TRANSCRIPT

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Commission Member Reflections

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OPENING REMARKS

DR. GUTMANN: Good morning, everybody. I'm Amy Gutmann and I Chair the Presidential Commission for the Study of Bioethical Issues and I also am the President of the University of Pennsylvania and I'm very pleased to welcome you all here in the new Henry Jordan Medical Education Center at our Perelman School of Medicine. I'm also pleased on behalf of myself and our Vice Chair, Jim Wagner, to welcome you to our 21st meeting of the Bioethics Commission.

I want to begin by noting the presence of our designated Federal official, Bioethics Commission Executive Director, Lisa M. Lee. Lisa, please stand so we can recognize you. Lisa makes this meeting official. So thank you for doing that, along with all the other things she does to lead the Bioethics Commission. And I thank you for that, as well, Lisa.

I would also like Bioethics Commission members to introduce themselves. And I'm going to begin by asking Christine to begin.

DR. GRADY: Good morning. I'm Christine Grady from the clinical -- NIH Clinical Center Department of Bioethics.

DR. HAUSER: Hello. I'm Stephen Hauser from the University of California-San Francisco, neurology.

DR. ATKINSON: Hi. I'm Barbara Atkinson. I'm the planning dean for new School of Medicine at UNLV in Las Vegas.

DR. WAGNER: And I'm James Wagner from Emory University.

DR. MICHAEL: I'm Nelson Michael from the Walter Reed Army Institute of Research.

DR. ALLEN: Hi. I'm Anita Allen, vice provost for faculty and professor of philosophy and law here at Penn.

DR. FARAHANY: Nita Farahany from Duke University.

DR. GUTMANN: And we're expecting Dan Sulmasy to arrive shortly. He is from the University of Chicago.

So this meeting, we're going to continue our work on deliberation in bioethics education. And this, in some sense, is a capstone report of the Commission. We are focusing on the symbiotic relationship of two twin pillars of public bioethics: education on the one hand and deliberation on the other. We have not only come to our work with these two pillars -- building on these two pillars, but we've also found through our work how important it is that education support deliberation and deliberation support education. It's a virtuous circle.
We also want to focus on some of the challenges, and there are many challenges, of having better public education of bioethics and better public deliberation of bioethics in the context that we find ourselves in the 21st Century not only, but in our society. We'll hear from various speakers about some of those challenges.

But what we're really focused on in our discussions are the value of engaging the public in bioethics and how best to integrate public dialogue and deliberation into bioethics decision making and education.

Before we begin, I'd like to take a moment to explain how we will take public comments. There are comment cards. They were at registration. But all of our staff members – hold up your hands -- have comment cards. Anyone who'd like to ask a question or make a comment, just ask for a card. Write it down. We'll pass it up to the front and either Jim or I will read the question and we will address it.

If we, by any chance, don't have time for that, we will enter those questions into the public comments and we will get back to you about them. We ask that you write these down so we have them as part of the public record. And it's worked quite well. So we really do -- we like to get your comments, so please don't hesitate to do that.

And I'm going to ask Jim Wagner to say a few words before we start our first session.

DR. WAGNER: Thank you, Amy.

You know, it's been observed that there are several matters important in society that are too important to be left to professionals and I think ethics, in general, and bioethics, in particular, is one of those, and I think that's why we can be excited that this area of democratic deliberation and education as a means to engage and learn from the public may be one of the most -- the results of this may be one of the most -- among the most enduring of activities that this particular Commission contributes toward.

It's a pleasure to be convened again a 21st time with colleagues and now friends, also with the staff that so ably support what we do, the experts that are here ready to share their insights and testimony, and with representatives of the public to whom we're ultimately accountable.

Welcome to everyone. It's good to be with you.

DR. GUTMANN: Thank you, Jim.

I'd just like to ask everybody on the Commission and the audience, as well, to -- before I do something that's more solemn -- this is in the spirit of education and deliberation – just reflect in your minds, and at some point we will discuss this, the difference in reaction to the use of vaccines in our society and the use of antibiotics.

We issued a report on how to -- whether and how to test vaccines, in the case of anthrax, on children, but it's well known that vaccines in our society are underutilized when -- after they've been determined to be safe and effective. It's also well known that antibiotics are overused in our
society. And both of those examples have enormous consequences, negative consequences, for individuals and societies now and moving forward.

The underuse of vaccines costs thousands and thousands of lives. The inability to -- if you want to go back to the institutional issue, the inability to fund the testing of vaccines in a proactive way costs thousands and thousands of lives. The overuse of antibiotics also is extremely threatening to the ability to treat diseases that need antibiotics. And they're overused by -- you know, by huge proportions.

So if you think about how you can deal with that, I know of no other way of dealing with that than having more effective education and more effective deliberation about them. I just throw that out as one example that is just extremely important for the future of health and public health in our society.

And we can talk about how challenging -- and it raises -- if you think about the actual examples, it raises how challenging it is and how much fear, on the one hand, of vaccines and desire, on the other hand, of popping antibiotics, popping pills, what the consequences are. And we have to come to grips with that.

REFLECTIONS IN MEMORY OF JOHN D. ARRAS

DR. GUTMANN: Okay. Now, I'm going to turn to something that's been very much on our minds as a Commission and is a really -- a very sad moment for our Commission. And that -- but I want to move from the sadness to reflecting on our loss, and the loss is of a beloved former Commission member, Dr. John Arras, who passed away on March 9th.

We were honored to have John as a thoroughly engaged, thoughtful, intellectually provocative and endlessly good humored colleague on the Commission for the past five years. You see some pictures of John here. He enlivened our deliberations and he contributed far more than his share to our painstaking work. And I say with no qualification that never, even when John was in pain, and he was in pain through some of this time, never did he approach this work as painstaking. He approached it with the greatest verve and good humor.

He was the Porterfield Professor of Biomedical Ethics and professor of philosophy and public health sciences at the University of Virginia, where he also directed its exemplary undergraduate program in bioethics. And prior to this, he was on the faculties of the University of the Redlands, the Albert Einstein College of Medicine at Yeshiva University, and he served as a Peace Corps volunteer in Sierra Leone.

John was a consummate teacher and he was an expert, caring teacher. He won prestigious teaching awards. But as meaningful, he received innumerable tributes from former students who vividly described his generosity as a teacher, his willingness to engage with them and to treat them with the respect of equal partners in intellectual debate.
And if you knew anything about John, you knew he loved to debate, and I emphasize the love as much as the debate. So when you were in a debate with John, you enjoyed it because he enjoyed it. And you knew it wasn't about winning and losing. It was about moving forward and learning.

We have called John and he – his wife has actually said he would love this -- he was a -- he was a Socratic gadfly. He loved to test the truth. And he, himself, described his relation to teaching, and I quote, “as a kind of secular blessedness. To love what you do over a very long stretch of time, that's as good as it gets.” As a lover of learning and seeker of justice for all, John Arras was as good as we can ever hope to get. We are grieving the tremendous loss of a great teacher, scholar and member of our bioethics family. And we already greatly miss him, but we will never forget him and we will carry his spirit on.

And in that spirit, I want to ask John's close friend and colleague, Dr. Thomas Murray, to share his reflections on John and his rich contribution to the field of bioethics.

Tom, if you would come up here.

Let me just briefly introduce Tom. So, Tom, as I know him, I've known him for many, many years and respected his work as president emeritus. He is now -- of the Hastings Center -- and he is now a visiting centennial professor in medical ethics at the School of Medicine at the National University of Singapore. He served as president and CEO of the Hastings Center from 1999 until 2012. And from 1996 through 2001, very relevant to us, he served on the National Bioethics Advisory Commission and as Chair of its genetics subcommittee. Tom's research interests include ethics and genetics as well as ethical issues in sports, and he has actually written about the widest range of issues in bioethics.

Welcome, Dr. Murray.

DR. MURRAY: Thanks so much. It's an honor to be speaking before the Commission. Really, a particularly great honor because it's in memory of my very dear friend, John Arras. And I have other very dear friends who are on this Commission, so it's good to be with you this morning.

"As a philosopher, my job is to make life more difficult for people." That's John. It's a passage from his new book that's not officially in press yet, but we think will be soon, The Ways We Reason Now: Skeptical Reflections on Method and Bioethics.

This is a very serious challenge you've given me. How am I going to reconcile our memories of John? Because he could indeed make life more difficult for you. Yes, he loved to debate and sometimes that's unsettling. He could particularly make life difficult if your actions or character were defective in his eyes. If you misused power or if your ideas were sloppy, he didn't have a lot of patience for any of that.

But how do we reconcile that with the John that we loved for many reasons? His encompassing sense of humor. John wielded the skewer of humor more skillfully than any human being I've ever known. I'm sure I've been the target of it, but he wielded it most often against himself. Now, this is being broadcast, I guess, so I can't use the actual expression John used. I'll just use
the initials "SFB," and I can tell you that the last two are "for brains." You can fill in the blank. He often referred to himself in those terms and it's become a family favorite for us, too. He saw the absurd in the details of everyday life, could describe it colorfully and hilariously.

John was also devoted to his family: To Liz Emrey, his wife of 47 years, his children, Melissa and Marina. He cared deeply about teaching, as Amy has said, and about his students as individuals.

I was -- Cynthia and I made it to the memorial service at UVA. We just thought we had to do that. Whatever barriers there were, we just had to go. And I heard some absolutely wonderful reflections particularly from John's students, current and former students, including Elizabeth Fenton, who is a staff of this Commission, who -- about whom he could not say greater things. He just loved Elizabeth.

John was also a loyal and abiding friend. He was with you in your happiness, and he grieved deeply with you at your losses. And we've known both and he's been with us at all times.

Now, the only way I can convey -- at least I can convey -- who he was as I understand him is through the story of our friendship. We met under the most unpromising circumstances imaginable. We met as rivals for a national endowment for the humanities fellowship. We both really wanted it. And we met at the Ardsley Acres Motel, which was said to rent rooms by the hour. Amy has been there. Yes. Oh, yeah. Seedy would be an upgrade for the Ardsley Acres Motel. I venture that there may be no other people who 36 -- is it 37 years later -- who first met at the Ardsley Acres Motel who were still friends or even acknowledged each other’s existence that many years later. So we had -- we had -- we went from there and had a wonderful year together as we both got the fellowship at the Hastings Center, along with another dear late friend, Nancy Roden.

So I learned a lot about John. John and his family liked to travel. He told one story about a cross-country drive when his daughters were in the backseat playing with his hair. And then he gets out of the car, I guess at a gas station, and he's receiving these curious looks and he realizes that his daughters had decorated his hair liberally with barrettes. So you see he had as much or more hair -- well, more hair back then.

He loved to be -- he loved fishing for trout. He was a fly fisherman. He describes on one of these trips finding a place that was just -- the fishing was just fabulous. Until the people started running at him and screaming because he was actually fishing in a hatchery. So that would be -- that would be typical of John.

In that first year together, the Hastings Center was we felt a little bit of a stuffy place, so we created a weekly occasion. We called it "pizza night." We would just -- anybody, staff, anybody who wanted to come threw in a buck or so and we'd order some pizzas from the local pizzeria and just hang out after work and talk. And the children -- children were invited, so you have to imagine a scene of nearly complete chaos with young children running down to photocopy parts of their bodies, crawling under the tables around which the meetings would usually be held, pizza strewn across the table, loud laughter from the group there.
In walked a Canadian philosopher, whose name, blessedly, I can't remember. He had just spent something like six months or a year at either Oxford or Cambridge. And he walks into the scene of, you know, utter chaos. John doesn't miss a beat. He says, "Hi, I'm John Arras. This is Liz Emrey, the woman I live with, and these are our children, Saphron and Free." I couldn't catch my breath. But that was John, quicker than anybody I've ever known.

There's one little known fact that I will share with this group. John owes all of his success to me. There's a direct causal link. In that year together as fellows, neither of us had a sport coat. I went out and bought one at, you know, whatever the discount place was. Every time John had a job interview, he borrowed my sport coat. So there's a but-for condition. He did grow beyond that however.

Our families grew very close that year. Sometimes too close. There was a day when his daughter, Marina, and our daughter, Nikki, were in the same class at the local school. On the playground, they bumped heads. And Nikki came home and reported that Melissa had to leave school with a possible pin cushion.

Our daughter, Emily, was born that year and Liz stayed with our son, Pete, and our daughter, Nikki. When we decided Emily should be baptized, we decided to baptize also Pete and Nikki and Pete wanted John to be his godfather, which we thought was a lovely thing. John was an atheist so he found that -- you know, he demurred with great regret, but it was just hard to be a godfather at a christening if -- given his beliefs.

There was an anniversary party that our daughter, Nikki, at age 11-and-a-half, organized, a sixth anniversary party, a surprise party for Cynthia and me at our house. And she pulled it off. John and Liz she told bring a main course for 25. And sure enough, they showed up with a roast turkey and it was more than enough.

There were stories, also, that have a more direct bioethics connection. There was a time when I was in the hospital, Montefiore, where John then worked. He had given an interview to the "New York Times" where he had been challenged by the reporter who said, "You know, some people think life is a gift from God and to ever, you know, turn down that gift would be wrong." And John said, "Well, I prefer to think of God as a benevolent innkeeper and if the stay gets really unpleasant, you can check out." Right after this was published, John walked into the hospital room where I was -- I'm very proud of this -- I grabbed the pillow, I held it up in front of me and said, "Oh, no, it's Dr. Checkout." He enjoyed that.

He also sat through an informed consent procedure -- informed consent for a procedure quietly in a corner of the room. And when the young physician left -- I think she was a fellow -- he could not talk. He was laughing so hard. It had been a very nice informed consent procedure. She had gone through all the details and asked if I had any questions. He said -- he finally gasped, "They know who you are." I said, "I've never seen anything like that before."

And after the surgery, John and another friend took Cynthia -- I was not looking very good at the moment -- took her to lunch. Now, I -- you know, one could think that this was a very
inappropriate time to make a move on a man's wife, but -- John wouldn't probably do that, but then I found out just yesterday that he signed all his e-mails to Cynthia, "love and kisses." So – but it's a little late to worry about that right now.

We learned some things at – I learned some things at the UVA memorial service. Liz, his widow now, worked for many years as a minister. She's ordained in the American Baptist Church. In 2002, she founded something called the New Beginnings Christian Community. This is Liz's description of her own ministry: "To ex-offenders, people with HIV/AIDS, alcoholics, addicts, refugees and the homeless." The choir of the NBCC sang at John's memorial service. In every conversation I ever had with John, his support for Liz and her mission never wavered.

I'm guessing he has done so much that we will never know about, so many small acts of kindness, that I've gotten hints of some of them. I also suspect that the people in that community probably knew him as Pastor Liz's husband. They may have no idea that he was a distinguished professor at the University of Virginia. And by the way, his own title for his Chair was the Lay-Z-Boy reclining Chair of bioethics at the University of Virginia.

Now to John as a scholar. So in preparation for this, I read the manuscript for his forthcoming book. More in a moment. I also searched all of his publications on -- using Google Scholar. I was very excited to find a patent when I did that search on hydraulic power transmission; however, it was the wrong Arras, so we'll just have to pass over that one.

But here's what I learned about John's scholarship: He resisted chasing the shiny object. This is a problem that many of us in bioethics have had from time to time, the fascinating new technology. He never cared about that. In fact, you could describe his scholarship in three categories. One is doing things helpful to teachers and students. "Ethical Issues in Modern Medicine," his reading collection, now in at least its 8th edition, is testament to that.

The biggest category were issues that genuinely mattered to people now: HIV/AIDS, how we die, advanced directives, physician-assisted suicide, family autonomy, persistent vegetative state, treatment and nontreatment decisions for imperiled newborns, organ transplantation, how to respond to public health emergencies. How do you -- for example, do you ration a vaccine in an epidemic?

High-tech home care. John was one of the first scholars to really think about what it meant to move the hospital and its equipment from that setting to a home setting. Fair benefits in international research and rights, justice and access to healthcare. That people should have access to healthcare. He cared mostly about the things that mattered most to people here and now. And I have great respect for that.

The third category, the final category, is he was not content with just thinking about these vital and vexed issues, but John reflected critically on -- he would say skeptically -- on how we think about them.
Of all the contributions I think John has made as a scholar, I suspect the most influential and enduring will be his trenchant, insightful reflections on method and theory in bioethics, on how we do practical, moral reasoning about these very complex issues.

I think I'll end by reading one quote from the book. This is from Chapter 9. "If all interpretive activity within the field were to depend upon the selection of a single superior moral political theory, practitioners hoping for assistance in dealing with real world clinical or policy problems would have to suffer a very long wait indeed." And then he has in parentheses, "be right with you as soon as we resolve the fundamental disagreements between consequentialists and deontologists. And as anybody here with a background in philosophy knows, that ain't going to happen any time soon, if ever."

I loved John. I miss him terribly, but I will never think of him without smiling because he brought such grace and good humor into our lives. Thank you for this opportunity.

DR. GUTMANN: Thank you very much. Thank you.

And I'd just like to open it up if any Commission members would like to say anything personal or professional about John. And I see Christine nodding. So Christine.

DR. GRADY: So I can't be as eloquent as Tom or Amy, but I wanted to reflect a little bit on -- I knew John, actually, before the Commission and was privileged to be his colleague both at the Hastings and ASBH and at the NIH. But I want to talk a little bit about his role on the Commission from my perspective and especially in light of what we're going to talk about today.

So I think, as everyone knows, he was intellectually sharp and rigorous, funny and provocative and just wonderful to have as part of any discussion, but his contributions to the Commission's work were pretty enormous. I mean, I think he really -- he always found an issue which piqued his interest and he would pursue it with a wealth of knowledge, with incisiveness and insight and a twinkle in his eye. Always a twinkle in his eye. And as Amy said, he loved debate. He loved deliberation and debate.

I was reading about -- I was reading some of the articles for today and the article, the famous article, that Amy and Dennis Thompson wrote in the Hastings Center some years back on deliberative democracy talks about how important the players are, the deliberations are. And so I'm going to quote one sentence from that because I think it reminds me of John. And not that John didn't have strong opinions. He had very strong opinions, but he was open. He was open to hearing others.

So this quote is: "Diversity of voices are not only or even the most important factor in deliberative democracy. The will of the deliberators themselves is critical. They must be willing to broaden their perspective in light of what they hear in the deliberative process. They must come to the forum open to changing their own minds as well as to changing the minds of their opponents."
And I think that's the way John not only participated in our Commission deliberations, but I think that's the way he lived his life. I mean, he was -- he had strong opinions. He really wanted people to hear them, but he listened to other people's as well.

So I want to end with just one -- the last conversation that he and I had on the phone before our last meeting. There was a part of the debate about the trial design in Ebola that he and I -- or at least the staff perceived that we disagreed about. So Lizzie Fenton suggested that we -- that John and I talk by phone, so we did. And we had about a 20-minute debate about clinical trial design. And you can just imagine how that debate went. And then, at the end, there was this deep sigh that John had, you know, deep sigh. He said, "Oh, Christine, you're right, but it's so boring." And that was John, quintessential John.

DR. GUTMANN: That's a wonderful capturing. Thank you. Thank you.

Would anyone else -- Anita.

DR. ALLEN: Thank you, Amy.

This Commission has been one of the most rewarding professional experiences of my life. And John was really a very important part of the reason why I enjoyed the work of the Commission so much. He was just a man full of warmth and joy and wit. And you talk about the twinkle in the eye. Always, no matter what the conversation.

He was a real philosopher. Subtle. Thoughtful. Big ideas were his friends. If you wanted to disagree with John, you could, but you had to do so with reasons and arguments and evidence in order to be accountable and to meet his formidable challenge.

I thought of John as my bioethics buddy. We had this wonderful, like, offline relationship. You know, chitchat about our aches and pains and our joys and our sorrows. It was a wonderful relationship. Not nearly, I'm sure, as deep as the one that Tom Murray discussed that he had with John, but we were buddies.

And Tom, in fact, one of the bonding experiences that John and I had was that we planned the going-away party for you in Minneapolis. And it was fun because there I was in Philadelphia. John was in Charlottesville. The party was in Minneapolis. And there's me and John, like Mom and Dad planning a wedding, trying to choose the wine and the caterer and the hors d'oeuvres. We had loads and loads of fun and laughed and laughed and laughed. And we did that together as members of the Hastings Center Fellows Council as you were leaving your role as CEO and Executive Director of the Hastings Center. That was great. And then to have the Commission be a place where John and I worked together, as well, was fabulous.

I just want to talk about what, for me, was probably John's shining moment on the Commission. There's this moment which I thought of as a show stopper. We were talking about the horrible Guatemala STD human subject research case. And when it was John's turn to talk about what was ethically problematic with the research, he just decided to read an account of U.S. Public Health Service doctor deliberately swabbing a dying woman with STD. I think it was her eyes,
her nose, her mouth. And the way he did that, the way he just read that account and just to underscore, triple underscore, the moral wrong, make it perfectly clear to everybody something happened that shouldn't happen, it was, for me, inspiring. And it made me feel that I should be -- we should all be bolder in our willingness to call a dog a dog, as he was willing to do. And I know that the media picked up on that particular moment because it was just a very distinct, clear moment when we could all say yes, now we understand why what happened should not have happened. I thank John for being the bold and morally righteous person that he -- that he indeed was.

So just in closing, I'm going to miss John. We -- like Christine, John and I had a conversation toward the end there. Ours was about human enhancements. And we disagreed about a portion of a report that we were drafting. And John was very, you know, feisty about that. He just wasn't going to back off and I wasn't inclined to back down. And we went at it a little bit, but it was such a -- you know, he was just someone you could disagree with knowing that the friendship was intact. You know, complete integrity, complete good intentions. And I think the report was much better for the conflict that we had. So thank you, John. And I'm going to miss you.

DR. GUTMANN: Nelson.

DR. MICHAEL: So truly, we've lost a great in the field of bioethics. But I think you're hearing from everybody the same theme. We've also lost a real mensch, a wonderful person and human being.

You know, I come from a research background. I'm a research physician. I specialize in HIV, especially vaccines. I couldn't be more different than the kind of intellectual upbringing that John Arras brought, but he was so intellectually curious with all of us as commissioners. He was respectful of all physicians. Lord knows he would debate us till the ends of the Earth. But at the end of that time, he really was trying to understand how all of us could best contribute. Not just how he could contribute, but how the Commission could best contribute. That intellectual curiosity, the desire to engage in an open and transparent debate where, 20 minutes later, you could be at a Commission dinner, everything’s fine again. It was wonderful. He was so respectful of other people's input and to their strengths and their weaknesses. Just a wonderful man.

He had a rapier-like intellect. And I learned so much from him and the other members of the Commission that are truly card-carrying bioethicists. And a man who brings a joyful approach to his work, especially when he debates, reminds me of the old expression that when you're wrestling with a pig, you should remember the pig likes to wrestle. And, yeah, so at some point you just have to understand maybe it's best to get out of the grease pit.

So we lost a wonderful human being, a wonderful colleague. And we all loved him deeply. Even though for some of us it's only been a handful of years, for people like you, it's been a lifetime. But he has left an indelible mark on this Commission and on the field and his memory lives on and we respect what he's done greatly.
DR. GUTMANN: Jim.

DR. WAGNER: I was just going to tell a very, very quick story. First of all, I think if John were here, he'd be humbled by -- I know he would be humbled by all of this. On the other hand, he justifiably should take pride in how he elevated the discourse in this group and the quality of the work. The story is that it was a Christmas Eve, and I wasn't going to tell this and so I didn't go back and figure out which one it was. It has to be five years ago, maybe, four years ago. He was hospitalized, actually, for an infection. Do you remember that?

DR. GUTMANN: Yes.

DR. WAGNER: And I called him on that Christmas Eve and we spoke a long time. He sounded wonderful and himself. And he even explained how the pain was such that to move from the bed to the toilet, he had to crawl on hands and knees to do this. Lots of detail. But a great spirit.

At our next meeting, I came to him and said how wonderful it was to see him and how I hoped he had -- had recovered fully. Made some reference to the phone call. And he had absolutely no recollection that we had had this phone call. He said -- he said something complimentary about the painkillers he was on, but he said nothing -- nothing about a recollection of the phone call.

And the reason I bring it after -- Tom, after hearing your comments, the reason I tell this story is that it was something -- you know, I had called out of caring and respect for him. It probably will do us well, out of caring and respect for him even though he will not be present as he was actually not present on that Christmas Eve, but it would be a service of caring and respect for him to continue to hold high our standards of discourse and the quality of the work that he helped us to set.

DR. GUTMANN: Here, here.

Steve.

DR. HAUSER: Thank you, Amy.

Well, I think it's evident from Tom and others' comments that, without question, John was the most politically incorrect member of this Commission. As someone, Nelson, like you, who got to know John through the Commission, he was great company. It was always a joy to spend time with him. And I really got to interact deeply with John, Anita, as you described during that Guatemala and the subsequent human studies protection reports. That was the second and third report of our Commission in '11.

And John and I worked together on the professional standards and trial design part of the human studies report. Here, the neophyte in bioethics working with the master. And it was right before Thanksgiving. John took the burden on himself, recognizing that he would be the driver of a high quality report.
And it was so evident then to me that he had a deep sense of what is right, but also compassion, sympathy, forgiveness for those who did wrong. But his forgiveness and compassion had limits. And as with your analogy, I remember when we were discussing the historically mitigating arguments that might have been in place for Guatemala. And we came across some information where John Cutler had urged his superiors to extend the funding from the PHS for the Guatemala research citing that we had a responsibility to the patients to make this happen. And John wrote to all of us. And I saved that quote. He wrote, "Wow, this is right up there with the Tuskegee docs who claimed that they had an ethical duty to their now sick or dead patients to finish the work in order to justify their sacrifices." That was very, I think, meaningful for me.

As you all know, I live in the world of medicine. I think about the body and how it works all the time. And yet, somehow recognizing the passage of time is not easier by that because of that occupation. We wear down. John was young to me. We knew he had health issues, but they seemed to be under control. And his premature death reminds me of the importance of living every day to the fullest and also the importance of devoting our time to principles and causes that are worth fighting for. And John certainly did that.

DR. GUTMANN: Barbara.

DR. ATKINSON: This is a hard group to follow because I think we have captured very much of John. I sort of see him sitting at one of these end places and still here. And it's that smile. I mean, that -- it's the twinkle that goes with it, but the smile that was most important, I think, to him as a person and to us. He really kept us on track morally and I think you've heard that from everybody.

I was thinking back to the very beginning of the Commission, and he didn't start right exactly at the beginning. It took a little longer to get him through all of the things. But I remember as we were talking about what kinds of topics we wanted to discuss, he wanted to talk about the underserved. You talked about his wife. He kept bringing that up every single time we talked about what the next topic ought to be. And he really cared about access to care. He cared about taking care of people that couldn't take care of themselves. That really was very, very vital to him.

The skeptical reflections, I think, also sums him up, I mean. And the compromise. It's all part of him and it was part of who he was. And I think we've all taken that piece away and I think it's really a tribute to him and all he did for this Commission and how we became friends very quickly, I think, especially with him and each of us separately. So I really appreciate it and miss him.

DR. GUTMANN: Thank you, Barbara.

Nita.

DR. FARAHANY: The news of – the news of his passing came right as I was in the throes of having a newborn at home and it caused me to reflect a lot about the beginning of life and the end of life. And it was difficult with so many emotions at the time to be able to even fully
process that we had lost John. And hearing everybody's remarks today, you know, it brings all of those emotions to the forefront.

He was extraordinarily encouraging to me. I met him only when the Commission started. But from the beginning, he treated me as a friend, a colleague and a mentor. He would often give me encouraging remarks at Commission meetings. You know, "that was a great point, a great thought, develop that further, that's a wonderful way to think about it." He would send me e-mails of encouragement if I would weigh in on issues at meetings or elsewhere. He, any time there was a media mention, would send me a personal note.

And that kind of mentorship, that kind of friendship, that kind of generosity is rare. And what I think is so extraordinary about how much effort he made with me and with others on the Commission and in his life is the fact that no matter what was going on with him, no matter what struggles he was facing with his health or anything else in life, he was always there, he was always present, he was always willing to give more of himself. I think I'm better as a scholar, as a person in bioethics, because of him. I think the Commission's work and all of our lives are extraordinarily better.

Just, you know, thinking about our most recent reports on the BRAIN Initiative and neuroethics, he really pushed us to make particularly the second report so much better. In fact, to the point where I think we really went back to the drawing board and started over because of John. And the quality of the work is so much better. The report, the recommendations, the deliberations were so much better.

And what I found notable about that is we're here at meeting 21. It's a lot of time and dedication over the years. And sometimes I think each of our own efforts has been at a peak or been at a trough, but never John. John was always critical of the reports. He was always careful. He always brought his best thoughts and best presence. And so for that, I'll always be grateful and I will remember him fondly.

I notice that we all smile much more than when you normally are thinking of someone that you've lost and that's because he brought so much joy to all of our lives. I'll always think of him with his hat. Because every time I saw it, it just made me smile. And his fun hair. Those -- and his smile will just keep me smiling forever. So I'll miss him. My life is so much better for having him in it.

DR. GUTMANN: Thank you.

Our life as a Bioethics Commission is so much better for having John Arras in it. And we will continue in the spirit that brings passion to our work, the lessons we learned, bring passion to our work, respect every individual on Earth not just in word but in deed. And lightness of being is fully compatible with death of thinking.

And thank you, Tom Murray, for being our friend and his friend and for being with us today.

DR. MURRAY: Thank you so much, Amy.
So I've learned something this morning as each of you have shared your reflections about John. John was a profoundly deeply decent human being. He had no patience with posers, frauds, users or anyone that he thought was not a good human being. Your reflections tell me that he must have loved all of you, and that speaks well for this whole Commission.

So in the spirit of trying to channel John, just wish you all the very best, all the commissioners, all the staff who have been so kind, the very best in your continued work and in your lives and thank you for this privilege.

DR. GUTMANN: Thank you.

DR. WAGNER: Thank you. And thanks to all of you. And it is in that spirit and with that challenge that we should move ahead.

DR. GUTMANN: Yes.