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May 13, 2013

Written testimony on HB 3345 Health Care and Human Services Committee

Today we have nearly 2.2 million Oregonians on the donor registry indicating their desire to donate organs, eyes and tissues for transplant at the time of their death. This represents 70% of drivers over the age of 18. But these numbers are deceiving. The actual number of donors is much higher as the public continues to be educated on the donation process. For 35 years, we have helped families navigate a passage that satisfies their cultural and religious obligations as well as their own personal feelings on helping others. For most, knowing their loved one is continuing, in death, a legacy of generosity they so nurtured in life is an important part of the mourning cycle and healing process.

Donate Life Northwest and their participating partners, Community Tissue Services, Lions VisionGift, Pacific Northwest Transplant Bank, and the American Red Cross Pacific Northwest Blood Services, attribute our success directly to trust. The decision to donate is an emotional one. Families of donors must trust their loved ones will be treated with a dignity defined by no other definition but their own, and only through transparency are they allowed to gather the information needed to make a more balanced decision. We have worked hard to establish that foundation of trust by adhering to strict guidelines, regulations and standards brought forth by various regulatory bodies including the FDA and US Health and Human Services.

Donate Life Northwest, Lions VisionGift, Community Tissue Service, Pacific Northwest Transplant Bank and the American Red Cross Pacific Northwest Blood Services are very much in support of HB 3345, a bill requiring non-transplant anatomical research organizations to be licensed by the Oregon Health Authority.

The past ten years have seen an increase in the number of unregulated anatomical research recovery organizations in the United States. These organizations have been brought to the forefront of public consciousness due to several scandals involving both regulated and unregulated agencies. This rise in bad publicity undermines the strides we have made as the media and the public begin to file these organizations into the same category as transplant organizations. The backlash of these types of scandals not only adversely affects all forms of donation, including life-saving and life-enhancing transplant donation, but calls into question the legacy of every donor who has ever saved life, sight or mobility in another. Educating the public on anatomical donation is a slow, arduous process, one fraught with the dangers of misconception and misinformation, and no matter how hard we try, one cannot unring a bell. If only one family declines donation out of fear of the unknown, then we have all failed. With people's lives in the balance, we have failed.

HB 3345 provides structure to agencies currently unregulated. It is, without a doubt, in the public's best interest to ensure safety as well as full disclosure for all donations. While we currently don't support the amendment of HB 3345 exempting hospitals, we do support the bill as a great **starting** point for ensuring public safety and trust, and encourage its swift passage through the Senate.

Sincerely,

Mary Jane Hunt, Donate Life Northwest Mike Seely, Pacific Northwest Transplant Bank Barbara Crow, Lions VisionGift Rob Boggs, Community Tissue Services Mary Jo Drew, MD, American Red Cross Pacific Northwest Blood Services