



www.FAIRFoundation.org

Sent: Sunday, December 28, 2008 9:58 AM

To: John Davis, CEO, NKF

Cc: Bryan N. Becker, MD, President, NKF; 'jill_canino@specter.senate.gov'

TO: National Kidney Foundation (NKF) Board of Directors
FROM: FAIR Foundation's CEO and 26-member Board of Directors, including transplant surgeons, medical directors, et al, representing our thousands of members and supporters who now reside in all fifty states

RE: NKF CEO John Davis's webinar request for input prior to your January Board meeting regarding incentivizing organ donation

Dear NKF Board members,

We urge you to follow the lead of various organizations and media, including the American Medical Association,^[1] the American Society of Transplantation,^[2] the Association of Kidney patients,^[3] the Polycystic Kidney Disease (PKD) Foundation,^[4] the Wall Street Journal^[5] and Transplant Recipients International Organization^[6] in supporting Senator Specter's bill, the "Organ Donation Clarification and Antitrafficking Act of 2008,"^[7] and/or pilot projects of financial incentives to increase organ recoveries.

Almost 101,000 dying patients are waiting for an organ today. One of them, or one who was taken off the list due to being too sick, dies every hour.^[8] Clearly, "altruism" alone is failing to meet the demand for organs and failing to end this organ-donor crisis.

Some stress the need for further education of Americans about the need for altruistic donation prior to adopting new OD policies. It must be noted that if such education was 100% successful and every deceased donor was utilized under our present system of altruism, there would still be a significant shortage of organs.^[9]

Thomas Mone is CEO of the largest organ procurement organization (OPO), the President of the Association of OPO's, and a Director at UNOS. In an article written in the LA Business Journal expressing his opinion, Tom has endorsed trial projects to incentivize kidney donation with the government providing health insurance to a living donor.

There are forty-six million Americans without health insurance^[10] and prior to our country's recent financial crisis seventy million also had medical expense debt problems.^[11] Clearly, the health insurance incentive would be attractive to millions and we believe the kidney waiting list would be completely eliminated within 5-10 years.

By including deceased donor families as being eligible to receive financial incentives, recoveries of all organs would be increased significantly and there would be no resentment by these deceased donor families when assessing the same benefit to living donors.

Sixty percent of transplants are kidneys. Each patient taken off of the kidney waiting list with transplant saves our government and insurance companies thousands of dollars in dialysis, ER, etc. expenses.

Note that when the National Organ Transplant Act (NOTA) was passed in 1984 to prevent "valuable consideration" for organs, UNOS had no waiting list and it was not until 1989 that one was started---it reached only 19,095 patients by 12/31 of that year.^[12] With almost 101,000 now waiting, we now have an exigent situation requiring a new remedy to this crisis.

NOTA rightfully allows payment to almost everyone in the transplant chain such as hospitals, OPO's, MD's, nurses, the recipient benefits with "life" and even the US tax-payer benefits financially when a patient comes off dialysis.^[13] Who is not reimbursed? The most important persons in providing the "Gift of Life": a living donor or a deceased donor family.

Imagine setting up a lucrative business with a product that costs you nothing to obtain? Companies such as Genzyme Biosurgery, LifeCell, LifeNet Health, etc. are expected to gross over \$200 million dollars by 2012. Their business is providing tissues and organs for transplant.^[14] Some of UNOS's OPO's are also in this business. Is it ethical to allow them to receive financial gain from patients' tissues and organs, while patients and their families receive no financial benefit? We believe it is not.

It is important to note that some of us are organ recipients. Incentivizing donation will never, ever diminish the immense respect and love we have for our donors or their families who were not able to participate in this much-needed new organ-donor policy.

On your website, your "History" link^[15] states, "The vision of the NKF is to enhance the lives of everyone with, at risk of or affected by kidney disease." "Throughout our history, NKF placed patients first and still does."

On behalf of the 76,000 waiting for a kidney transplant today and thousands more on dialysis but not on the UNOS list, we thank you for your consideration of our request that you support the Specter bill and trial projects of financial incentives to increase recoveries.

With great respect for your efforts, we are,

Richard Darling, President, CEO, the FAIR Foundation & our Board of Directors below:

John Fung, MD, Ph.D., FACS, Chairman, Department of General Surgery; Director, Transplant Center, Cleveland Clinic Foundation

Phil Berry, M.D., Advisory Committee for Organ Transplantation (ACOT) appointed by Secretary Tommie Thompson, Health & Human Services, 2001-2004; Past President, Texas Medical Association; President, Texas Medical Assoc. Foundation; Past Member, Board of Directors and Finance Committee, UNOS

Waldo Concepcion, MD; FACS, Associate Professor of Surgery, Chief of Clinical Transplantation, Chief of Pediatric Kidney Transplantation, Stanford University School of Medicine

Donald Hillebrand, MD, Hepatologist; Medical Director, Liver Transplantation, Associate Professor of Medicine, Scripps Green Transplant Center, La Jolla, CA

Bob Gish, MD, Medical Director of the Liver Disease Management and Transplant Program at California Pacific Medical Center (CPMC); Division Chief, Hepatology and Complex Gastroenterology at CPMC Physicians Foundation; Associate Clinical Professor of Medicine at the University of Nevada in Reno and at University of CA San Francisco; Member of the American Association for the Study of the Liver, the American Gastroenterological Association, the American Society of Transplant Physicians, and the International Liver Transplant Society.

Charles J. Goodacre, DDS, MSD; Dean of the Loma Linda University School of Dentistry; President of the American College of Prosthodontists; Recipient of the William J. Gies Awards for Vision, Innovation, and Achievement, recognizing outstanding innovation by a dental educator. Past President of the American Board of Prosthodontics ; Executive Council Member of the Academy of Prosthodontics.

Pedro W. Baron, MD, Director of Pediatric and Adult Liver Transplantation; Associate Professor of Surgery, Loma Linda University Medical Center

Melba Moore, MS, Commissioner of Health, St. Louis City Department of Health, St. Louis, Missouri; Member, Webster University's Arts and Sciences Advisory Board, St. Louis Connect Care, and the Regional Health Commission; John F. Kennedy School of Government for State and Local Executives; 20 years experience in the public sector, management and executive leadership.

Leonard J. Morse, MD; Commissioner of Public Health, Worcester, Massachusetts; Professor of Clinical Medicine and Family Medicine and Community Health, University of Massachusetts Medical School; Chair Emeritus, American Medical Association's Council on Ethical and Judicial Affairs; Past-President of the Massachusetts Medical Society.

Jacqueline Marcell, Caregiving Advocate: Alzheimer's Disease; Author, *Elder Rage* / Publisher / Radio Host / Speaker / Eldercare Advocate

Okechukwa Ojogho, MD, Director, Pediatric and Adult Kidney, Pancreas Transplantation; Associate Past Director, Liver Transplantation; Associate Professor of Surgery, Loma Linda University Medical Center

Jill Weissman, PharmD, Transplant Pharmacist; Assistant Professor, Department of Pharmacy Practice, Loma Linda University School of Pharmacy

Bill Remak, B.Sc.MT, BA PHA Chairman, California Hepatitis C Task Force, Founder: National Association of Hepatitis Task Forces

Lorenzo Rossaro, M.D., Medical Director, Liver Transplant Program; Chief, Division of Gastroenterology and Hepatology, University of California, Davis Medical Center

Ray Hill, Patient Advocate: HIV/AIDS & Hepatitis C

Richard Swabb, M.D., Board Certified in Nephrology and Board Certified in Internal Medicine, Loma Linda University Medical Center

Sandra Rogers, Patient Advocate: Parkinson's Disease & Stroke

Norman Kay, Patient Advocate: Prostate Disease

Philip Rugo, Patient Advocate: Alcoholic Liver Disease (ALD); Past Director, Harrison House Substance Abuse Rehabilitation Center

Art Curley, Attorney-at-Law; President, Bradley Curley Asiano Barrabee & Crawford, PC

Leigh Aveling, D.Min. MFT, Chaplain: Loma Linda University Medical Center and Loma Linda University Behavioral Medicine Clinic; Adjunct Assistant Professor, Faculty of Religion, Loma Linda University. Loma Linda, California

James M. Ward Captain, SC, USNR (Ret.), Patient Advocate: Heart Disease

Dave Courtney, Patient Advocate: Alpha-1-antitrypsin lung/liver disease; Vice President, The Presumed Consent Foundation

Kress Darling, Patient Advocate, Migraine Headache & Osteoporosis

Other eminent physicians and organ-donor advocates in favor of Senator Specter's bill and pilot projects of financial incentives can be viewed [here](#).

[1] http://fairfoundation.org/AMA_financial_incentives.pdf

[2] Dr. David Cohen, AST Public Policy Committee Co-Chairman spoke in a 10/21/08 Senate briefing in support of Specter's bill

[3] <http://www.aakp.org/press/press-releases/2008/Incentives-for-Organ-Donation/>

[4]

<http://www.pkdcure.org/InternalPages/2008/OrganDonationLegislation111708/tabid/1071/Default.aspx>

[5] <http://online.wsj.com/article/SB122948107890913051.html>

[6] http://fairfoundation.org/news_letter/2008/04dec/TRIO_PR_11-19-08.pdf

[7] http://fairfoundation.org/organdonation/specter_bill.pdf and <http://www.nysun.com/opinion/new-hope-on-organ-donation/86471/>

[8] http://fairfoundation.org/organdonation/waiting_list_death_rate.htm

[9] Arthur Matas, MD, Past President: American Society of Transplant Surgeons at the CATO Institute

[10] http://fairfoundation.org...n_no_health_insurance.pdf

[11] http://fairfoundation.org..._million_medical_debt.pdf

[12] http://fairfoundation.org/organdonation/UNOS_waiting_list_history.pdf

[13] Amy Friedman, MD, Associate Professor and kidney transplant surgeon, Yale University

[14] http://fairfoundation.org...raft_market_will_grow.pdf

[15] <http://www.kidney.org/about/history.cfm>