

*The New Genetics:
Progress, Promises and Pitfalls*

Panel Discussion Summary



HOLLYWOOD, HEALTH & SOCIETY

Writers Guild of America, west

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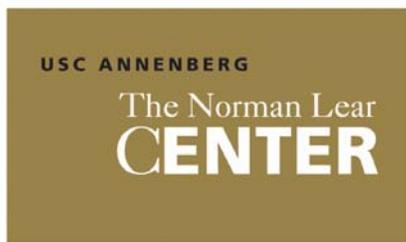
The Norman Lear

CENTERTAINMENT

Exploring Implications of the Convergence of Entertainment, Commerce, and Society

The Norman Lear Center

Founded in January 2000, the Norman Lear Center is a multidisciplinary research and public policy center exploring implications of the convergence of entertainment, commerce and society. On campus, from its base in the USC Annenberg School for Communication, 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 fellows, 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.



March of Dimes

The March of Dimes' mission is to improve the health of babies by preventing birth defects, premature birth, and infant mortality. It carries out this mission through research, community services, education and advocacy to save babies' lives. March of Dimes researchers, volunteers, educators, outreach workers and advocates work together to give all babies a fighting chance against the threats to their health: prematurity, birth defects, low birthweight.

Hollywood, Health & Society

Hollywood, Health & Society is a project at the USC Annenberg Norman Lear Center that provides entertainment industry professionals with accurate and timely information for health storylines through expert consultations and briefings, panel discussions and online tip sheets. Funded by the Centers for Disease Control and Prevention and the NIH's National Cancer Institute, the project recognizes the profound impact that entertainment media have on individual behavior and works to encourage accurate health messages in popular entertainment media like daytime and prime time TV shows.



HOLLYWOOD HEALTH & SOCIETY



Writers Guild of America, west

The WGAw represents writers in the motion picture, broadcast, cable and new technologies industries. The Writers Guild of America is the sole collective bargaining representative for writers in the motion picture, broadcast, cable, interactive and new media industries. It has numerous affiliation agreements with other U.S. and international writing organizations, and is in the forefront of the debates concerning economic and creative rights for writers. Visit the Web site at www.wga.org.

The New Genetics: Progress, Promises and Pitfalls

As scientists learn more about the human genome, important and challenging questions continue to arise. If you carry a gene mutation linked to cancer, can you do anything to prevent or delay the onset of the disease? Could genetic information be used against you by insurers or employers? Is new genetic knowledge also leading to new treatments? Ethical issues are also surfacing. Why do babies in some states receive screening for certain genetic disorders while infants in other states don't? Will genetic testing and treatment be available only to those who can afford it? Will human cloning and selective reproduction become commonplace? These issues and questions fueled an informative panel discussion among nationally recognized experts and people whose lives have been deeply affected by them.

The evening began with greetings from Marty Kaplan, director of the Norman Lear Center. Actor and author David Lander then offered introductory comments about his own experience with Multiple Sclerosis, a disease for which a genetic predisposition is currently being researched. Neal Baer, Executive Producer of *Law & Order: SVU* and co-chair of the Hollywood, Health & Society advisory board, moderated the panel discussion, which is summarized below. A technical problem with an audio recording prevented a complete transcription of the event.

David Swift and Newborn Screening for Metabolic Disorders

David Swift and his wife, Lori, have a daughter named Giana who was born with a rare, genetic disorder called 3-Methylcrotonyl-CoA Carboxylase Deficiency (3-MCC), which was detected during a newborn screening pilot program. David recalls the moment when he received the call notifying them that Giana had tested positive for this rare disorder. He said at the time he thought it was the worst moment of his life, but today he describes it as "the best." Because the condition was recognized at birth and the Swifts then knew to keep their daughter on a strict diet, Giana is currently a thriving and healthy 2½ year old.

David has met with, and testified before, state senators in support of a recently passed bill expanding newborn screening in California. The experience of his daughter's genetic disorder recently motivated David to write a black comedy/horror spoof of cloning called *Elvis' Mole*.

Dr. Stephen Cederbaum and the State of the New Genetics

Dr. Cederbaum is a Professor of Psychiatry, Pediatrics and Human Genetics and Chief Emeritus of the Division of Genetics in the UCLA Department of Pediatrics. As Head of Clinical Services in the division, he is responsible for the clinical evaluation and care of patients with genetic conditions. Dr. Cederbaum has been studying and caring for patients with genetic disorders, including Giana Swift, for more than 30 years. He explained that newborn screening for treatable metabolic diseases has been going on since 1966. He told the story of a patient who was born seemingly healthy and had an uneventful early life. At 9 months of age he caught a cold, became unusually lethargic and eventually was placed on intravenous feeding. After a period of some days, a diagnosis of Glutaric acidemia was made and an appropriate dietary and prophylactic regime was instituted. When he

recovered from this episode, its legacy was severe brain damage. At age 8 he cannot stand, cannot speak and understands speech very poorly. He never will become substantially better.

The tragedy is compounded by the fact that this dilemma today is largely preventable. With technology used for all births in some states now and to be initiated in California in July 2005, the condition would have been diagnosed at birth, treated by dietary manipulation and more rapid intervention for infection and other illness, and the outcome would have been a child who walks, talks, plays and who might have been entirely normal. By ages 4 to 5, the risks would have been eliminated and the diet liberalized if not normalized.

Dr. Cederbaum also relayed the story of a Jose, a man with a strong family history of Huntington's Disease. His mother is affected with Huntington's Disease as are one maternal uncle and one aunt. Jose's grandmother and a number of other relatives died from this condition. The chance that Jose carries the gene and will develop the condition is 50%. It would not develop earlier than ages 40 to 50. Jose elects to have a vasectomy, unbeknownst to the aunt and uncle who are raising him. Jose is now 55 and a successful professional. He is married to a woman who accepted the risk of living with a man who might become an invalid in his middle years. He has two adopted daughters who are married with children, and who face no risk of Huntington's Disease. A DNA test for Huntington's Disease now exists, and Jose decides to take the test. He tests negative – a weight of 40 years duration was lifted from his shoulders. His three sisters have elected not to be tested.

Dr. Maren T. Scheuner and the Role of Family History

Dr. Scheuner is a fellow at CDC's Office of Genomics and Disease Prevention. She also is a visiting Associate Professor in the Department of Health Services at the UCLA School of Public Health and a Senior Researcher at the UCLA Center for Health Policy Research. Dr. Scheuner is trained both in internal medicine and medical genetics. She has over 10 years of clinical experience providing genetic services for adult-onset conditions, such as cardiovascular disease and cancer. She has been involved in several genomics initiatives of national importance, though her primary interest has been the CDC Family History Public Health Initiative. The purpose of this initiative is to develop and evaluate a practical, valid and useful "genomics tool" that uses family history to assess disease risk and inform prevention strategies.

At the UCLA Center for Health Policy Research, Dr. Scheuner is developing a family history module to collect pertinent data that will enable researchers to assess family history as a disease risk factor. From 1995 to 2003 she was the director of the GenRISK Program at Cedars-Sinai Medical Center and a faculty member in the Division of Medical Genetics at Cedars-Sinai and the Department of Medicine at the David Geffen School of Medicine at UCLA.

Selma R. Schimmel and Her Personal Experience With Breast and Ovarian Cancer

Selma Schimmel is a breast and ovarian cancer survivor who was diagnosed with breast cancer at age 28 and ovarian cancer in her late 40s. Selma told her own personal story and described its impact on her entire family. After being diagnosed with breast cancer, Selma received testing for gene mutations known to be associated with breast and ovarian cancer. She was found to carry the BRCA1 mutation, as was her sister. Her sister's

daughters were also tested and none are carriers of the mutation. “Thankfully,” she says, “the mutation ended with my sister and me.”

Selma is the CEO and Founder of Vital Options® International TeleSupport® Cancer Network, an international not-for-profit cancer communications, advocacy and support organization. The nation's first organization to address the needs of young adults with cancer, Vital Options® has expanded to include people of all ages who have been touched by cancer. As host of *The Group Room*®, the nationally syndicated cancer talk radio show, Schimmel talks each Sunday with more than half a million listeners affected by cancer. In its 10th year on the air in the United States, the show also broadcasts regularly from Europe and can also be heard via satellite radio and Internet simulcast. Schimmel's book, *Cancer Talk: Voices of Hope and Endurance from “The Group Room,” the World's Largest Cancer Support Group*, was published in 1999 by Broadway Books, a division of Random House.

Steven K. Libutti, MD and Cutting-Edge Genetic Therapies for Cancer

Dr. Libutti was a Clinical Associate in Surgical Oncology at the National Cancer Institute (NCI) prior to becoming a Clinical Investigator and then Senior Investigator in the Surgery Branch. Dr. Libutti has received numerous honors and awards throughout his medical career including the Blakemore Award for Outstanding Research in Surgery and the NCI's Technology Transfer Award. He serves on the editorial boards for the journals *Biological Therapy, Molecular Imaging, Translational Medicine* and *Journal of Immunotherapy*, as well as several journal and grant review boards relating to cancer research. His research interests include tumor angiogenesis, anti-angiogenic gene therapy, gene expression profiling, regional perfusion therapy of malignant lesions, isolation and characterization of unique tumor cytokines and tumor-host interactions. Dr. Libutti received his MD from the College of Physicians and Surgeons of Columbia University and completed his internship and surgical residency at the Presbyterian Hospital in New York.

Dr. Libutti discussed his work in detection and treatment of colon cancer, which strikes 130 thousand people a year. Colon cancer is the second leading cause of cancer death in the United States, and has a mortality rate of nearly 50 percent. He discussed new detection and treatment options currently under study to increase survival, including local ablative therapy, anti-angiogenic therapy, and new ways to deliver chemotherapy.