



Presidential Commission
for the Study of Bioethical Issues

TRANSCRIPT

Kathleen Sebelius, M.P.A.

Former Secretary

U.S. Department of Health and Human Services

Meeting 22, Session One
August 31, 2016
Philadelphia, PA

SESSION ONE: VIDEO MESSAGE

DR. GUTMANN: So, with that as the background, we're going to get started in an unusual way today with a video message. And we'll begin on the impact of national bioethics advisory bodies with a message from a person who was critical to the formation and success of this commission. President Obama appointed us, and Kathleen Sebelius, the former U.S. Secretary of Health and Human Services, was very important to our work and, actually, one of the people who – or the person, I should say – along with the President, who charged us with the single most challenging task. It was an ask, but our view is: When the President or the Secretary of HHS asks, we do. Right? So, the Honorable Kathleen Sebelius served as U.S. Secretary of HHS from 2009 to 2014 and as Governor of Kansas from 2003 to 2009. She's now the President and CEO of Sebelius Resources, LLC, which provides strategic advice to companies, investors and nonprofit organizations. Secretary Sebelius serves as a senior advisor to the Aspen Institute, where she co-chairs the Aspen Health Strategy Group, and as a member of the board of directors for a wide range of companies. She earned a Master of Public Administration from the University of Kansas and a Bachelor of Arts degree from Trinity Washington University. So, during her time as Secretary of HHS, Secretary Sebelius was instrumental in the establishment of the Presidential Commission by Executive Order in November 2009. And at our very first meeting here, not here [in Philadelphia], but in Washington, D.C., in July of 2010, she joined us on behalf of the President to swear us in as members of the Commission. And then we had the pleasure of speaking with her again in May 2012 at our ninth meeting, and, there, she joined us shortly after she issued the charge for us to consider the ethical issues of testing medical countermeasures in children. In that presentation, she noted that HHS was relying on us to deliver, and I quote, “rational, independent, evidence-based advice to develop a pathway to figure out how to keep our children safe and secure in the event that something occurs”, the something being an anthrax attack. That charge led us to release our fifth report, which we entitled, *Safeguarding Children: Pediatric Medical Countermeasure Research*. Secretary Sebelius has been extremely supportive of us in our work, and on behalf of us all, I want to thank her for her commitment to this commission. And I haven't viewed her message, but I'm told that it is on video. And so, whoever is in charge of the video, if you would please roll it for us.

SECRETARY SEBELIUS: I'm so sorry I'm not with you today in person, but I've made a commitment to my spouse a while ago that I would join him in a long-scheduled conference. But I'm delighted to have a chance to visit with you by video and start with saying thank you, thank you, thank you. Thank you to Amy Gutmann for chairing this commission, and thank you to all the members who were willing to volunteer your time and efforts and expertise to helping this Administration deal with some very thorny issues. You helped us navigate through Guatemala [the Guatemala experiments], figuring out ways to put guidelines out that it will never happen again. You helped us sort through how the testing protocol for children with novel medicines and vaccines should be structured. Safety and security is paramount, but not testing may put children in a much more difficult position. So, balancing those issues was something that your recommendations were very helpful to do. When Ebola hit the United States, you helped us sort through some of the issues around that. And as science is finding dazzling, new pathways, sorting through the privacy issues around genomic sequencing and DNA screening has been critically important. I was so impressed with your willingness and foresight to reach out to colleagues and peers in other countries to see what their protocols and practices have been. Since none of these challenges stop at our borders and these are all global ethical issues, having other people, other cultures advise the United States can only make our guidelines even stronger. We're in an era where artificial intelligence may push the boundaries of things that we have never seen and where science may get well ahead of what people are ready to deal with in terms of payment or practices, so I have no doubt that a continuing focus on bioethics will be critical on into the future. But for now, this Bioethics Commission has helped to make sure that research, healthcare, and technological innovations remain ethically responsible. And for that, I am grateful, the President of the United States is grateful, and the millions of Americans whose lives you have touched in a positive way will always be grateful. Thank you.

DR. GUTMANN: Thank you. Also, I should single out not only the President, but the Vice President of the United States, who welcomed us to his home at the Naval Observatory and spent two hours with us talking about the work of the Commission and how important it was to the Administration. It is inherently something I believe is important – to serve our country and to do public service. But, it's particularly gratifying when the people who are, day in and day out, leading the country show their appreciation. So, thanks to Kathleen Sebelius. I thought I'd ask Barbara, who hails from Kansas, [about] when she started on the Commission, to say – if you

want to reflect a little on your sense of what it's [Secretary Sebelius' involvement] has meant for the Commission.

DR. ATKINSON: Kathleen was an amazing governor, and she has such great healthcare experience and had it as a governor. She did so many things for the state, including putting in the first appropriation to help us get an NCI-designated cancer center in Kansas. That would not have happened without her support. She's just an amazing person and it was really wonderful to see her thanking us because I feel very much like I should be thanking her for having suggested me for this Commission.