



Quarterly Meeting Agenda October 23, 2018 Jackson, Mississippi

Tuesday, October 23, 2018

10:00 AM Eastern, 9:00 AM Central, 8:00 AM Mountain, **7:00 AM Pacific**

LOCATION: Hilton Garden Inn Jackson/Downtown, Triple C's: Club, Crown, Coronet
2nd Floor, 235 W Capitol Street, Jackson, MS 39201

CALL-IN NUMBER: 800-667-5617, Conference ID: 6973399; Conference Title: NCD Meeting; Host Name: Neil Romano

CART: <http://www.streamtext.net/player?event=NCD-QUARTERLY>

AGENDA (Central Time)

9:00 am - 9:15 am **Welcome and Introductions, Chairman Neil Romano**

- Acceptance of Agenda
- Roll Call of NCD Council Members and Staff

9:15 am - 9:45 am **Executive Reports**

- Chairman's Report, Neil Romano
- Executive Director's Report, Lisa Grubb
- Financial Representative's Report, Billy Altom
- Governance Representative's Report, Rabia Belt
- Director of Policy Report, Joan Durocher
- Director of Legislative Affairs Report, Anne Sommers

9:45 am - 11:45 am -

tune in at 7:45 AM Pacific time to hear what Shaun Bickley, representing the Arc of King County has to contribute to this conversation.

National Disability Employment Policy, From the New Deal to the Real Deal: Joining the Industries of the Future

- Regina Kline, Inclusivity Strategic Consulting
- Andrew J. McQuaide, Perspectives Corporation
- Jennifer White, Able Opportunities, Inc.
- **Shaun Bickley, Arc of King County**
- Edward McLaughlin, Employee, Volunteer, and Self Advocate

11:45 am - 1:15 pm **Lunch, On Your Own**

To help reduce exposure to fragrances for those with multiple chemical sensitivities, please refrain from wearing scented personal care products such as perfumes, hairsprays, colognes, and deodorants.



Quarterly Meeting Agenda October 23, 2018 Jackson, Mississippi

1:15 pm - 3:15 pm

Bioethics and Disability Panel

Ethical questions that arise in the context of access to medical interventions and potential impacts of emerging genetic technologies on the lives of people with disabilities.

- David Wasserman, National Institutes of Health – Clinical Center Department of Bioethics - Disability issues in healthcare allocation, fetal medicine, and gene editing
- Gregor Wolbring, University of Calgary – Genetic testing to gene editing
- Karen Corby, Mother – Disability discrimination in organ transplants
- Ari Ne’eman, mysupport.com – Medical Futility and “Quality Adjusted Life Years”
- Cathy Ludlum, Second Thoughts Connecticut – Disability issues in assisted suicide

3:15 pm - 3:30 pm

Break

3:30 pm - 4:15 pm

Institutionalization of Persons with Disabilities during and after Disasters Report Update

- Melissa Marshall Disability Consulting, LLC
- Marcie Roth, Partnership for Inclusive Disaster Strategies

4:15 pm - 4:45 pm

Town Hall to receive Public comments on Bioethics and Disability

We’re want to hear from you!

Your insight is instrumental and helps to steer the direction of NCD’s reports. Work is underway in the following areas and we’re ready to hear from you about those topics.

The five areas NCD intends to look at are organ transplants; medical futility; Quality Adjusted Life Years; Physician Assisted Suicide; and Genetic Testing.

Despite the growing understanding that disability is a normal part of the human experience, the lives of people with disabilities continue to be devalued in medical

To help reduce exposure to fragrances for those with multiple chemical sensitivities, please refrain from wearing scented personal care products such as perfumes, hairsprays, colognes, and deodorants.



Quarterly Meeting Agenda October 23, 2018 Jackson, Mississippi

decision-making. The devaluation of people with disabilities has been widely recognized, and is apparent on the face of laws and policies that allow hospitals and physicians to deny or withhold care based on subjective criteria on quality of life, such as denying a young boy a life-saving liver transplant because he has autism, and denying a life-sustaining medical treatment to a woman with quadriplegia because the medical team determines that she will be dependent on the care of others if she survives. It is heard in the advice given to families of people with disabilities, or to people with disabilities themselves, to forgo or end medical care rather than continue life with a disability; and when a doctor describes to expectant parents that it will be expensive and emotionally burdensome if they choose to have a child that genetic tests show may have a disability. The devaluation is implicit in the lack of federal guidance making clear to the medical community that it is a violation of the Americans with Disabilities Act to discriminate in the provision of medical care based on a person's disability.

4:45 pm - 5:00 pm **Unfinished Business**

5:00 pm **Adjourn**

To help reduce exposure to fragrances for those with multiple chemical sensitivities, please refrain from wearing scented personal care products such as perfumes, hairsprays, colognes, and deodorants.