm familiar with is hospital sort of activity," admits transplant physician William Harmon.

Realizing that UNOS is out of control, Shalala has put out feelers for a replacement. "I hope we have some bidders this time," sighs Claude Fox, a pediatrician who, as administrator of the Health Resources & Services Administration, oversees transplants for Shalala. The only prospect so far is Santa Monica-based Rand.

Determined to see that Rand does not walk off with the contract, UNOS' lobbyists are pushing for a law that would insure that Graham's group will keep the contract forever. Last month Bliley's committee held hearings on a bill which would require the

organ rationing contractor to have experience, something no group but UNOS has. It would also allow UNOS' members to vote on the choice.

"Anything that gives them more of a stranglehold isn't in the public interest," says Fox. "It's like giving the EPA to some land-fill company," says Dr. Fung.

It would be nice if UNOS didn't have a lock on this business. Better still if the federal government stepped out of the process altogether and let doctors come up with creative ways to increase the supply of organs. (How about giving people who sign up as potential donors when they are young some priority in getting organs when they are older?) Once there are enough hearts and livers to go around, there won't be unaccountable arbiters holding sway over our lives.

IN SPECIAL RECOGNITION OF DICK G. LAM, JR.

HON. EDOLPHUS TOWNS

OF NEW YORK

IN THE HOUSE OF REPRESENTATIVES

Thursday, November 4, 1999

Mr. TOWNS. Mr. Speaker, I rise today to recognize the accomplishments of Dick G. Lam, Jr. He has been instrumental in developing and implementing economic and academic development programs. Dick remains committed to improving the quality of life in his community. Presently, Dick is the President of Operation Salvation for Youth (OSY). As the president, he directs a Brooklyn based organization devoted to helping youth gain digital literacy and access to new technology. In the program, special emphasis is placed on welfare mothers who have young children. The OSY is currently working with the New York City Housing Authority, the Miracle Makers, Inc., and several private firms on the development of a new project.

Dick's work continues to provide a foundation for social progress. As a Senior Fellow for the Department of Urban Affairs and Planning at Hunter College, he worked to develop a Spatial Analysis Management System to analyze a range of urban problems, including transportation, housing and welfare to work issues. Dick also holds advisory positions as the Senior U.S. Consultant to the Tianjin Municipal Utility Bureau, The Peoples Republic of China and the Senior U.S. Consultant to the All China Taxi Association, The Peoples Republic of China.

Our community is a better place today because Dick has chosen to commit himself to urban renewal and development. Dick has accomplished his objectives by working in key positions such as: Director of the Mayor's Office of Midtown Manhattan Planning and Development, New York City, Director of Transportation and Regional Planning, New York City Planning Commission, and Special Assistant to the Deputy Under Secretary, United States Department of Transportation. Our society is a better place today because of the contributions made by Dick.

I commend Dick G. Lam, Jr. and pray that he will succeed in all future endeavors.