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Recommendations of Two Additional Members of the Institute of Medicine’s Transforming End of Life Care Committee

I represent a national disability rights group, Not Dead Yet, which addresses public policy issues impacting what is widely referred to as end-of-life care. We are submitting two recommendations for appointments to the IOM Transforming End of Life Care Committee: Dr. Ira Byock and Kelly Buckland. We recognize that the existing appointments may be considered to be sufficient, but hope that the appointing authority will not only find the proposed candidates eminently qualified, but recognize that it would be a glaring omission to leave them out of the Committee.

First, although Dr. Ira Byock’s expertise on the issues the Committee will consider should be well known to the other Committee members and IOM leadership, I am including the following biographical information for your convenience:

*Ira Byock, M.D. is a palliative care physician and long-time public advocate for improving care through the end of life. His books on the subject of improving end of life care include Dying Well (1997), The Four Things That Matter Most (2004) and The Best Care Possible: A Physician’s Quest to Transform Care Through the End of Life (2012).*

*Dr. Byock is Director of Palliative Medicine at Dartmouth Hitchcock Medical Center and Professor of Anesthesiology and Community and Family Medicine at Dartmouth Medical School. Board certifications include Family Practice, Emergency Medicine (1988-1998) and Hospice and Palliative Medicine. He was co-founder and principal investigator of Life’s End Institute (previously the Missoula Demonstration Project), a community-based research and quality improvement organization focused on end-of-life experience and care. He is a past president of the American Academy of Hospice and Palliative Medicine (1997), and recipient of the Academy’s Distinguished Service Award in 2002. He has published numerous academic articles on ethics and practice of end-of-life care. He serves on numerous advisory committees and the editorial boards of several professional publications and has participated in discussions of ethical issues related to end-of-life care on innumerable radio and television broadcasts including: The Jim Lehrer News Hour, Talk of the Nation, Nightline, All Things Considered (NPR), 60 Minutes and many others.*

Most importantly, from a disability community perspective, we recommend that a qualified disability rights advocate be added to the Committee. While the relevance of this may not be immediately obvious, the factors impacting people with life threatening health conditions very often derive from the presence of disabilities that accompany a terminal illness. While people may not immediately think “disability” when they think of terminal illnesses, functional losses and the need for assistance in the activities of daily living are central issues in advanced terminal illness, and that means disability is a central issue. Disability experts in the field of independent living are people with disabilities who have first hand experience in how to maximize functional activities despite impairments, how to use adaptive devices and technology, how to maintain a sense of personal control and how to achieve the best possible “quality of life.”

We recommend Kelly Buckland, Executive Director of the National Council on Independent Living, for appointment to the Committee. Biographical information on Mr. Buckland follows below:

*Kelly Buckland is a person with a disability who has been actively involved in disability issues since 1979. Kelly started his career as an employee for Idaho’s Protection and Advocacy system.  He served for over twenty years as the Executive Director of the Boise CIL, Living Independence Network Corp. and the Idaho State Independent Living Council.  He has served on the Idaho Developmental Disabilities Council, the State Employment and Training Council, and the State Help America Vote Act Steering Committee.  He has worked on issues affecting people with disabilities, including passage of the Personal Assistance Services Act and the Fathers and Mothers Independently Living with their Youth (FAMILY) Child Custody Laws*

*In 1978, Kelly graduated from Boise State University with a B.A. in Social Work and in 1988 Summa Cum Laude from Drake University with a Masters in Rehabilitation Counseling.  In recent years, Kelly has been honored with numerous state and national awards, including the University of Idaho President’s Medallion, the United Vision for Idaho Lifetime Achievement Award, the Hewlett-Packard Distinguished Achievement in Human Rights Award, and induction into the National Spinal Cord Injury Hall of Fame.*

*Kelly has testified before Congress several times on issues such as universal health care, Fair Housing and appropriations for centers for independent living. He has been closely involved with the direct-service and systemic change aspects of the Independent Living movement*

*Additionally, Kelly has a long history with the National Council on Independent Living (NCIL).  He has served on numerous NCIL Legislative and Advocacy Subcommittees and other standing NCIL committees, the NCIL Governing Board since 1998, as NCIL Vice-President from 2001-2005, and as NCIL President from 2005 to 2009.  Kelly is currently employed as the Executive Director of NCIL.*