# You Wanna PIECE OF ME?

**Organ Transplantation Stories From the Real World** 



USC ANNENBERG

The Norman Lear CENTER

An edited transcript of a panel discussion held on March 11, 2010 at the Writers Guild of America, West



### THE NORMAN LEAR CENTER

The Norman Lear Center is a nonpartisan research and public policy center that studies the social, political, economic and cultural impact of entertainment on the world. The Lear Center translates its findings into action through testimony, journalism, strategic research and innovative public outreach campaigns. On campus, from its base in the USC Annenberg School for Communication & Journalism, the Lear Center builds bridges between schools and disciplines whose faculty study aspects of entertainment, media and culture. Beyond campus, it bridges the gap between the entertainment industry and academia, and between them and the public. Through scholarship and research; through its conferences, public events and publications; and in its attempts to illuminate and repair the world, the Lear Center works to be at the forefront of discussion and practice in the field.

For more information, please visit: www.learcenter.org.



### HOLLYWOOD, HEALTH & SOCIETY

Hollywood, Health & Society (HH&S), a program of the Norman Lear Center, provides entertainment industry professionals with accurate and timely information for health storylines. Funded by the Centers for Disease Control and Prevention, The Bill and Melinda Gates Foundation, The California Endowment and the National Institutes of Health, HH&S recognizes the profound impact that entertainment media have on individual knowledge and behavior. HH&S supplies writers and producers with accurate health information through individual consultations, tip sheets, group briefings, a technical assistance hotline, panel discussions at the Writers Guild of America, West, a quarterly newsletter and Web links to health information and public service announcements. The program also conducts extensive evaluations on the content and impact of TV health storylines.

For more information, please visit: www.usc.edu/hhs.

### YOU WANT A PIECE OF ME? ORGAN TRANSPLANTATION STORIES FROM THE REAL WORLD

If you were given the chance to save eight lives, wouldn't you take it? Come listen to experts discuss leading edge technology and therapy and expose the myths of organ donation. Hear personal stories about the second chance of life from real organ recipients and donors, and see how a popular primetime drama addressed this compelling issue.

A video of the program can be watched in its entirety online at: <a href="http://youtu.be/DKgooHK2wo8">http://youtu.be/DKgooHK2wo8</a>

# **PARTICIPANTS**



NEAL BAER, MD, is a Harvard-trained physician, practicing pediatrician, and award-winning television writer and producer. Since 2000 he has been the Showrunner and Executive Producer of the NBC series Law and Order: Special Victims Unit. Before his tenure at Law and Order, he was Executive Producer of ER. Recently, his mentorship of a Mozambican HIV/AIDS orphan resulted in the documentary film Home Is Where You Find It. He was also an adjunct professor (2001–2005) at the University of Southern California teaching in the area of

health communications, health promotion and disease prevention, and sex education. He is also Co-Chair of Hollywood, Health & Society.



ROBERT A. MONTGOMERY, MD, DPHIL, FACS, is the inaugural recipient of the Margery K. and Thomas Pozefsky Professorship in Kidney Transplantation. He is an Associate Professor of Surgery, Director of the Incompatible Kidney Transplant Program, Chief of the Division of Transplantation, and Director of the Comprehensive Transplant Center at the Johns Hopkins University and Hospital. He received his Doctor of Medicine with Honor from the University of Rochester School of Medicine. He received his Doctor of Philosophy from Balliol College, The University of Oxford, England in Molecular Immunology, Dr. Montgomery

completed his general surgical training, multi-organ transplantation fellowship, and postdoctoral fellowship in Human Molecular Genetics at Johns Hopkins. Dr. Montgomery has been involved in the development of innovative approaches to expanding live donor renal transplantation including: the laparoscopic donor nephrectomy, positive crossmatch and ABO incompatible transplantation, paired kidney exchange, and altruistic donor programs. His other clinical interests include the use of expanded criteria donors and pulsatile perfusion pumping to preserve and rescue organs that previously were not used for transplantation.



JOE SACHS, MD, is a Consulting Producer on the NBC dramatic series Mercy. He served many years as a writer and Executive Producer of the Emmy Award winning television program ER, writing 36 episodes of the medical drama, including the teleplay for Exodus, nominated by the Writers Guild of America as the outstanding television script of 1998. Dr. Sachs is a graduate of Yale College and the Stanford University School of Medicine. During medical school, he began his interdisciplinary career in the arts and the sciences by pursuing a Master's degree in film-making at Stanford. Moving to Los Angeles, he then completed a com-

bined residency in Internal Medicine and Emergency Medicine at UCLA. While currently developing new television dramas, Dr. Sachs also serves as an attending physician in the Trauma Center at Northridge Hospital and maintains a teaching position on the clinical faculty at the UCLA School of Medicine



JAMES REDFORD is Founder of The James Redford Institute for Transplant Awareness (JRI), a nonprofit organization dedicated to educating the public about the need for organ and tissue donation through film, educational outreach and the web. Redford founded the organization in 1995, two years after receiving a liver transplant at the University of Nebraska Medical Center. To meet this goal, he produced The Kindness of Strangers, an award-winning HBO documentary film. The Kindness of Strangers won the Crystal Heart Award at the Heartland Film

Festival and Best Documentary at the Chicago Alternative Film Festival. Through JRI, Redford also produced Flow, a short drama targeted to high schools and community-based youth programs. Flow is accompanied by an Educational Outreach Kit, which contains the video, lesson plans and support materials for high school teachers and community leaders and is currently in use in schools and community organizations across the country. Redford holds a Bachelor's degree in creative writing and film from the University of Colorado, Boulder, and a Master's degree in literature from Northwestern University. He co-founded the Redford Center, which opened offices in Berkeley in March 2009.



ANDREW KLEIN, MD, MBA, is the Esther and Mark Schulman Chair in Surgery and Transplant Medicine and Director of the Cedars-Sinai Comprehensive Transplant Center. In this capacity he provides oversight and programmatic direction for the institution's liver, kidney, pancreas, heart and lung transplant programs. He was appointed Professor of Surgery at The David Geffen School of Medicine at UCLA in 2005. Dr. Klein received his undergraduate degree from Duke University and his MD degree from Johns Hopkins University. He completed residency train-

ing at The Johns Hopkins Hospital, was a Harvard research fellow in transplantation immunology at The Massachusetts General Hospital, served as a Surgical Registrar at The John Radcliffe Hospital, Oxford University, and was a fellow in liver transplantation at UCLA. Dr. Klein was appointed tenured Professor of Surgery at The Johns Hopkins University School of Medicine in 2000. He was the founding Director of the Johns Hopkins Comprehensive Transplant Center and served in that capacity from 1996 to 2003. While at Hopkins, he was Director of Liver Transplantation and Chief of the Division of Transplantation. He is a skilled technical surgeon with expertise in liver and bile duct surgery and liver transplantation. He is regarded as an expert in the fields of liver failure, liver cancer and organ transplantation.

# PARTICIPANTS, CONTINUED



THOMAS MONE is the CEO of OneLegacy, the US's largest organ recovery agency, serving 19 million people, 200+ hospitals and 13 transplant centers. OneLegacy, annually recovers 400 organ donors and 1300 organs for transplant, a 60% increase in the past 6 years, and 1800 tissue donors. Tom has led the development of the first industry standard of web-based organ placement, prospective NAT/PCR testing of all donors since 2004 and Chagas testing since 2007, as well as paid media advertising and a 100% multilingual family care staff to increase ethnic community donation from 45% to 75%, and has overseen the

founding of the Donate Life Rose Parade Float that has 60+ national and international partners that has inspired documented 15-20% seasonal increases in donation rates by communicating the value and need for donation to over 300 million people. Tom is Past President of the Association of Organ Procurement Organizations (AOPO) and a founding member of AOPO's Multicultural Council; he is also an AOPO Accreditation Surveyor and Committee member. Tom is a former Director of the United Network for Organ Sharing Board of Directors.



KENNETH P. MORITSUGU, MD, MPH, FACPM, is the Vice President for Global Strategic Affairs at Johnson & Johnson Diabetes Family of Companies where he is responsible for coordinating the strategic efforts of the Johnson & Johnson Diabetes Franchise in addressing the increasing epidemic of diabetes worldwide. He also serves as the Chairman of the Johnson & Johnson Diabetes Institutes, providing leadership and direction for all aspects of the Institutes worldwide. Prior to his current position, Dr. Moritsugu was the Acting Surgeon General of the United States, serving as the nation's top doctor and communicating the

best available science and information to the American people. Dr. Moritsugu is a dedicated advocate for organ and tissue donation and transplantation, as well as a key speaker at numerous international, national and local programs on the subject. In recognition of his continuing efforts in this field, in 2007, the International Congress on Organ Donation named him its inaugural International Ambassador for Organ and Tissue Donation. Also an educator, Dr. Moritsugu is an Adjunct Professor of Global Health at the George Washington University School of Public Health and Health Services. After attending Chaminade College for two years, he received his Baccalaureate Degree with Honors in Classical Languages from the University of Hawaii in 1967, an MD from the George Washington University School of Medicine in 1971 and an MPH in Health Administration and Planning from the University of California, Berkeley in 1975. Dr. Moritsugu lost his wife, Donna Lee Jones Moritsugu, in an automobile accident in 1992, and his daughter Vikki Lianne in a separate automobile accident in 1996. Both were organ and tissue donors.



MELODIE WILLIAMS is known for her whimsical sense of humor and neverending care for others. She is a vibrant, goal-oriented woman who is always on the go. At an early age, she was taught the value of helping others, especially family and those less fortunate. Throughout her life, Williams has devoted her time as a mentor to others and has helped see many of her family members become successful at their crafts. With a career in Business Finance and Administration within Architecture, Construction and Interior Design, Williams has successfully improved the growth of the companies she has been a part of. In her

down time, Williams enjoys longs walks, traveling, watching movies and being a mentor to others. She also enjoys donating to several organizations, including the AIDS Foundation, the Los Angeles Food Bank and Los Angeles Mission. In addition, after recently donating a kidney to her daughter, Crystal, Williams began volunteering her services to Cedars-Sinai Medical Center in an effort to help bring awareness to individuals suffering from various kidney diseases.



SANDRA DE CASTRO BUFFINGTON, MPH, is the Director of Hollywood, Health & Society, a program of the USC Annenberg Norman Lear Center that leverages the power of the entertainment industry to improve the health and well-being of individuals and communities worldwide. The program provides resources to leading scriptwriters and producers with the goal of improving the accuracy of health-related storylines on top television programs. Funded by the CDC, The California Endowment, The Bill & Melinda Gates Foundation, HRSA's Division of Transplantation, ONDCP and the NIH, the program recognizes the pro-

found impact that entertainment media has on individual knowledge and behavior. She is known for her award-winning work in global health and social transformation. She has nearly 30 years of experience working in global health, entertainment education and emergence technologies; 20 years were spent working internationally, and five of those years were spent in residence overseas.



MARTIN KAPLAN, PhD is the Lear Center founding director Martin Kaplan, a former associate dean of the USC Annenberg School, holds the Norman Lear Chair in Entertainment, Media and Society. A summa cum laude graduate of Harvard in molecular biology, a Marshall Scholar in English at Cambridge University, and a Stanford PhD in modern thought and literature, he was Vice President Walter Mondale's chief speechwriter and deputy presidential campaign manager. He has been a Disney Studios vice president of motion picture production, a film and television writer and producer, a radio host, print columnist and blogger.

# YOU WANT A PIECE OF ME?

**Martin Kaplan:** Good evening. Thank you all for coming. We're going to have a terrific evening, a lot of amazing people with amazing stories to tell. And if you're in the market for stories, you're in the right place.

I'm Marty Kaplan, the director of the Norman Lear Center. Hollywood, Health & Society is a program of the Lear Center.

You'll hear a lot about it tonight, but just to put in a plug for the umbrella under which it comes, the Lear Center studies and shapes the impact of media and entertainment on society. If the idea of doing that interests you or the idea of a place named after Norman Lear interests you, I welcome you to our website, which is hearCenter.org.

We're very glad you came here tonight. We're grateful that our panel could be here tonight. Now I'm going to introduce to you the director of our Hollywood, Health & Society program, who will be our sherpa for the evening, Sandra de Castro Buffington. Thank you.

**Sandra de Castro Buffington:** Thank you, Marty, and welcome, everyone. It's so good to see you tonight.

I'd like to start by giving a special welcome to Hollywood, Health & Society's donors. They make it possible for us to serve as a free resource to the creative community to provide medical experts and expertise for your scripts.

We'd like to start with thanking Mary Ganikos, who's here from the Health Resources and Services Administration's Department of Transplantation. Mary has been a longstanding partner and guiding force. Thank you.

I'd also like to recognize our Hollywood, Health & Society board members. We have with us Traci Blackwell, Diana Bonta, Mary Ganikos, Donna Kanter, Aliza Lifshitz, Doe Mayer, Michael Taylor, Socorro Serrano, and James Redford. Thank you.

# [Applause]

Thanks, also, to the Norman Lear Center and Hollywood, Health & Society staff, who have organized this wonderful program for us tonight.

Hollywood, Health & Society provides television and film writers with a free service to help them get accurate medical information from experts for their scripts. For nearly a decade, Hollywood, Health & Society has served as a credible source of public health information while understanding the dramatic needs of Hollywood's master storytellers.



Sandra de Castro Buffington

And speaking of drama, there is no health topic as dramatic and compelling as organ transplantation. other health topic riddled with ethical moral dilemmas. and emotion, controversy, ticking clocks, tragic endings, and happily-everafters. It's no wonder that TV shows and films are increasingly portraying organ transplantation in their storylines.

No other health topic is riddled with ethical and moral dilemmas, controversy, emotion, ticking clocks, tragic endings, and happily-everafters.

Sandra de Castro Buffington

Tonight, we have an extraordinary panel who will speak to you about the many facets of organ transplantation.

You'll hear from a world expert on transplantation from Johns Hopkins University, and an organ transplant recipient, whose nonprofit organization is dedicated to educating the public about the need for organ and tissue donation through



Dr. Robert A. Montgomery

film and the Web.

We have an established television writer and producer who will talk about creating and writing powerful, award-winning shows about organ transplantation.

Also on the panel is a well-known expert from Cedars-Sinai, who will expose the common myths of transplantation.

We'll hear some compelling personal stories from a husband and father who made the important decision to donate his family members' organs and from a mother who stepped up to the plate when her daughter needed a kidney.

Finally, we have the CEO of the largest organ recovery agency in the world.

To speak with us tonight about innovative new approaches in the field of organ transplantation, I'm delighted to introduce our keynote speaker, Dr. Robert Montgomery. Dr. Montgomery is an associate professor of surgery, director of the Incompatible Kidney Transplant Program, chief of the Division of Transplantation and director of the Comprehensive Transplant Center at the Johns Hopkins University and Hospital.

Dr. Montgomery, considered a world's expert on kidney transplantation of complex patients and patients with incompatible donors, was part of the team that developed the laparoscopic procedure for live kidney donation, a procedure which has become the standard throughout the world. He also led the team that performed the first triple swap, the triple domino swap, and the world's first quintuple kidney pair donation.

We very much look forward to hearing his presentation, so please join me in giving a warm welcome to Dr. Robert Montgomery.

**Robert A. Montgomery**: Thank you, Sandra. That was very nice. And good evening. Thank you all for coming.

I'm in the category tonight of best short presentation.

# [Laughter]

I thought I would start out with a story. One of Dr. Klein's coworkers at Cedars-Sinai is Don Dafoe, who has a very famous brother, Willem Dafoe. One night, Don and I were out to dinner, and he was talking about his brother and how self-absorbed actors are. He mentioned that his brother had just finished doing a film with Robert Redford, and Willem was saying, "Did you know that Robert Redford's son had received a liver transplant?" And Don said to him, "Well, did you tell Robert Redford that your brother is a liver transplant surgeon?" And Willem Dafoe said, "It never really occurred to me."

## [Laughter]

I wanted to start out by just showing you a couple of film clips.

[Video clip]

**Robert A. Montgomery**: Now, there's some material! [Laughter]

A year ago, we did in fact remove a kidney through a woman's vagina. We, at Hopkins, have been very focused on expanding live donation. One of the things that we've tried to do is to make it as easy as possible to donate a kidney. We initially developed a minimally invasive way of removing a kidney.

The operation used to be a large incision. And frequently, the recipient of the kidney would leave the hospital before the donor.

The new technology inserts small cameras into the abdomen and the new instrumentation allows one to perform an operation through very tiny incisions. We started to remove kidneys for donation through that technique. This is the logical extension of that sort of technology.

There's an area in surgery now called NOTES surgery, and the idea of NOTES surgery is that you use a natural orifice to do surgery.

For instance, gallbladders are removed by putting fiber optic scopes into a person's mouth, down through their stomach. An incision is made in the stomach and then the gallbladder is removed that way.

While I was reading an article about that new frontier of surgery, it occured to me. Why not? Why couldn't we use a natural orifice to remove a kidney? The first patient in the world who donated a kidney to her niece through a vaginal extraction went home the next day, didn't receive any pain medication after the operation, and said that her pain was just like a bad menstrual cramp.

I thought I'd mention what I think are some of the interesting new frontiers in transplantation that might be fodder for stories. When we begin to answer questions as a panel, we can get into a lot of the mythology and the human interest stories. I want to outline a few things like this that might not be obvious to everyone.

One of the things that we have been working on, which turned into a storyline on *Grey's Anatomy* called, "There's no 'I' in Team," is the idea of "multiple swaps."

A large percentage of patients who have a living, willing donor are unable to receive a kidney from that donor because they're incompatible either by blood or tissue. Kidney pair donations, or "swaps," are a way around that.

A donor gives his or her kidney to a stranger so that their loved one can receive a compatible organ. It is an interesting new development in transplantation that is ripe for the "humanness" of those kinds of decisions. You get to meet the stranger who has donated the organ, in a procedure that used to occur only in deceased donation. Occassionally people would meet the family of the person who had died and donated the organ. But in live donations, the donor has always been known, and usually is a family member or loved one.

This opens a whole new area of relationships and what happens frequently is that people want to meet each other after the transplant. we do allow that.

Then there is this other group. About 100 people every year in the United States come forward and say, "I want to donate my kidney to anyone who needs it." We call them "non-directed donors" or "altruistic donors" – although all donors are altruistic. We try to help these donors fully realize their altruism by starting a whole domino of transplants. We try to find a compatible organ for somebody who has a willing live donor. These altruistic donors can set off six, seven, eight transplants and be responsible for their gift for all those transplants.

Those people are fascinating and a few of my patients were

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the subject of a really nice article in the *New Yorker* about what motivates people to do this. I think that's a really interesting potential story because these people are unlike anyone you can imagine.

But the reasons, the motivations are quite varied. One of my patients had lost her son at age six. One of the neighbors had backed up over the child in a very horrible, tragic accident, and the child died instantly. They were unable to donate the organs, and so she did this in his honor.

There was another patient whose wife died from ALS.

He was powerless to help her during this process, so he wanted to give an organ because it was something he'd have control over.

In another iteresting new development in transplantation, we now have two types of deceased donors. There is the traditional donor who is brain-dead. And in our society we define death as the cessation of brain function. These individuals' hearts are still beating. They're still on life support, but they're brain-dead.

In recent years, we have begun to utilize organs from another type of donor, called a "donor after cardiac death." This has been somewhat controversial. The patient is someone who is neurologically devastated and has no chance of recovery but doesn't strictly fulfill the criteria of brain death. The family decides that they want to withdraw support and have the tubes taken out. The family decides that they want to donate their organs. So the patient's heart stops and a doctor declares the patient dead. Then the patient is taken into the operating room and their organs are removed.

There is another category called "uncontrolled donors after cardiac death." These are victims of crime. For example, someone comes into the emergency room and have been shot several times and lost all their blood. There is a lot of controversy about whether the process of removing their organs or preserving their organs

should occur right there in the emergency room. It's being done in other countries, and we're testing the water to see what the public response might be to that concept.

There's a lot of debate now in transplantation about paying for donors. There are certain countries that have national schemes where it's legal for a donor to receive money for donating an organ. The idea of either paying for the donor, or minimizing the expenses that the donor might incur during the donation process, is hotly debated in our field right now. Sometimes people have to travel great distances, and the travel expenses aren't reimbursed. There is a spectrum of ideas and feelings about how far to go with helping donors to realize their gift. Certainly, there are people within our field who strongly advocate for paying for organs as a way to solve this terrible crisis of scarcity.

There are about 80,000 people waiting for a kidney transplant. Last year, we performed about 16,000 kidney transplants. About 7,000 people died waiting for a transplant. Those numbers are sobering. What we do is directed at trying to figure out ways to increase the number of organs that are available.

A future advancement involves the idea of using stem cells or cells that can be coaxed into being any cells in the body, because they haven't differentiated yet. That some day we could grow an organ in a laboratory is a very interesting development. I don't expect to see results in my lifetime, but great strides are being made in the science of stem cell therapy.

The greatest use I can provide is by answering questions that you all have about transplantation: what's real and what's not, and what's interesting and new. Thank you very much for your attention.

**Sandra de Castro Buffington:** Thank you, Dr. Montgomery, for sharing your insights with us. Next, I'd like to introduce our panelists.

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Dr. Robert A. Montgomery

First, we have Dr. Neal Baer. Neal is a Harvard-trained physician, a pediatrician, and a former executive producer of the Emmy Award-winning series ER. He's currently executive producer of Law & Order: Special Victims Unit, and he is the co-chair of the Hollywood, Health & Society Board.

We're also joined by Dr. Joe Sachs, a consulting producer on the NBC dramatic series Mercy. He's served many years as a writer and executive producer of the award-winning series ER, writing 36 episodes of the medical drama, including the teleplay for "Exodus," nominated by the Writers Guild of America as the Outstanding Television Script of 1998. Hollywood, Health & Society recently awarded ER with two Sentinel for Health Awards for an episode on organ transplantation for a major storyline and a minor storyline, and Joe graciously accepted on the show's behalf.

Then we have Jamie Redford, president of The James Redford Institute for Transplant Awareness and co-producer of "Share the Beat." Jamie, who received a liver transplant in 1995, is also the producer of The Kindness of Strangers, an award-winning HBO documentary film, and Flow, a short drama targeted to high schools and community-based youth programs.

Tonight we also welcome a renowned transplant surgeon, Dr. Andrew Klein. Dr. Klein is the director of the Cedars-Sinai Comprehensive Transplant Center, where he provides oversight and programmatic direction for the institution's liver, kidney, pancreas, heart, and lung transplant programs. Dr. Klein is also a professor of surgery at the David Geffen School of Medicine at UCLA

Our next two panelists have extraordinary and compelling personal stories to share.

Dr. Kenneth Moritsugu is the chairman of the Johnson & Johnson Diabetes Institute. Prior to his current position, Dr. Moritsugu was the acting Surgeon General of the United States, serving as



(From left): James Redford, Neal Baer, Joel Sachs, Robert Mongtomery, Sandra de Castro Buffington, Andrew Klein, Melodie Williams, Thomas Mone and Kenneth Moritsugu

the nation's top doctor and communicating the best available science and information to the American people. For 15 years, he was a board member of the Washington Regional Transplant Community, the organ procurement organization serving the Metropolitan Washington, D.C. area. His personal story of the tragic loss of two family members is powerful and inspirational, and we look forward to hearing from him.

I'm also very pleased to welcome Melodie Williams. Melodie says that at an early age, she was taught the value of helping others, especially family and those less fortunate. That life lesson served her well when her daughter Crystal needed a kidney transplant. Tonight, Melodie will share her true story about the gift of life.

And last but not least, I'd like to introduce chief executive officer and executive vice president of OneLegacy, Mr. Thomas Mone. Mr. Mone leads the US's largest organ recovery agency, serving 19 million people. OneLegacy annually recovers 400 organ donors and 1,300 organs for transplant. Tom has led the development of the first industry standard of a Web-based organ placement, and we look forward to hearing from you tonight, as well.

I'll turn it over to Neal

Neal Baer: Thank you, Sandra. Thank you all for coming. We'll begin with Joe Sachs, and it's really my pleasure to start with Joe because I worked with Joe.



Robert Montgomery speaks to the audience at the Writers Guild of America,

Joe started on *ER* with me in 1994, the show's first year, and he stayed until last year, which is an accomplishment in and of itself. And Joe really did do the medicine on the show and was very much responsible for the accuracy of the medicine on the show, as well.

If you ever want to learn how to suture, just ask Joe because he taught Noah Wiley and Eriq La Salle using chicken parts, right? I remember.

Anyways, we're going to start with Joe, and first, we're going to show some clips from *ER*, and then Joe will speak briefly about them. Then I'll ask him a question because you probably have more questions tonight, and then we'll move on to each panel member. So save your questions until the end, and then we'll ask for them. Can we start with Joe's clips?

[Shows video clips]

**Joe Sachs:** Thank you. And thank you, Hollywood, Health & Society, for inviting me to this panel.

I will start with a story about an interaction with a transplant recipient. In 2001, I went scuba diving at possibly the most remote place that you can go in Fiji. We flew to a little island in Fiji and my wife and I took a single-prop plane to another tiny island and

then it was about an hour-and-a-half to get to this dive site in the

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Joel Sachs

Channel, 77

middle of nowhere. As a doctor, I always travel with a medical kit just so I'll have everything that I could possibly need to handle emergencies.

We got there, and who should be there diving with us but David Crosby, who is a liver transplant recipient. As you know, it's very important for transplant recipients to stay close to hospitals because they're on powerful immunosuppressive drugs, and if you get sick, you want to be near a hospital. So I'm thinking, "What an idiot. He's scuba diving. It would be 12 hours to the nearest hospital." And I'm thinking, "Oh, boy, something's going to happen this week." I just have this feeling.

Sure enough, about three days into the trip, my wife got violently ill with a stomach virus, and the Compazine that I had didn't do anything to help her. But David had this new drug, Zofran, that saved her. She was better the next day. He ended up helping me. So it all worked out. Thank you, David.

I want to talk about how we create stories because I'm here as a writer. When we create medical stories, we never start with the medicine, which may come as a surprise. We always start with the dramatic needs of the character. These programs are not about the medicine. If they were, people would be watching the Discovery Channel or the Learning Channel. There have to be great dramatic situations. So I thought talk about how those two stories you just saw were created.

First, was the death of Greg Pratt, Mekhi Pfifer's character. This was my burden. How are you going to kill off a TV character in a new way? The old way is that you do CPR on him, pumping his chest and then someone says, "We're going to call it." They look up at the clock and say, "Time of death, 8:15" and everybody's sad.

Instead we thought of a very emotional and new way to do it; he was a victim of a blast injury, he had an air embolus that went

to his brain, he was brain-dead. And his brother, who was the paramedic, had to come to terms with accepting that he was brain-dead and was going to be an organ donor.

It was a very interesting, compelling emotional story for the brother and also for the whole department because as he was wheeled to the elevator for surgery, it was a funeral procession. All of his friends and colleagues and loved ones watched him pass one last time.

It was great drama, but as a side effect, people learned about brain death. They learned about the apnea test. They learned about the EEG that was used, and how family members come to terms with donation. It was a great story and people learned from it, so that's great.

Then the Clooney clip was supposed to be the season finale of *ER*. But it wasn't because at the last minute, NBC said they wanted four more. So it was the fourth from the last one. We had all these intricate stories laid out, so we had to put it earlier in the year.

But the challenge in that episode was how do you reconnect a beloved character who hasn't been on the show in 10 years? He's in Seattle, so I figured he's a pediatrician in Seattle. We're going to make his wife, Carol Hathaway, a transplant coordinator. Two doctors from our hospital go, and they are delayed because Clooney has to convince the grandmother to consent to organ donation.

In the very dramatic scene, you saw the tenderness, you saw the compassion, you saw the way in which consent was obtained. We also had some other technical details with cerebral blood flow that's a very real way to prove brain death. The final twist was that because of the delay, they had an extra kidney that they sent back to some doctor who needed a transplant in Chicago. And they ended up saving Noah Wiley's character's life because he needed a kidney transplant.



Joel Sachs

We start with drama, we add the medicine that fits, and my thanks really goes out to Hollywood, Health & Society and to organizations such as Donate Life, who have helped us so much with these stories.

We always look for expert guidance. Expert guidance gives you great detail that makes your stories real, different. You can tell great stories, but as a side effect, people learn and are educated.

**Neal Baer**: Joe, because you did a lot of transplantation stories over the 15 years of *ER*, what was the impact of those stories? Can you give us some examples of how stories made a difference?

**Joe Sachs:** I don't think I can speak to that, but we know that from surveys of regular viewers of *ER* that close to 60% learned new things about medicine and health from the show, and 33% actually learned something that helped them or a family member. That impact is huge when you think that in the early seasons of *ER*, 40 million people were watching the show every week.

**Neal Baer:** So it pays to be accurate then.

Joe Sachs: Yes, it does.

**Neal Baer:** We always agreed about that even though he's an emergency physician and I'm a pediatrician. We did agree that accuracy was really important because millions of people saw those two clips, and people still see them over and over. If you're putting out stories, especially about things that are fairly controversial, I

think it's fair to say we think that's important.

Joe Sachs: Yes, in fact, I just axed a story on *Mercy* that was very close to happening because it was inaccurate in checking with transplant authorities. It was about the so-called "living donor split liver," where a living donor can donate a lobe of their liver, which regenerates both in the donor and the recipient. It was a situation where the living donor was going to be a sister who had a terrible injury and was in a coma, and that can't happen. To be a living donor, you have to be 100% healthy, and that is an important message to get out there. I did not want an inaccurate story, so we had to change and modify the story that they'd created.

**Neal Baer**: Good. I'm glad you did. Thanks, Joe.

We'll move on to Jamie Redford. I met Jamie actually during the first year of *ER* and was able to learn about his multiple transplantations. Right, Jamie? Knowing someone is also a real help to a writer. When you get to hear his or her story, that's always where we started on *ER*, too, and certainly interviewing people allows writers to really get the nuances of their stories.

Jamie, please tell us about your organization and about your passion in getting the word out.

James Redford: Well, it's obviously personal. I was diagnosed in the late 1980s with an end-stage liver disease and told I had five years, which ended up being exactly right, a slow slide into pretty bad shape. Transplant for me was sort of unique in that the first operation didn't work. There were problems with the artery blood flow, and it killed off part of the donated organ. I was in limbo for about four months because they couldn't technically declare me – and this gets into the intricacies of things that can be interesting that aren't necessarily headline news.

The doctors said, "Off the record, I don't think this liver's going to make it. But right now, your numbers are good enough that

we have to formally release you from the hospital. But we don't anticipate that you're going to make it in the long run. But because the list is complicated and there are people waiting, we have criteria for what's considered a healthy transplant. You're going to have to move out and stay here in Omaha for a while. We'll just have to see how you do."

That was a really fun time, I tell you, living at home eating English muffins, wondering what's going to happen. Inevitably, their hunches were correct, I went downhill. Then I was re-transplanted, and everything's been terrific since then.

When I re-entered into the world, I would come across occasional news reports or television shows, not all of them as thoughtful as *ER*. I thought, "Well, this is a shame." This looks nothing like my experience, and the big thing missing here is the donor family. In the early mid-'90s, there was just no exploration of the miracle of the gift going on as far as I was concerned.

At the same time, there was a lot of criticism within the medical establishment about what was happening on television in those days. I was encouraged to speak out. But you see, I've written and directed some movies, produced some docs, and I'm doing what you guys are doing. And it felt wrong to take on the attitude of being a censor or coming out and saying, "Don't do this."

I made a decision to tell the right story from what my own direct experience was, so I did a documentary. The documentary was a wonderful thing. It reached a lot of people on HBO, as you can imagine.

It's always bittersweet with transplant because you're intertwining life and death. It's always bittersweet. I got a phone call from one of the organ procurement organizations we had worked with in our documentary – the organization handles the delivery of the organs and procurement – who just wanted me to know that they had just done a harvesting, which is my least favorite word. If

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James Redford

you can do one thing, get rid of the word "harvest" because it doesn't make any sense.

But they'd gone in to talk to a family just like this conversation here. The OPO worker went in to have the discussion – it was a child, and the mother and father said, "No, no, no. We just saw this documentary last week, and we had decided we wanted to do this, so just do it."



James Redford

So in this case, I don't know specifically, but the movie was life saving to a number of people, I'm sure. Although most of the time, you don't really know. I produced it with the belief that if you kept telling stories, it would reach people.

I've now focused on trying to reach kids with Annie Aft, who runs the foundation. She's a dynamo, and she would love to talk to any of you. If you wanted to reach her through the website, she's enormously knowledgeable.

We're doing outreach to kids too.

Neal Baer: Thanks, Jamie.

Can you speak more specifically about how you work with kids because as writers, we do write for children, as well, and this is a topic that some people feel may be too adult or too dark or too difficult. How have you addressed those issues? How can one write for kids, and what are some of the projects that you all are doing that can inspire some of the writers here?

James Redford: There is a project called the Redford Animation

Project. It's being run by Annie Aft, who's not here tonight. She goes to schools and holds animation workshops. It's storytelling, animation, and that's what the kids get from us. They learn how to tell a short story in 30 seconds, and they also learn how to animate traditionally.

In return, it has to be a PSA for organ donation. We're giving them some skills, but I think our nasty little agenda is that if kids have to actually inhabit the storytelling role and tell the story, it'll be a far deeper awareness for them of what organ donation is.

**Neal Baer**: So the key is getting them to be able to tell the story and understand the story. You expose them to stories so that they have a deeper understanding; it's not such a mystery.

James Redford: Yes.

**Neal Baer:** Thank you. Dr. Kenneth Moritsugu has a personal story that he's going to share with us now.

**Kenneth P. Moritsugu:** I'd like you to imagine the following scenario.

You're driving back home from a day of sightseeing with visiting relatives when your pager goes off. You call your office, and your assistant informs you that there has been a terrible automobile accident involving your wife. You immediately head to the hospital.

A nurse ombudsman meets you as soon as you walk in to the emergency room, and you identify yourself to the clerk. She escorts you to a small, quiet, private room off to the side. She informs you that your wife has been severely injured. She offers you coffee, access to a phone, and invites you to remain in the room, assuring you that she will help keep you informed. She returns periodically to advise you of what's happening. It's not good.

A trauma surgeon stops in. The team has stabilized vital functions,

but there has been severe head trauma. The neurosurgeon is with your wife. A chaplain arrives unsummoned and offers comfort.

The neurosurgeon enters and describes what has happened. "Your wife has sustained such severe head trauma that while her heart is still beating, she's lost blood flow to the brain. She's dead."

This is a human

story with human

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giving to other

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families reaching

out, often during

periods of tragedy

Kenneth P. Moritsugu

and grief... "

The doctor remains to answer questions and then leaves you to your grief with your family, who has now gathered. Shortly after, the nurse ombudsman returns again and escorts you to the trauma room to see your wife, who's been cleaned from her injuries. It's a tragic moment.

Later, as you're leaving her side, the neurosurgeon joins you, walks down the corridor with you, and gently raises the question of what would you like to do.

His question jogs your memory of an earlier discussion years before between you and your wife. You each had decided to be organ donors on your deaths and had discussed this with each other. What would you do now?

This scenario is not the script. This scenario is real life. It happened to me and to my family nearly 18 years ago.

Eighteen years ago, my wife, Donna Lee, died in an automobile accident, and because of her generosity, a man in Tampa, Florida received her heart and a new lease on life for seven years; a teenage boy in Washington, DC, failing in school because of his disease, received a kidney and a pancreas; a hospital custodian received her other kidney; a woman in Pennsylvania received her liver; a retarded young woman in Baltimore, Maryland received one cornea; and a government worker received the other.

But that's not the end of the story because four years later, my daughter, Vikki Lianne, died in a separate automobile accident. Again, because of the professionalism and the caring of so many

individuals, a mother of five children from upstate New York received a heart and a new lease on life for herself and for her family; a widow with four children received her lung; a 59-year-old man from Washington DC, active with a local charity received her liver; a widower with one daughter received one kidney; a married working father of several children received the other kidney; a 26-year-old man in Florida received one cornea; and a 60-year-old woman in Pennsylvania received the other.

This is a human story with human impact. It's about individuals giving to other individuals; families reaching out, often during periods of tragedy and grief, to help other families; professionals, physicians, nurses, physician assistants, administrators mobilizing to secure this marvelous gift of life, mobilizing to recover and to transplant this life-saving, this life-enhancing gift.

And while we were making the decision to donate, in each instance, professional staff from the local organ procurement organization were there to help us in a caring and respectful manner to make these gifts of life happen.

When Donna died in 1992, 18 years ago, there were about 30,000 people on the waiting list for a solid organ, and she helped remove four people from that list into a renewed life.

When Vikki died four years later, 50,000 occupied the waiting list, and she helped remove five people from that list.

But, today, there are in excess of 106,000 people waiting. That's enough to fill the new LA stadium, which will hold up to 80,000 spectators to overflowing, with 26,000 more people waiting to get in.

Organ procurement organizations are a key element in this human system that help people help others through their generosity. It's their responsibility to approach families and next of kin to ask for organ and tissue donation and to assure that every organ and







(From left): Kenneth P. Moritsugu and Andrew Klein

tissue is transplanted effectively to benefit people. And over the years, their roles and responsibilities have continued to grow – to increase awareness; to educate professionals in the community; to support families in time of grief and tragedy; to help next of kin to consider donating their loved ones organs and tissues; to mobilize the resources and the organizations to recover organs and tissues; to place them where they will do the most good in concert with the national organ matching program; and to assure that this legacy of life will go on.

Today, nearly two decades after my family lost a wife, a mother, a daughter, a sister, an aunt, a friend, and nearly 15 years after my family lost a daughter, a sister, a niece, we still take comfort in the realization that while we could not have prevented their deaths, we have facilitated their legacies, their life-giving gifts to humanity, to people, as do all donors from their gifts of hearts and kidneys and livers and lungs and pancreas, corneas, and other organs and tissues.

These donors save lives, improve the quality of lives, as I have shown by the impact the two people in my family have had on so many others.

Organ donation and transplantation is not the result of any one

person but rather that of a finely coordinated team of people. It's the gift of hope. It's truly a legacy of life.

**Neal Baer:** Thank you for sharing that deeply personal story with us. The audience was rapt. You can see still that they're quite affected by the story that you told. And there were so many elements in the story that one could certainly draw on and craft into a story that could be powerful dramatically.

If I came to you as a writer and said I was doing a show, I wanted to do an episode about organ donation, what's the one thing you would tell me to get right?

**Kenneth P. Moritsugu:** What I'd say is that transplantation is the gift of life, but no transplantation can occur without a donation. Donors and donor families are humans, and the message that really needs to get across to everyone is that donor families want to help. They also want to be treated with respect. And if that message can get across, that will help.

**Neal Baer:** Thank you. We're going to move on to Dr. Andrew Klein, who's the director of the Cedars-Sinai Comprehensive Transplant Center.

**Andrew S. Klein:** Thank you. I was so happy to see Ken when I walked in tonight because our paths have crossed previously. But then I realized I had to speak after he did. And after you've heard his beautiful and compelling story, you can understand – this has happened twice before to me – that it doesn't get any easier after every time.

But I thought instead of giving you my opinions about some of the perceptions of organ donation and transplantation, I actually want to hear yours, and so I've posed some questions that are going to be based upon some popular mythology about organ donation and transplantation, and we're going to gauge it to one of the polls that's been taken, this one by Donate Life America in 2009.

Donors and donor families are humans, and the message that really needs to get across to everyone is that donor families want to help. They also want to be treated with respect.

Kenneth P. Moritsugu

What I'd ask you to do is please respond the way you really believe, not the way you think is correct politically or that is the right answer. I think the better we understand what the perception is of a group like this, I think we can probably make some significant gains.

So the first question is: Doctors may not try as hard to save my life if they know I wish to be an organ donor or a tissue donor.

True or false? All those who say true, please raise your hand. See, there's a modest few people there.

Well, 51% of the population who voted on this said they thought this was "true" or they "didn't know." So half the people actually believe that if you agree to be an organ donor, if it's on your donor card, then for some reason, they're going to treat you differently.

Second question: Organ or tissue donation is against my religion.

True or false? If it's true, please raise your hand. One person, two people. Okay.

Only 28% either agreed with that or did not know.

This is a good one: In the US, people with money and power have a better chance of receiving donated organs than other people.

True? Now we have some honesty here.

Okay, 85% of the people either "agreed" or "didn't know" that if you have money or power, you have better access; that you have a better chance of receiving a donated organ.

This next question was alluded to in the piece that was shown from ER.

It is possible for a brain-dead person to recover from his or her



Audience members answer

injuries

Anyone say true? Okay.

This was actually featured – and I won't embarrass the show – on a very popular drama where a woman comes out of the intensive care room. She's just seen her husband, and she says, "Well, he was brain-dead, but now they think he's going to recover."

So when you hear that, it makes you lose the credibility we have in the transplant community to reassure people that if you're braindead, it's not like sort-of-dead or almost-dead or nearly dead; it really means that you've died.

In the US, there's a black market for which people can buy or sell organs.

True? 85% of the people who took this poll said true or they did not know.

And the final question I have – this actually isn't a question. I'll just give you the answer straight out. So it says:

In general, have the TV shows or movies you've seen about organ or tissue donation made you more interested or less interested in becoming an organ or tissue donor? increases the need and decreases the availability of organs.

Andrew S. Klein

79% said they "hadn't seen anything" or it had "no effect"; 16% said they became "more interested" in donating; and 4% said they became "less interested" in donating.

I think the truth is the better we can address this mythology – this is really for you – the better you can address this mythology and eliminate some of the disincentives for organ



Andrew S. Klein

donation, I think that's going to be a very powerful message and a very positive impact on organ transplantation.

**Neal Baer:** Thank you. I have two questions. My first is about childhood obesity. There's a huge increase in type-2 diabetes, which affects kidneys and may increase the need for transplantation at some point. Do you see an increasing need for transplantation in the future?

**Dr. Andrew S. Klein**: Well, actually, I'll answer it in a reversed way. The problem with obesity is it's negative effect on the quality of organs that we get. Especially in liver transplantation – which is what I primarily do – the idea of using a fatty liver or a liver from someone who is type-2 diabetic (who has a higher likelihood of having a fatty liver) has made the organ supply even lower. Couple that with the fact that obesity will lead to end-organ problems, especially liver failure, as well as the more popular kidney failure and diabetes. So it works both ways. It increases the need and decreases the availability of organs.

**Neal Baer:** Could you talk about disparities ethnically and racially in terms of the need for donations? Is there a difference between the need for donations amongst African Americans versus Caucasians in the US? What causes that disparity, and what can we do about it?

**Andrew S. Klein:** There is a disparity principally because certain diseases tend to be more prevalent in certain ethnic populations.

This year was the first year since we've been recording data that the number of deceased donors in this country actually declined. And it actually declined most severely in the African American population compared to other minorities or the white population. Again, it cuts both ways. We have more people who are in need, and we have less people who are donors, specifically in the ethnic minorities.

**Neal Baer:** You posed the question and you told what the poll said about whether wealthy people can get organs versus not. What's the answer to that question in the United States?

**Andrew S. Klein:** The true answer is actually yes, they can, because – and I have to give a caveat there – it's not because they're given a more favorable position. But if you're wealthy, you actually have more access to care, and you're allowed in this country to put your name on more than one waiting list.

Now, certain insurance companies only let you put your name on waiting lists if you have state aid, for instance, you can only put your name on a list from that state. But if you're independently wealthy, you could put your name on 60 lists potentially. So there is actually a wealth advantage, but it's not because we take that into account when the person's name comes up on a waiting list.

**Neal Baer:** So does that still account for a disparity then in African Americans versus others?

We have more people who are in need, and we have less people who are donors, specifically in the ethnic minorities.

Andrew S. Klein

**Andrew S. Klein:** I think that's a very good point. I think that actually may be part of the explanation.

**Neal Baer:** Thank you very much. Now, we're going to move on to Melodie Williams, and she also has a compelling story to share with us.

**Melodie Williams:** It was a year ago that I received a call from my daughter's boyfriend saying that my daughter, Crystal, was in the hospital. I immediately went to the hospital and and asked, "What's going on?" She said, "Dr. Kaplan sent me over because I was complaining about chest pains."

When I got to the hospital, they kind of swarmed on her because they thought it was her heart. But they couldn't figure out why her blood pressure was still high. So they ran a lot of tests, and then they decided they're going to do a biopsy.

So the next day, I was at work, and she calls me, and you could hear she had been crying. And she said, "It's my kidneys." And I said, "What do you mean it's your kidneys?" And she said, "It's my kidneys. They said I need a kidney transplant." And I said, "You're joking." And she said, "No." And I said, "Well, I'll be there in a few minutes." And she said, "Well, I'm going to rest."

I hung up the phone, and I just put my hands in my face. I thought, "What in the world is going on?" I thought about my niece who a couple years ago had a kidney transplant. My family has a history of high blood pressure and diabetes. I wondered, "What did I do wrong as a parent? I can't believe it." She was in the hospital and they said she would be on medication and she needed to get a kidney transplant as soon as possible. And I thought, "Okay."

She came home we went to the doctor together. Crystal said, "Now, Mom, don't say nothing. Don't say anything." I said, "Okay, I won't say anything."

was adamant about not going on dialysis right away.

I said, "Well, I can be a donor," and my daughter said, "No, I don't

The doctor came into the room, and he starts talking, and he said,

"You know, it's good she's young, and she's going to get on the list, and we have medication that we can give her" – because she

want you to be a donor because I need somebody to take care of me." I said, "Okay."

But Crystal did end up giving them my name, and I ended up going through the procedures. I did all the tests, but came to find out we are two different blood types. I've always heard you had to be compatible. I thought, "We've got to get through this."

Remarkably, we ended up doing the transplant. I went through all of the tests. But it was the emotional part of my daughter needing a kidney that was so draining because I just couldn't do anything. I did not want her to go to dialysis three times a week and be trapped to this machine.

And without her knowledge, I would ask friends, "What blood type are you? Are you O?" And people are like, "Is she crazy?" I was literally out there looking for a kidney for my daughter because I thought you had to be the same blood type.

The hardest part was watching her go through this and not knowing that I was compatible because you always hear on the TV shows "You've got to be perfect match." And I wasn't. We were not. But Cedars pulled it off, and I am so grateful to Cedars. There's nothing that hospital could say. If they needed me to tell our complete story about this whole process, I would.

My daughter is sitting there in the audience, and she's up and running. She's able to travel. I am so happy that I was able to do it. In spite of my family's history, I was able to give a kidney. I always have my little dot on my driver's license, but I never imagined that

People can donate money, they can do charitable work, but I've literally given something of myself to somebody else, and I can see the end result.

 $Melodie\ Williams$ 

I would've ended up giving a kidney. Usually you give them when you pass on, but I was able to do it now. And I can see the results of my daughter being here. So I'm just very thankful.

**Neal Baer:** Thank you, Melodie. Can you briefly tell us how you're different after going through this experience?

**Melodie Williams:** Well, I look at it as I've given something of myself. People can donate money, they can do charitable work, but I've literally given something of myself to somebody else, and I can see the end result.

Neal Baer: How has it changed your life?

**Melodie Williams:** I'm trying to spread the word. There are so many people out here who need an organ, and people should really step up to the plate. If you know somebody who needs help, volunteer. Like I said, it's changed my life.

**Neal Baer:** When you saw your daughter in recovery, well, you gave the kidney, too, so the first time you saw your daughter?

**Melodie Williams:** She was sitting up, and I was so happy. I was just so happy to see her healthy, you know?

**Neal Baer:** So that's a great detail. Thank you so much.

Melodie Williams: Thank you.

**Neal Baer**: We'll now hear from Thomas Mone, who's the executive vice president of OneLegacy, and then we'll take questions from you all.

**Thomas Mone**: Thanks very much.

First off, I want to let Jamie know that the word "harvest" and "harvesting" was officially retired by the donation and

transplantation community about three-and-a-half years ago. It still shows up now and then in the OR late at night, uttered usually by older transplant surgeons. We don't have any of those at this panel. And you'll also hear it routinely in television shows and the movies because it is such a visceral and visual word.

One of the things we struggle with in working in the field of donation – in how it relates to the media – there is great drama in the whole notion of transplantation. There is no doubt that the subject of death, while eerie and frightening and, therefore, emotionally laden, has a lot of opportunity to expand upon dramatically. If I were a writer, I would run rampant with that because there are a lot of fun things to play with.

As a result of some of that are some of the statistics that Dr. Klein shared here. And that, in fact, was borne out of a study done at Purdue University by Dr. Susan Morgan, who found that public attitudes were specifically related back to TV show and movie episodes about transplantation and donation, in particular.

One of our favorites, and probably the most powerful one out there, is that if I have a donor card, the EMTs won't try to save my life. If I show up in the ER, they'll stop taking care of me because they want my organs. As the statistics Dr. Klein shared with you, this is compelling and meaningful to a lot of people. Frankly, I presume most of us here are from Southern California. We have an even greater challenge here because we have the largest population of people who have immigrated to this country from places where, if they know about transplantation, we're lucky. If they've ever had experience dealing with donation, we're shocked. That's not to be surprising, but it's a fact of life and what we have to deal with.

Where do they learn about these things? Where do they learn about donation and transplantation? We learn most of our information from television, radio and movies. That type of misinformation clouds the efforts to try to get the message to

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The audience at the Writers Guild of America, West

these people about the value and the good from donation.

The good news here – and there is some good news – is that 10 years ago, only 50% of the people in this country who could donate at the time of death did so. This last year, it was 71%. That's a pretty dramatic improvement, and there are not many areas of social giving at that level of donation. Blood donation is only 7%.

So it's not all a bad story, but we also know there are 106,000 people waiting, and that number grows every year. So we have to continue to grow this.

Melodie has made a tremendous donation, and living donation is probably the biggest part of the solution here. But deceased donation remains a possibility.

Some people like Dr. Sachs have received awards from Donate Life Hollywood this last year at the film festival for his great work on *ER*, and we applaud him for that because it was exceptional and it sent the right message out. You saw someone's examples of the humanity there.

There are still shows – *Mercy* and *Desperate Housewives* – who portrayed surgeons and organ recovery/Donate Life professionals as vultures wandering around looking for organs.

takes them from being victims to taking hold of their life and finding opportunity again in lives that can be fulfilled into the future.

Thomas Mone

What we know at the front lines, when we're working with families who have just lost someone, families like Ken and his family, is that at the time of death and the time of talking about the opportunity to donate, that it is not about taking organs. It is not about asking someone to give you their organs. It's about giving them the opportunity to take back a piece of life and control. It's about the opportunity to make something good and fulfill a life that's cut short. That is the message that is the compelling story because that's transformational for those families. It takes them from being victims to taking hold of their life and finding opportunity again in lives that can be fulfilled into the future.

I'll end with my very first donor case 10 years ago.

I walked in, and the coordinator said, "I'm going to introduce you to the donor mom." All of a sudden around the corner comes this woman, and she looks at me, and she wraps her arms around me and says, "Thank you. Thank you for helping my son live his life. I know he died. He was 18, but he's saved five other lives tonight, and he's lived his life. Thank you."

She will mourn that death. She'll probably mourn that death to her dying day, but she saw her son have a fulfilled life. And that is the most compelling story because we watched right there the transformation from loss and grief to hope and future.

**Neal Baer:** I think Dr. Montgomery said that between 19 and 20 people die per day on average for lack of an organ. The Institute of Medicine fairly recently started to talk about paying donors. Since you're in the thick of it, what do you think about that? I know people want to ask questions. What do you think about that? Does that raise any problems?

**Thomas Mone:** This is sitting on the governor's desk here in California right now. We were asked to talk with the governor's office about ways to increase donation in the state. He had a very compelling meeting with Steve Jobs, someone who did not get



liver appropriately but found his way and could afford his private Gulfstream to get there to Memphis, Tennessee, where the list is very short.

We talked about tax incentives? What about tax breaks for donors?

bumped up the list. Got his

Tax breaks for living donors, frankly, there's a pretty compelling argument. To be

Neal Baer

a living donor, you had to give up some time of your life and probably time at work and some income and a lot of other expenses associated with that. There's probably some real value in that. It's not about making money. I'm not selling my organ. I'm sure you didn't do that for the money.

Melodie Williams: No.

**Thomas Mone:** But the deceased donor family is not really losing any economic gain. Instead, they have a tremendous emotional loss. The ethics of this is a tough debate in the community because you're not about offsetting expenses; you're about rewarding somebody for the organ.

When you look at the places in the world where this is done – the Philippines, Pakistan, India and Iran – where it's state sanctioned, you develop a donor class. That actually is now called a vendor class, people who vend, who sell their organs. Every study out there says that a year later, they regret it and they are in worse physical shape than when they started.

The evidence is not very positive about paying people to donate. There is probably a place for covering some of the costs, but is not very positive on the social ethics standpoint.

**Neal Baer**: Thanks. Plenty to write about for writers. Questions? We'll take a few questions.

**Audience Participant:** How do you solve the problem of the wrong blood type? What do you do to make that work?

**Andrew S. Klein**: There are a number of strategies you can do to transplant across blood types. Some of them involve giving certain medications that help trick the immune system. Sometimes if it's actually across blood types, you have to remove the spleen, but there are ways where you can, as I said, trick the immune system into not having a violent response even though the blood types are different.

**Robert A. Montgomery**: There's "swapping" so that you can get the appropriate blood type.

**Audience Participant:** I've been in a number of emergency rooms. I do a lot of volunteer work, and even today I was with my uncle at USC's emergency room, and I never see anything about donations there. Are you not allowed to put the material where people live or where people die?

**Thomas Mone:** I can comment on that. In general, we find when people walk into a hospital, they're a little scared. It's really not where you want to first raise the topic. Hopefully, they've thought



(From left): James Redford, Kenneth P. Moritsugu, Andrew Klein and Melody Williams

about it beforehand.

For a while, hospitals were asking people when they registered, "Name, insurance company, who's your next of kin, do you want to donate your organs in case you die on the table?" Not the right message for the hospitals. So hospitals have backed away from doing that and we in the organ recovery business support them. We'd rather have that conversation beforehand. On the other hand, to have that in your doctor's office would be great.

**Audience Participant:** There was nothing to do. I was just sitting there for hours just looking for reading materials.

[Laughter]

**Thomas Mone:** Actually, to be honest, we're putting them now in a place where you stand around with nothing to do for a long time – at the DMV. And we're putting in video PSAs.

**Neal Baer:** Jamie, how are you doing at Outreach with kids?

**James Redford**: It's hard to get into the schools, obviously. That's a tough thing, and there's competing time. There are limitations. It's very hard.

I'm a believer in, love it or not, it's all about television and media. You're dealing with a very powerful medium in terms of communicating knowledge to people. If you break apart how kids



An audience member asks a question.

spend their time – and I have two of them – you don't have the time as you would hope to stop and ask questions about what they're seeing. I don't think that's going to change. So in my mind, it's about just trying to get the accurate information.

**Robert A. Montgomery:** There's a great precedent for this, though. What's the first thing that your kids say when you get in the car? "Dad, put your seatbelt on," right? Kids know that when you get in a car, you put your seatbelt on. When you die, you donate your organs.

I think you're right about reaching out to kids because their minds are not set yet, and they haven't been exposed to the mystical forces and various reasons why people don't donate their organs.

**Thomas Mone:** Kids learn in their health class. There's a bill in the state legislature this year to incorporate 30 minutes of organ donation education in health class.

**Neal Baer:** Great. I saw people give you a puzzled look when you said organ swapping. Can you explain that?

**Robert A. Montgomery:** Yes. As I mentioned earlier, there are a couple of ways that people can be incompatible with a potential donor.

If you take any two people in this room, there's a 35% chance that they'll be blood type incompatible. About 30% of the people who are waiting on the list, either from pregnancies, blood transfusions, or previous transplants, have been exposed to other people's tissue and have become sensitized against that tissue, just like you would with an allergy. That sensitization can cause an immediate rejection of the organ.

This is a large public health problem – incompatibilities. As Dr. Klein said, there are two ways to deal with it. You can trick the immune system into not recognizing the organ as being incompatible. Or

you can find someone else who has the opposite incompatibility and have your donor donate to their recipient and their donor donate to you. Then everybody gets a compatible organ. That's been termed "kidney swaps," and there are more and more of those that are being done every year.

There is a pilot study that we're a part of to take the initial steps towards creating a national database for swapping. There are computer algorithms that have been developed. One of them was featured on the show *Numb3rs* that was developed at our institution. It is like a dating service by matching compatible pairs.

We've estimated that we could do an additional 3,000 transplants a year if we could get around these incompatibilities at a large scale, at a national level. You would be increasing the number of live donors by 50%. This is a big thing.

**Neal Baer:** I wonder how you could use Chatroulette for organ donation or the Internet. Seriously.

**Robert A. Montgomery:** Well, the public is always way ahead of us, and that is happening. It's called MatchingDonors.com, and it's an online reservoir of stories – moving stories of people who need organs. You can get online and decide that you want to give an organ to a particular person because his or her story touches you.

**Neal Baer**: That's a good story for an episode.

**Audience Participant**: I have a problem with all of this as it seems that the part of me that's a writer/film maker is always in a reactive position. The part of me that's a doctor/bioethicist is always trying to think ahead.

Dr. Montgomery, is there an algorithm that you can think of with points that have to be covered that would make people understand transplant better over time?

When you react to different things – start with children, we have to get information out, dispel myths, and those kind of things, but if I wanted to do a series of points, educational pieces or narrative pieces, is there an algorithm that's been established by people who know the business?

**Robert A. Montgomery:** Well, I think I would probably defer to somebody who's involved in education, but it's an incredibly complex, difficult topic to get your arms around.

As Dr. Klein mentioned, part of it is that there are these very powerful myths out there that distract people. There are also equally powerful human interest stories out there. So there are a lot of mixed messages about transplantation.

Indeed, for a physician, it's a very unusual field to be in. We were discussing this earlier, because on one hand, you're the shepherd of a scarce resource, and on the other hand, you're an advocate for your particular patients. You have to balance those pressures every day. Has your patient become too ill to benefit from a transplant? Because if you take an organ and try to save that patient when it's futile, you take that organ away from someone else.

It's a field that is very charged because there are these life and death decisions made, and it is very dramatic. It is enormously complex for the people who do it everyday, and to try to make it easier to understand for the public, I think, is a real challenge.



The audience at the Writers Guild of America, West

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Robert A. Montgomery

**Neal Baer**: That makes it interesting for writers because it's full of minefields and ethical dilemmas. We've heard so many of the different parts of wealth, ethnicity, race, class, access, which make it pretty complicated.

**Audience Participant:** Can you speak to us a little bit about the doctor experience and the emotional impact that you deal with every day?

**Robert A. Montgomery**: Well, I just touched on one of the very interesting tensions that exist in what we do, which I actually find very challenging and interesting. You have to keep your ethical compass in line because you're constantly being challenged.

You're being called in the middle of the night with an offer for a patient on your list, and most organs are not quite perfect in some way. You have to decide whether it's a good enough organ to use and you're tired, and you have to have a tremendous amount of fortitude to keep doing that day in, day out, to make these decisions; to ignore some of your own needs in order to do the best you possibly can; not just for your patients but for humanity because these decisions that you make affect other people. If you decide to take an organ or not to take an organ for your patient, it affects other people, as well.

**Audience Participant**: What do you do to keep yourself that available for those really big decisions? How do you recover day in and day out?

**Robert A. Montgomery**: There are few things in medicine that are as dramatic as taking an organ from a dead person or a live person and shifting it into another person and restoring their health and their life.

To be involved in those dramas and to get the feedback from your patients about how this has affected their lives. I have a bulletin board in my office that has countless Christmas cards and letters: "I just walked my daughter down the aisle, which would've never



Melodie Williams with her daughter, Crystal

happened if you hadn't done my transplant." "I'm the coach for my son's baseball team, and that wouldn't have ever happened." These really dramatic real-life stories about how you've impacted someone's life; that's what keeps me going for sure.

**Andrew S. Klein**: I would agree with what Dr. Montgomery said. I would add that it's an amazing gift that's probably unlike anything else that we do in medicine. You develop relationships with your patients that are unlike the ones you might if you took someone's appendix out and saw them once and never saw them again.

I was interested to see that Joe is a scuba diver, so I'll tell you one quick story. The first person who I ever transplanted, he and I now go scuba diving every year. The first time we were diving, it was on the Cayman wall, so I'm at 100 feet, and I realize that five years ago, he put his life in my hands. Now, my life is in his hands. It makes you really think about life when you had those experiences.

**Sandra de Castro Buffington**: Thank you, all, for what has been a wonderful and inspiring event, and for the writers out there, please know that you can call on Hollywood, Health & Society for any time you're working on a health storyline on organ transplantation or any other health topic. I'd like to extend a warm thank you to all of tonight's speakers. This has been an extraordinary evening.

Thank you, all, and thank you, panelists.