TRANSCRIPT

ELSI Friday Forum: Remembering 9/11: Ethical, Legal, and Social Issues with Using DNA for Disaster Victim Identification

Friday, September 10, 9am PT/12pm ET
Speakers: Amy Mundorff and Jay Aronson
Moderator: Jennifer Wagner
CERA Moderator: Sandra Lee

SANDRA LEE: Good morning! Afternoon, or evening, depending on which part of the world you are Zooming into today. I'm Sandra Lee from the Division of Ethics at Columbia University, and I am delighted to welcome you to our first ELSI Friday Forum for the 21-22 academic year.

Today, our panel presentation is on Remembering 9/11: Ethical, Legal and Social issues with Using DNA for Disaster Victim Identification. In light of the anniversary tomorrow, today's discussion provides an opportunity for reflection, and I'm grateful for our speakers who will be leading this important discussion.

For those of you who are joining us for the first time, ELSI Friday Forum is hosted by the Center for ELSI Resources and Analysis, or CERA. It is held on the second Friday of every month for one hour starting at 12:00 noon eastern time. Following today's session, we invite you to a separate Zoom room for a half hour of continued discussion. The link will be posted in the chat box at the end of this session.

The CERA is a multidisciplinary, multi-institutional center that aims to foster a community for scientists, scholars, policy-makers, journalists, members of the public, and all who are interested in research on the Ethical, Legal and Social Implications of Genomic Research, otherwise known as ELSI. CERA is funded by the National Human Genome Research Institute at NIH and is managed by teams at Stanford and Columbia Universities in partnership with the Hastings Center and Harvard University.

CERA's online platform ELSIhub.org offers a number of resources including the recording and transcript of this forum, associated reference material, as well as an ELSI literature database, research instrument repository, scholar directory, news and events and many more resources. I encourage you to go to the website to sign up for newsletters and other events like this one at ELSIhub.org and get daily updates and news on Twitter @elsihub.

We would like to announce the publication of a new ELSIhub Collection. Please use the link in the chat to access Ethical, Legal and Social Implications of DNA-based Technologies for Disaster Victim Identification. This collection of scholarly works has been curated by Sara Katsanis and Diana Madden and explores ethical considerations in the use of DNA-based forensic technologies in humanitarian efforts and the lessons offered by the mass fatality events of September 11, 2001.

Now for just a few housekeeping tips. If you wish to use closed captioning, please turn on the CC button at the bottom of your screen. We encourage an active exchange of ideas between our panelists and all of you. The panelists' presentations will be very brief, so we hope to use a significant portion of our time in discussion. Please use your Q&A button, which you will find at the bottom of your screen, to ask the panelists questions. You can register your enthusiasm for a question and elevate it up the list by using the upvote button in the Q&A box.

We will be posting links to resources referenced in today's discussion in the chat. The resources in the chat will also be e-mailed to registrants after the forum.

If you have questions at any time, please e-mail info@ELSIhub.org.

Now it is my absolute pleasure to introduce Jenn Wagner, who is an assistant professor of law, policy, and engineering at Penn State University. Prior to assuming her position at Penn State, Dr. Wagner conducted ELSI research at Duke University's Institute for Genome Sciences & Policy, the University of Pennsylvania's Center for the Integration of Genetic Healthcare Technologies, and Geisinger's Center for Translational Bioethics & Health Care Policy. She is former chair of the American society of human genetics Social Issues Committee, former cochair of the Ethics Committee for the American Association of Biological Anthropologists, current member of the Pennsylvania Bar Association's Cybersecurity & Data Privacy Committee, and a member of the Scientific Advisory Board for SAGE Bionetworks. Dr. Wagner's research has focused on the international human right to science, including matters of discrimination, privacy, and equity with genetic and genomic and mobile health technologies. She is on Twitter @DNAlawyer.

Before I turn it over to Dr. Wagner, I'd like our audience to know that there may be images that will be shared as part of the presentations that could be potentially disturbing. We have asked presenters to give a warning in these instances.

And with that, I will now turn the moderation over to Jenn!

JENN WAGNER: Thank you. It's really an honor to be hosting the discussion today on Remembering 9/11: Ethical, Legal and Social issues with Using DNA for Disaster Victim Identification. As we know, on September 11, 2001, terrorists hijacked four planes and used them to attack the Pentagon, the World Trade Center, and an unidentified target with a plane that ultimately crashed in Pennsylvania.

When I realized this year would mark 20 years since that fateful day, I thought it would be appropriate for an ELSI Friday Forum to commemorate this event. Lives of so many were irrevocably altered that day. There were 753 people killed at the World Trade Center. The 9/11 Memorial and Museum website notes, and I quote here: "The legacies of the attacks continue to affect foreign policy, national security, civil discourse, airline security, building safety, the law, and countless individual lives." Close quote.

Another aspect relevant for us, the ELSI community, is that the 9/11 attacks also left a legacy affecting the use of DNA in disaster victim identification.

Now, before we hear from our speakers and then engage in the panel discussion, I would ask that you all join me, wherever you are, in a moment of silence to remember and honor those lost on September 11th.

(silence)

The identification of victims of the 9/11 attacks has been described as the greatest forensic challenge ever undertaken in this country. This work to identify victims is ongoing! Barbara Sampson, Chief Medical Examiner for New York City, reportedly said, quote, "20 years ago, we made a promise of the families of the World Trade Center victims to do whatever it takes, for as long as it takes, to identify their loved ones," close quote. And she called this task a sacred obligation. The New York Times and other media outlets reported just this week that two more individuals have been identified with DNA, just days ago, bringing the total number of victims identified to 1,647 individuals. However, 40% of the deaths at ground zero remain unidentified, and thousands of bone fragments remain unidentified. While some people have remarked that it's impossible to identify everyone, that is precisely what the officials are attempting to do. Many individuals -- about 730 -- were identified by May 2002 without genetic technologies! And while genetic technologies are not the ONLY way to identify disaster victims, in some instances genetic technologies might offer one last hope.

Over the past two decades, genetic technologies have improved quite dramatically, and this year the New York City Medical Examiner's Office was approved to use next-generation sequencing. Mark Desire, manager of the New York City DNA identification team, has called this, quote, a game-changer.

Today, I'm honored to be joined by Dr. Amy Mundorff and Dr. Jay Aronson to discuss the ethical, legal, and social issues of using DNA for disaster victim identification.

Amy Mundorff is an associate professor in the department of anthropology at the University of Tennessee. She is a biological anthropologist specializing in forensic anthropology and disaster victim identification management. Her research is directly informed by her experience as the forensic anthropologist for the Office of Chief Medical Examiner, the City of New York, 1999 to 2004, where she analyzed forensic cases and was part of the World Trade Center disaster mortuary operations. Mundorff now conducts research that is practical in nature, focusing on managerial aspects of disaster victim identification, developing new techniques to locate clandestine burials, and identifying human identification methods.

We'll then hear from Dr. Jay Aronson. Dr. Aronson is the founder and the director of the Center for Human Rights Science at Carnegie Mellon University. He's also a professor of science, technology, and society in the history department. Aronson's research and teaching focus on the interactions of science, technology, law, media, and human rights in a variety of contexts. He is currently writing a book with Dr. Roger Mitchell, Jr., the former Chief Medical Examiner and Deputy Mayor of Washington, D.C., now a professor at Howard University's College of Medicine, that addresses significant shortcomings in the way police killings and deaths in custody are recorded and investigated in the United States. He is also engaged in a long-term project on the use of video evidence in human rights investigations. Previously, Dr. Aronson spent nearly a decade examining the ethical, political, and social dimensions of

post-conflict and post-disaster identification of the missing and disappeared, including after 9/11, in collaboration with a team of anthropologists, bio-ethicists, and forensic scientists he assembled. He's also been involved in a variety of projects with colleagues from statistics, political science, and conflict monitoring community to improve the quality of civilian casualty recording and estimation in times of con -- in times of conflict, excuse me.

And with that! It is my pleasure to introduce Dr. Amy Mundorff, who will be giving the first remarks.

AMY MUNDORFF: Thank you, Jenn. And thank you, everyone, for attending, and for the invitation to be here today. I'm just going to share my screen. Okay. Everybody see that okay? Okay.

I, I appreciate the invitation. I was honored to be invited, and to be part of the ELSI Friday Forum. I was asked to give a little presentation in the beginning kind of... setting the scene and the background. And I thought, hmm, I've given that presentation before, and it was about two hours. So, I won't -- you know? (chuckles) I'm going to try to talk about the aspects of what happened on 9/11 that I think are very pertinent to the DNA work that we're focusing on today. But I know that there are a lot of people alive right now who were not even born for the events of September 11. So I'm just gonna give a brief overview of what happened.

On that morning -- and it was a beautiful morning -- the north tower was struck between the 94th and the 98th floor at 8:46 in the morning. The south tower was struck between the 78th and the 84th floor about 15 minutes later. Because the south tower was struck lower, that was one of the contributing reasons to why the tower fell earlier. That tower fell after 55 minutes. About a half hour later, the north tower fell.

And I think it's important to reflect on the amazing, unprecedented evacuation that the Port Authority police coordinated that day. Because there were tens of thousands of people in those buildings. And most of the people that died were at or above the level of impact. Everybody else was safely evacuated.

So I have this image here because I know a lot of people have seen this one, the one with the building imploding and those little sticks flying out of the building. But not a lot of people know that those little sticks are 5,000-pound steel beams. Each one of those is a 5,000-pound steel beam.

And the site itself was a pile of these steel beams, intermixed with the human remains. And so, the destruction, the level of destruction, was just really beyond what anyone could get their mind around at the time.

Ground zero itself was not just the collapse of the north and south tower. There were actually five buildings that were destroyed that day, and two more that were heavily damaged. The site itself encompassed 16 acres and was excavated down 40 feet below the ground surface. And also piled about nearly 100 feet above the ground surface. So it was a very, very complicated and dangerous site, and it was massive.

And if you look at the dust cloud here in this image on the upper right, in that cloud, as the buildings fell, were small fragments of human remains that were then distributed blocks and blocks and blocks away throughout the city. On top of nearby buildings, et cetera.

So, it was even -- the site itself was even beyond those 16 acres of ground zero.

It's hard to sum up the challenges we had. There -- eventually, over 22,000 fragments of human remains recovered. There was an unknown number and composition of victims. And this, in the disaster world, is described as an "open" population. So if you think about a plane crash, you have a manifest. You know who's missing! You can use that manifest to immediately start accessing the victims' information, antemortem information. But we didn't know who was even there that day. There were international victims.

And then there was an incredible emotional impact on the city, and the nation, and the workers! Who were doing this work. And we had no disaster DNA plan. We did have a disaster plan, at the medical examiner's office. But it was geared towards a disaster about the size of a plane crash. We had no concept of something of this magnitude.

When you think about DNA work, it's important to remember the state of DNA in 2001. We did not have in-house capacity for thousands of samples. At the time, most DNA was what we would describe as boutique work: Each case was done by hand. And it was incredibly labor-intensive. There was no matching statistical software available for this number of samples, and for a population like this. We didn't have IT capability. We didn't have tracking for samples. And we didn't have a family coordination plan on how to collect family DNA, or... to collect their antemortem DNA to make these identifications.

The International Commission on Missing Persons, which were conducting DNA in Bosnia and Yugoslavia, had still not made a DNA ID yet. So, we had nothing to go on.

And then down at ground zero, there were other problems that complicated not just the recovery efforts but the condition of the remains that we received that we would then have to identify. So the site itself was very dangerous. There was a three-week search and recovery operation for living individuals. There were complicating recovery factors. And what I mean by that is that, if you think back to those 5,000-pound steel beams, the site itself had to be deconstructed. It couldn't -- it wasn't like an archaeological excavation, where you could just dig. And it wasn't like a plane crash, where you were gonna collect remains on the surface. The site itself had to be deconstructed in order to access the remains.

There -- most of the remains were fragmented and compromised. And when I say "compromised," I mean things like decomposed, because the excavations took eight months, or commingled, or... affected by the recovery operations. Like the grapplers that needed to do the deconstruction.

And then we needed to develop a missing person list. And while this sounds like something simple, it was probably the most complicated aspect of the entire operation.

And you can see here on September 11th, there were actually about 20,000 people reported missing. In two months, that number went down to 7,000. And that's because the majority of the difference were actually alive. They weren't missing. In the next two months,

the number dropped again in half. And that's because people had been reported missing more than once.

It was a little bit slower after that to get to the final number. And the number I have up here is 2,749, because that's the reported missing from 9/11. The number is different in the public now, because first responders have since died, and they're included in the death toll. These are the people that were missing because of the actual events of 9/11 that day.

And those last cases were cases of fraud. And you can see that that final number didn't happen until 2004. That's how complicated it was to sort out each and every case.

So I just have some images here so people can understand what I was trying to say. You can see the site down here, how complicated it was, in terms of being dangerous for the people doing the recoveries. The fires that burned at the site burned for about three months. So there were three hotspots that burned at about 2,000 degrees. If you think about a commercial cremation, which is at 800 degrees for less than 8 hours... we're talking any human remains near those hotspots were completely incinerated. For those of you who know about DNA, warm water is not a friend to DNA. And in order to make the site safe enough for the first responders to work on it, they were watering the site with water from the east river, which is brackish. So you're introducing salty water to heat. And that will strip the muscle away from bone, exposing the bone to other contaminants and causing further DNA contamination and destruction.

And then interestingly, as I mentioned those steel beams, not only did we have to deconstruct the site, but first they had to bring in welders from all over the U.S. Because there weren't enough welders in New York City to even take these beams apart.

And then it's downtown Manhattan! There is no room to do any work outside of those 16 acres. And the streets are too full. So the remains and the debris were taken down and loaded onto these barges. And the barges followed the old barge route to the Staten Island landfill, which was a capped, closed landfill.

At the landfill operation, dirt and debris were initially sorted through by hand to separate them, and then all of the loose material was sent to these gigantic screens and sifters, which then put out the -- any item that came through the sifter onto a conveyor belt, which was monitored 24 hours a day, 7 days a week, by members of service, where they would remove what they thought might be human remains. Which were then sent to the medical examiner's office for identification.

Simultaneously, we had the Family Assistance Center, which was not initially run by the medical examiner's office; it was run by the police department. This is where families filled out their comprehensive questionnaire to report someone missing. Their hair color, their eye color, how tall they were. All the information that might contribute to an identification. They were given instructions for DNA submissions. Because we'd used family members as exemplars to make a DNA ID. They were told how to fill out an affidavit in order to receive a death certificate without human remains! Which was something our office put together in about three weeks. Because we KNEW there were people who either wouldn't be identified or family members who didn't want to wait for human remains. And there were grief counselors.

And if you think about working with a family member in the initial state of grieving, filling out these questionnaires, asking for DNA -- this was done by the police department. And police are very well trained in interrogations. But this is not an interrogation. So the questioning was very different. And there was a breakdown of information that happened here that contributed toward some of the other challenges in making DNA identifications.

For example, they were... not comfortable pushing, in terms of asking questions. So when someone said, "Is the victim -- what's your relation to the victim?" "Mother." They wrote down "mother." We didn't know if the victim was their mother, or they were the victim's mother!

Our mandate at the office was different than what we normally dealt with. We normally do cause and manner of death. But here, our primary mandate was identification only. We had an influx of people helping, so we had to become managers ourselves. Our physical layout couldn't handle... couldn't handle all of this work, so we had to actually create a new area to process these remains. We didn't have enough refrigeration space.

This is just an image of Memorial Park. So we brought in 16 tractor trailers, which is where the remains were kept until they were identified.

Another challenge that we had not experienced before was what happens when an entire sample is submitted for DNA? How do you track that? We came up with a sticker, a simple sticker that said "entire sample for DNA."

We had new technology coming online that had never been used before.

We had questions on preservation and holding onto samples in perpetuity.

We had families calling in after about a year that didn't have identifications! So we set up a hotline! So they could find out if they even had an exemplar that worked on file. We could get more detailed worksheets.

As I mentioned earlier, we established the DX, which is a death certificate without remains.

And then, we needed to establish a release authorization. Because if you think about the process, this was months and years' worth of work. And because of the level of fragmentation, people were receiving identifications weeks, months, years apart. And we were re-traumatizing families by calling them every time.

So we came up with, working with families, an authorization to give them choices. And I think... this was -- (squeaking in background) I think this was probably the result of our weekly meetings with families. Which I would say is probably the most important thing we did, in terms of not doing a top-down approach but including families in the decision-making process.

And I will turn it over to Jay from here.

JAY D. ARONSON: Great. Thank you so much, Amy. And thank you to Jenn, and all of the organizers. And Columbia for hosting us.

I... I think that was a great introduction to what I wanna talk about. Although I'm gonna -- (chuckles) Go to a totally different place. (scraping across mic) Than Amy did, and sort of talk about the broader context in which all of this was taking place.

As Jenn mentioned, the work that I'm going to talk to you about today emerged from a larger project -- (scraping on mic) On the ethical, legal, and political dimensions of the identification of the missing after conflict and disaster. And the core of that project was an effort to understand what happens when large people -- large numbers of people go missing after conflict or disaster, and what the impact of identifying them or not identifying them is on social reconstruction and long-term stability.

And so, for most of the cases that I was focusing on, or that my colleagues and partners were focusing on, a lack of resources or political will, often coupled with a desire to cover up crimes or negligence by those in power, hampered the recovery identification and memorialization process. And when I first began to focus on the World Trade Center effort, I saw it as a real counterpoint about what could happen when significant resources are marshalled for the recovery and identification of the missing. But the story turned out to be not that simple at all. If the story was just about the science and technology and the extraordinary work that Amy and her colleagues did, then, you know, there wouldn't be that much else to say! But the reality is that all of that work took place within a much broader social, political, and economic context.

And so, what I found was that contradictory motives, contradictory imperatives, different ideologies, and, at the end of the day, outsized egos, meant that the process was anything but smooth. And that despite the incredible identification work done, there was still a great deal of pain caused to survivors and families of victims. And that there were many points at which the entire recovery, identification, and memorialization process became an embarrassment to the city, to the citizens of New York, to the region, and to the country.

And so, what I wanna do today is tell you a little bit about two things that I think are relevant that aren't typically discussed in the context of bio-ethics or when we're talking about science and technology of identification. And the first one, I just wanted to give you a really quick sense of the debates that took place around the ownership and control of the remains of 9/11 victims. (scraping over mic) And then end with a question about what happened in the name of these victims. So, we identified these victims, and their identities became enrolled in much broader affairs that most of the families probably didn't wanna be associated with.

So, I just wanted to mention that the work is funded by an R01 grant from NIH. And no conflicts. It doesn't seem like we needed to do this here, but I always do it.

I also wanted to mention that there are a couple of potentially disturbing images in the talk. They -- you've seen everything that I'm going to show you with respect to the World Trade Center site. But there is a slide, the second to last slide contains an image from a funeral for victims of a 2006 drone strike in Pakistan. (scraping on mic) So, just to give you a heads up on that.

So. I don't need to do any of this, which I normally do.

I just wanted to reiterate that it very quickly became clear that searching for the -- searching through the debris for remains at the Trade Center site would be incredibly challenging, for all of the reasons that Amy laid out. And the city decided that Fresh Kills Landfill, that this landfill -- former landfill that was being closed, and in the process of actually being turned into public space, would be an ideal place to do the sorting of the material and the search for smaller remains that weren't obvious when they, when the site was being deconstructed.

And this decision was no doubt a boon to efficiency. But there were many family members who were upset about it! Despite the fact that the, that this landfill was decommissioned and that it was going to be a public park of some sort, several of them found the idea that their loved ones being -- that the remains of their loved ones being found at this site was too much for them to bear, and it led them into the world of activism for the first time.

A group calling itself World Trade Center Families for a Proper Burial actually sued the city to demand that the finest debris that was being stored at Fresh Kills, after it was separated from larger debris, which almost certainly contained unidentifiable human remains that had either been burned or damaged beyond recognition or didn't meet the quarter-inch threshold for forensic investigation be returned to the World Trade Center site or a more dignified location. So the idea was that there was this material that the medical examiners couldn't really do anything with, because it was either pulverized and damaged or it was smaller than the quarter-inch threshold. And these families did not want this material stored at Fresh Kills. They wanted it removed. They argued that the city was violating the sanctity of human remains by processing these remains at a former landfill and denying the property and religious rights of relatives of victims. They were, in essence, making a collective property claim over remains that could not be individually identified and returned to particular families.

City officials and the legal system obviously saw this situation differently. The special court that would be set up by the Federal Government to hear all 9/11-related claims concluded that, in accordance with New York State law, families only had a legitimate claim over remains that could be definitively tied to their particular loved one through a valid identification method. In other words, the law said that if you can't prove that this particular remain is... yours, is the remain of your loved one, you have no say over what happens to it.

The judge determined that this fine material -- it was called "fine," literally because it was fine, because it fit through a quarter-inch sieve -- was merely an undifferentiated, unidentifiable mass of dirt, which meant that the families had no collective claim to determine its fate. The families actually appealed the ruling and eventually took it to the U.S. Supreme Court, but neither court found any error with the ruling.

The cleanup effort was completed in spring of 2002, which was well ahead of schedule. And Amy showed you how the number of victims went down over time. The final number that is most typically expressed today is 27 -- 2,753, plus 9 terrorists. There were, in the early stages, around 293 complete bodies that were recovered, along with around 22,000 fragments. Sometimes these fragments were things like limbs; there were cases where torsos

were recovered. But as often, or more often, the remains that were recovered were unrecognizable bits of flesh or bone.

And so you can see in this image -- this is the fire department's mapping, supposed mapping of where they recovered remains during the recovery effort. There are issues with this; I don't have time to get into them. But this map is, ah... is most likely not very accurate. I'll just say that.

A defining moment in the recovery effort occurred shortly after the attacks, when Chief Medical Examiner Charles Hirsch promised families that he and his colleagues, of whom Amy was one at the time, would do more than just confirm the identity of the individuals who were killed, which was the standard operating procedure after a mass fatality event with a closed manifest. So remember: When there's a plane crash, you typically know who's in that crash. But this was an open, a case where there were no lists of people who had been killed. And so, the -- this was the -- I mean, on the one hand, it was a kind of very... ah, it was almost a crazy thing to say? But on the other hand, it was the logical thing to say! Because Hirsch had no idea how many people were involved, had no idea who they were, had no idea if they would ever have a definitive list of people that they could match to the remains. And so, this was the most sensible thing for him to do at the time. And he said we will -- (flipping papers) Seek to identify, or to provide an identity, for every remain that was larger than a thumbnail, and we will continue to do this in perpetuity as new techniques and methods emerge.

I, ah, I normally talk about the importance of DNA at this point. I think that, from what Amy told you, I think it's pretty obvious. I go into pretty significant detail about just the incredible work that needed to be done to extract DNA from these very badly damaged and degraded remains. The incredible statistical work, managerial work, and just pure sleuthing that needed to be done to match the DNA profiles from remains -- which were often only partial profiles -- with the reference profiles that were given by families. And in many cases, it was difficult to understand who the family members actually were, because of the way the initial information was collected.

And I just show, like, these diagrams that show how information flowed and how remains flowed, and how various outside laboratories were enrolled in this massive project that had really never been carried out before. Nothing like it had ever been carried out before. Except in Bosnia, where the process was just being built around the same time.

Oh, I also -- I mean, I wanted to mention that I'm certainly happy to talk about things like incidental findings, the challenges of gathering and maintaining large reference sample databases, and... all sorts of more traditional or standard bio-ethics issues. But I just wanted to highlight some things that maybe, that people in the audience hadn't really thought about today. So if you do have those questions, I'm happy to take those questions as well.

So, once engaged, the families that contested the storage of remains at Fresh Kills would continue to challenge decisions being made by New York City officials around the quality of the recovery efforts at the site, memorialization efforts, and the storage of unclaimed and unidentified remains in perpetuity. The one thing that almost every family member told me when I spoke to them was how grateful they were for the work of the

medical examiner and his staff. And pretty much everything else, they complained about. There were obviously families that didn't complain, but there were many that did.

Commentators and city officials often claimed that these active, politically active families, were behaving irrationally or out of grief. And one of the core aspects of my project was to try and understand their perspective. Because they did things that didn't really make sense to me. They said things that I thought were factually wrong. But I really wanted to understand what was going on.

And I argue in my book that it's crucial to understand the broader context in which the identification effort and their activism was taking place. Specifically, the very public controversies that surrounded the redevelopment of the site, the scope and design of the memorial and museum that would be built, who would pay for the project, and... just the kind of political infighting that took place when people like George Pataki and Rudy Giuliani and Michael Bloomberg and others were involved. The project ran way over budget and ultimately had to be rethought to bring it back within a reasonable budget.

The only thing I wanted to end on -- because I think I'm running out of time already -- is that many families were upset about the decision to place the medical examiner's repository for unclaimed and unidentified remains at bedrock within the museum environment. They argued that it would make their loved ones an element of the museum, and therefore a tourist attraction. It was, in their view, a violation of their ownership and their loved one -- of their loved one's remains and legacies.

This, ah, this repository was necessary because of the promise that Charles Hirsch made that there would never be a moment where these remains would be considered unidentifiable and buried in a collective grave, as was traditional in many other -- not in all other cases, but in many other cases. That there needed to be a scientific, accessible place where remains would be stored, when families decided they did not want to get any more calls or until a new technology would be developed that would allow the OCME to actually do what they did over the last two weeks, which is identify more victims of the attacks.

I can, you know, discuss that more. But the final thing that I wanted to address was that... well. In addition to the idea that these remains can't be part of the past, or they can't be officially laid to rest? And so, we're kind of stuck in this situation where we have an ongoing investigation.

By way of conclusion, I want to address one thing that was often asked when I was writing the book, and one thing that I often thought about and talked about with people, was whether the effort was worth it. Other than the undocumented migrants who were never officially reported missing, it's unlikely that any of the victims of the World Trade Center attacks suffered an anonymous death. Most victims are named on the parapets around the void and pictured in the museum. And even after a few years, I don't think there were many families that had not received remains that believed their loved ones were anything but dead.

Yet the thought of unidentified remains is unnerving, especially for a society that wants to believe it has the technical capacity to provide some measure of certainty in an uncertain world. This sentiment seems particularly important in the aftermath of an attack that targeted

ordinary people from all walks of life, religions, and natural origins, and killed them as representatives of a monolithic United States.

It's ironic, then, that the politicalization of the victims of the World Trade Center made it palatable for the U.S. government to participate in what until recently seemed a very palatable war against Pakistan, Libya, Syria, and elsewhere.

One final uncomfortable question that I really think we need to ask is whether the same kind of scientific effort will ever been undertaken to identify these victims. The answer highlights the incredibly political nature of the deployment of genetic technologies on behalf of the victims of mass atrocity.

I obviously have a lot more that I would love to say, but I think I will end there so that we can make sure there is time for conversation. So, thank you very much. (scraping papers against mic)

JENN WAGNER: Thank you, Amy and Jay. I know you could speak for quite some time on this topic. And I believe we already are having some questions come in from the audience. Anyone, if you have questions, please do use that Q&A feature. And we'll turn our attention to some of those questions.

I'm actually gonna take the opportunity to ask one of my own before we turn to the first audience question. Amy, you mentioned in your remarks, you know, some of the challenges with communication. And you know, you mentioned even in the intake process that it was difficult, with the police department managing the questioning, not maybe getting the information that you would need to do the work as efficiently as we might do it if we were doing it today. And also, you know, we've already remarked that this DNA-based identification process is now 20 years ongoing, and that managing expectations over such a long period of time can be quite challenging.

I'm wondering if you could talk to us about your observations or insights regarding managing expectations of family members, of survivors, during processes like this. You know, I venture to, you know, think that family members don't always agree, and that there might be different perspectives over getting every update you might have, every fragment that might be discovered, versus "I only wanna know major developments, or something that's definitive," or maybe to bring closure.

And so I'm wondering if you could talk about some of those challenges that relate to the DNA-based identification. Because I know we have those similar related challenges with communication and managing expectations when we're thinking about DNA results in a clinical context, or in research settings. (scraping over mic)

AMY MUNDORFF: Mm-hmm. Yeah, that's a really good question, thank you. I think that... reflecting on this years later, I understand now some of what we did a little bit better. And in speaking to a colleague who worked extensively in Bosnia, one of the things that I realized was that we were working with families who were in a very heightened state of grief and trauma. So -- which is a little bit different if you think of post-conflict, where sometimes years have passed before the identifications start. When we met with families early on to

explain the process and have them sign forms and stuff -- such as, do you want to be notified every time, or just once, or just at the end -- many times, they didn't even remember signing that form.

And I think in terms of managing expectations, what we learned from that... was what we think families can absorb? They may not always be able to, in that state of grief.

And so, we learned... how to also work with family representatives. How to disseminate information that maybe a year later people, family members weren't quite sure what was going on.

In terms of managing expectations, and in terms of communication, think about Thanksgiving at your own house! With one family! You know. We were, we're talking thousands of families! And I feel, personally, lucky that this happened in New York, and not in a state where certain... certain versions of next of kin would be challenged! So, for example, in New York City, Dr. Hirsch decided early on to recognize same-sex marriage, even though it wasn't legal at the time. Because we had victims from, from other countries, where same-sex marriage was legal! And therefore, their spouse was the next of kin! We had individuals from other countries that had multiple spouses!

And so, we had to not just manage family expectations, but also our own! What is next of kin? WHO is next of kin? And when there's a process of IDs that last years, the victim's 15-year-old child three years later is now next of kin, and might have different ideas of whether they want the remains than the parents did!

So, there were many challenges --

JENN WAGNER: Yeah.

AMY MUNDORFF: -- that we just couldn't conceive of at the time.

JENN WAGNER: And I guess a follow-up question that I believe some of the members of our audience have brought up, too, is how did those challenges that you encountered of not having a roadmap, so to speak, for dealing with these communication issues, how did this particular event and DNA identification effort influence future -- how we would respond to future incidents? Are there now guides in... in existence? Or, emerging better practices?

AMY MUNDORFF: Y- -- yes and no. (chuckles) Um. You know, it -- I think we were able to show things that worked and things that didn't. And we were very proactive in terms of explaining both. We didn't hide mistakes. And we were very proud of when we found mistakes, not only drilling down to see how it happened, but then putting into place new policies to fix it. And putting that out there so other, other incidents didn't have to have the same challenges that we did.

But, I think something that Dr. Hirsch started early on, that has since been taken up by other disasters, was meeting with families and being transparent. And initially, he was meeting with them daily. And then it was weekly. And then it was monthly. And it was monthly... until I left in 2004! Every month. Anyone could show up at the meeting! And if you didn't want to show up, there were family groups that had representatives that showed up to disseminate information. And we included them in a lot of our decision-making processes.

And we explained to them what was going on. Why it was taking so long. Why we couldn't make a DNA identification yet, because we didn't have a database in place to be able to do the calculations! And when we were gonna preserve the remains, what kind of options we had, and what did they think of that? And what did they think about who was working on it?

And I think meeting with the families and giving them... ownership? Because ultimately, we shouldn't be making the decisions. What we do, we do for the families! And it's up to them. And I think back to... was it worth it? And I'm not sure that's even a question... we get to answer! Right. I think that's a question for the families! Because everything we do is for them. It's not about us.

JENN WAGNER: I'm gonna turn to a question from the audience. This is the first one, actually, that came in. Sara Katsanis had asked, can you address the emotional reasoning behind ongoing DNA identification, now that we know the names of the 2,749 people that died? Is it helpful to families in recovering their loved ones, or harmful to re-traumatize families with additional fragments found over time?

AMY MUNDORFF: I think that's -- I think every family member might have a different answer to that question. I know personally what I think. But... but what I think is, is not based on their experiences! I do, I do sometimes question... now, if families that have been missing KNOW that it continues. You know, I heard an interview with someone who just got an ID who didn't realize they were still doing it.

So if it IS going to continue, that communication has to be more in the forefront. And maybe it's time to do an opt-in, opt-out again.

JAY D. ARONSON: Can I just add something here really quickly?

JENN WAGNER: Yes.

JAY D. ARONSON: One thing that I discovered in talking to many families in, on many sides of many arguments, is that there really isn't a single family perspective. And that pretty much every -- well, not quite every. But there were certainly camps, but. You can't really say anything about the impact of any of this on any one -- on the families as a whole; it's kind of a very individual thing.

And so... the challenge then becomes how do we make policy when you're dealing with thousands of families, and within those families there isn't agreement about what should be done. And yet, the medical examiner's office has to make a decision about all of these things.

And so, you're -- one of the things that I found when I was talking to families is when policies are made that they disagree with, they want to know why, and they want to be leveled with, and they want an honest answer about why. And what was interesting was that the medical examiner was generally held up as the city entity that got things right most of the time. And when they got things wrong, they apologized. But all of this happened in a context where there were so many other actors involved. And I just -- I don't, I don't know how you can separate them. I obviously -- you know, I couldn't in my own work. But I had to talk about the redevelopment and the money and the politics. You had three people who wanted to be president all controlling the big decisions that were being made.

And so, you know, it gets really messy really quickly. And so I think that... in future events, that that messiness isn't always going to be there. So it might even be easier to figure out some of these things, before. But the medical examiner was not operating in a vacuum, in a political or social vacuum. Had they been the only city entity involved, it probably would have been a much smoother process. Despite the fact that they made mistakes and had to change their policies from time to time.

JENN WAGNER: Yeah. I know we have a lot of questions to get to. I had some questions for you, and we'll continue this discussion informally a bit later. I think we can take maybe one more question from the audience. There actually were two questions that related somewhat to one another. Again, that the... how this influences future plans. But also, Barbara Kennig has asked the question thinking back to the work of Mary-Claire King in Argentina, how does efforts to identify victims intersect with the development of DNA technologies? So I mentioned in my opening that it was only recently that next-gen sequencing technologies were approved for use in this effort. But could you talk about the effect of incidents like this for the development of DNA technologies?

AMY MUNDORFF: I think that... this disaster, and the unprecedented amount of money that was thrown at it, really pushed the science forward faster than it -- anyone could have thought would have happened. (cell phone dinging) You know, we brought online snips. We brought online combining nuclear and mitochondrial. There were new technologies that came out. And they came out fast. And they were vetted through a panel of international experts that... that really put their heads together to see how we could do this work fast. We didn't work in a void; we didn't have the capability to do it ourselves. And there were people from all over the world that really pushed DNA science forward. And it's amazing, I think, to see where we are now, compared to where we were 20 years ago.

JAY D. ARONSON: Yeah. I just, I only wanted to add that so much of the development of the technology was actually managerial and managing information flows. And that's not as exciting as, ah, you know, as some of the like fancy machines or snips or anything like that. But really, without that process shift, none of this would have happened. And I think we do need to remember the money came largely because this was a politically relevant event. And when we don't have that, the money doesn't flow. And obviously, the benefits of the technology that was developed after 9/11 are being showered upon situations that normally wouldn't have the ability to do this kind of identification. But we need to keep all of that in mind -- I think! -- when we're talking about the development of new technologies and new techniques.

JENN WAGNER: I think Dr. Lee is here to have us wrap up. I wanna thank both of you again for being part of this webinar, and I look forward to continuing this discussion. I know we have many more questions to discuss in the informal session.

SANDRA LEE: Yeah. And I'd like to thank all three of you for such a rich discussion, and invite everyone in the audience to continue the conversation in our post-event discussion Zoom, which should be in the chat. Our next event will take place on October 8, and it will be on Genomic Data Sharing: Putting Principles and Policy into Practice. Our panelists will include Heidi Rehm, Keolu Fox, and it will be moderated by Malia Fullerton.

You will receive a survey shortly, so please do complete it. Send us your thoughts and ideas. We really value your input. Thank you so much for participating today, and please take good care.