Hereditary Disease Foundation

Winter 2010 Number 17

3960 Broadway, 6th Floor, New York, NY 10032 tel: 212-928-2121 fax: 212-928-2172
cures@hdfoundation.org www.hdfoundation.org

Dear Friends,

We just accomplished an extraordinary year!!

We celebrated our first *Leslie Gehry Brenner Award for Innovation in Science*. The Prize is to honor the memory of Leslie Gehry Brenner, the late daughter of Vice President and Founding Director, **Frank Gehry**.

In Frank's words:

> "Leslie was a wonderfully talented, original, free spirit. Leslie made us better by her presence and we mourn her absence. She was a gifted artist – creative with everything she touched – jewelry-making, photography, painting and filmmaking.
>
> I am pleased to congratulate **David Housman, Ph.D.**, the first recipient of *The Leslie Gehry Brenner Prize for Innovation in Science*.
>
> David's paradigm-breaking research – beginning in 1978 – to discover the Huntington's disease gene helped launch the Human Genome Project. The continuing ingenuity, originality and creativity in his work today make him the ideal first recipient of *The Leslie Gehry Brenner Prize for Innovation in Science*. Most accomplishments in Huntington's disease research have depended on his breakthrough.
>
> David's achievements honor Leslie's spirit and memory."

To launch *The Leslie Gehry Brenner Prize for Innovation in Science*, **Berta and Frank Gehry** gave an extraordinarily generous gift of **$1,000,000**!!

Prize recipients receive **$100,000** for research.

We held a Symposium and Dinner on Saturday, March 6, 2010 at the Casa Del Mar, Santa Monica, CA, to award the first Prize. We almost matched Berta and Frank's special gift. We raised a total of **$1,600,000** from the amazing outpouring of empathy and love for Frank, the Gehry family, Leslie and David. These pioneers make visible our passionate commitment to find treatments and cures to end pain and suffering.

August 4-7, 2010, the Hereditary Disease Foundation celebrated our 7th biennial symposium, **HD 2010: "The Milton Wexler Celebration of Life,"** in Cambridge, MA. Over 350 people came from throughout the world to share three days of scintillating science. From the quality of the science and comments during and after the meeting – this was our best symposium ever!

The work we support is moving us ever closer to clinical trials to prevent, delay, slow down, halt and even reverse Huntington's disease. This is the gold standard of our dreams! The sizzling mix of dynamic, committed, energetic investigators at the top-of-their-art, science and craft

was exhilarating! Everyone talked – all night and into the dawn – shared, formed new collaborations and strengthened old ones!

We are continuing to fund state-of-the-art research – 3 Contracts, 5 Grants and 9 Postdoctoral Fellowships totaling over **$800,000**. Our continuity of funding is especially critical when Federal sources of funding are imperiled. We continue to fund cutting-edge science that galvanizes us towards the cure.

We've also made our mark in the press this year. We had feature stories on NBC, BBC, NPR, *The Lancet*, *Financial Times* and *Panorama*. Please visit our website – www.hdfoundation.org – for details.

We are sad to say goodbye to friends and family who have been part of the Hereditary Disease Foundation's DNA since we were born. These stellar and creative individuals helped us leap frog to our current success.

We mourn the elegant, talented and vivacious **Jennifer Jones Simon**, a true original! Jennifer generously

*Please see **Letter from Nancy**, page 2*

Letter from Nancy

continued from previous page

donated an endowed program to support the Hereditary Disease Foundation's innovative, original, creative and unique Workshop Program. Originally named for Jennifer's late daughter, Mary Jennifer Selznick, the program was later named to honor **Milton Wexler**. Jennifer's critical support meant that these Workshops were the birthplace of finding the Huntington's disease marker in 1983, and later the gene in 1993. Now they are the focus of finding new treatments and cures for Huntington's disease.

Of all the things that Dad accomplished in his life of almost a century, he was the proudest of starting the Hereditary Disease Foundation. And he was even prouder still of the extraordinary Workshop Program which was truly a scene for unleashing genius. Jennifer's generosity made this possible.

Jennifer and her late husband, **Norton Simon**, often hosted Workshops in their home. They also threw spectacular parties for our Board of Trustees, Scientific Advisory Board and Workshop participants. Scientists and Board members were astonished by the extraordinary art in their home – from Henry Moore sculptures to the dancing Shiva and many wonderful Buddhas. The stunning creativity of their Frank Gehry-designed home, the mesmerizing art, and Jennifer and Norton's dazzle sent reverberations of originality through the scientists and into the science!!

Jennifer Jones Simon also played a critical starring role as a member of the Congressionally-mandated **Commission for the Control of Huntington's Disease and Its Consequences**, established by Congress in 1977. She was a committed and enthusiastic participant who faithfully attended all the meetings. These included public hearings around the country. Jennifer graciously listened to public testimony of patients, families, doctors and others. People from all walks of life spoke before the Commission and poured out their heartfelt stories. Jennifer was always warm, encouraging and accepting.

Nancy Wexler and Jennifer Jones Simon, 2009

The Commission made very specific recommendations to President Carter, Congress and the National Institutes of Health. Most people, however, had never heard of Huntington's disease and were totally unaware of its symptoms and staggering emotional and physical costs.

Jennifer narrated an extraordinary movie, giving voice to the hidden horror that is Huntington's disease. Jennifer and Norton then arranged for a special hearing to be held on Capitol Hill officially to give the Commission's recommendations to the President and Congress. It was a bipartisan love-fest, hosted by Ted Kennedy, Birch Bayh, and Jacob Javits, among others. When Birch Bayh listened to Jennifer's narration of the movie, he immediately nominated her for another Academy Award! In addition, Congress increased, by a substantial amount, the appropriations for research on Huntington's disease and the brain at the National Institute of Neurological Disorders and Stroke (NINDS, NIH).

Jennifer continued to play a critical role accomplishing essentially all of the Commission's recommendations!

She was an amazing woman with incredible qualities that are unequalled.

Our family first met **Harry Lieberman** when we began the Hereditary Disease Foundation in 1968. Harry was a man on a mission. His wife had recently been diagnosed with Huntington's disease and their three beautiful daughters each had a 50-50 chance of inheriting it as well.

Harry nursed his wife until she passed away from HD. He later married the elegant and beautiful, Evelyn, his partner and soulmate.

Harry was an impatient man – for very good reasons.

The terror of a loving father captured Harry as he watched movements envelop his gorgeous, eldest daughter, Joan. He understood her fears of what lay ahead. He appreciated her intelligence. He empathized with her independence and her desire to live on her own.

Harry gently persuaded Joan to move from Wisconsin to the Laurel Lake

Continued on next page

Letter from Nancy

continued from previous page

Harry and Evelyn Lieberman, 2004

Center for Health and Rehabilitation in Lee, MA, specializing in treating people with Huntington's disease. He moved heaven and earth to enable her to be admitted. Harry and Evelyn, along with Joan's children, visited her frequently until she passed away in 2005.

Harry watched in horror as the symptoms of Huntington's began to emerge and take hold of another of his three daughters, Barbara. Harry stood by her, watched over her, and was her support and advocate for many decades.

Tragically, Barbara died of HD only a month after Harry passed away.

Debbie Fine, Harry's third daughter, lived close by him in Philadelphia. She is a superbly evocative painter. Her latest show is now at The Rosenfeld Gallery in Philadelphia.

Harry was father, mother, chief advocate, defender, advisor, supporter in everything – emotional, financial, and all ways possible. He was the constant person in their lives upon whom all his children, grandchildren and great-grandchildren could rely and depend.

Harry was their Knight-in-Shining-Armor.

Harry often said to me, "I'm a man in a hurry – and you know why!!!!" He frequently cried when he said this – from fear, frustration, empathy and sadness. He fought for treatments and cures for his daughters, grandchildren and great-grandchildren. He helped his grandchildren think through whether or not to take the genetic test that could predict their future. He helped them cope with the results. Harry experienced the same relief from the knowledge that some would be spared and terror in knowing what others faced in their futures. He helped them with IVF and adoption.

Even though Harry's HD gene was normal, he struggled with HD as much as if it wracked his own body! He understood its terror and potency – as if in his own body – because his children and grandchildren had his DNA as well. In Harry's family, those not destined to follow down the HD path are inextricably intertwined in loving, caring for, fighting for, advocating, championing, mourning, and loving again. In Harry's family – everyone struggles with Huntington's disease, whether or not it is in their DNA – just like Harry.

Harry was extremely financially generous to his family – realizing that he would need to carry them far in the future.

Harry was also very generous to the Hereditary Disease Foundation. He was a Founding Trustee of the HDF. After we discovered the HD gene in 1993, Harry created **The Lieberman Award** to stimulate innovative, creative, imaginative research to find treatments and cures for HD. The Lieberman Awards were the most prestigious awards the HDF created and were given annually. The Lieberman Award supported Gillian Bates to create the very first mouse model of HD, and others who were studying fruit flies and cellular models, cutting-edge microscopes, RNA interference, and many more.

The list of winners is:

1994 – Gillian Bates, Ph.D., Guy's Hospital, London

1997 - Gillian Bates, Ph.D., Guy's Hospital, London, for her project entitled "Transgenic approaches toward an understanding of the molecular basis of Huntington's disease."

The Hereditary Disease Foundation was honored to TWICE award Gill the prestigious Lieberman Award for the development of her mouse and for further therapeutic studies. Her research has been featured on TWO covers of the prestigious science journal Cell.

1996 - Jacqueline White, Ph.D., Massachusetts General Hospital, for her postdoctoral fellowship project entitled "Generation and Analysis of a Murine Model for Huntington's Disease."

1998 - Leslie Thompson, Ph.D., University of California Irvine, for

Continued on next page

Letter from Nancy

continued from previous page

her project entitled "Cellular mechanisms of triplet repeat pathogenesis."

2000 - David Lovinger, Ph.D., Vanderbilt University for his project entitled "Development of Cortico- striatal Synapsis in HD Model Mice"

2002 - Russell Margolis, M.D., Johns Hopkins University

2003 - Lynn Raymond, Ph.D., University of British Columbia, for "Molecular Mechanisms of Enhanced Excitotoxicity in YAC Transgenic Mouse Models of HD."

2005 - Steven Finkbeiner, M.D., Ph.D., of the Gladstone Institute of Neurological Disease at UCSF.

Max Palevsky and Jodie Evans, 2009

Finkbeiner was recognized for resolving a mystery associated with Huntington's disease, using a robotic microscope that he custom-designed to allow the tracking of changes in cells, including those associated with neurodegeneration, over long periods of time. He is using the microscope to elucidate which forms of mutant huntingtin are most poisonous. Identifying these toxic forms could reveal how mutant huntingtin causes degeneration and may lead to specific therapies that block it.

2007 - Albert La Spada, M.D., Ph.D., University of Washington, Seattle, WA for "Elucidating the mechanism of energy disruption in Huntington's disease."

Max Palevsky's amazing intelligence, sophistication, and rigorous support of the Hereditary Disease Foundation were critical – especially in our earliest days. I remember vividly when he gave Dad stocks of Intel for the Hereditary Disease Foundation and said, "Don't sell it until it goes way up!" Max understood science and making a difference in the world. Dad began to panic because the stock was going down. But Max persuaded him to be patient. Max's Intel gift of stock supported many creative scientists for decades.

Brandon Roberts was so intelligent, sweet, soft, and astonishingly good looking that he took your breath away! He could have had a starring role in the movies! Instead, he starred as an action hero – Superman, Spiderman, and Batman all rolled into one!!!!!! His life saga was an action hero's success story. He wrote and taught us all a brand new script for how to live with grace and dignity. He is sorely missed.

Brandon was warm, affectionate, brilliant, sweet, and charismatic, with a winsome smile and astonishing hugs. While his body was growing and developing to maturity like a young steer, a gene inside his body began acting up. This gene, causing Huntington's disease, is just a tiny gene on the top of chromosome 4. But it directly affects the brain. And it delivers a powerful knock-out punch. As Brandon was maturing, this Huntington's disease gene began unraveling his every accomplishment. Brandon would work around the gene – and the gene would fight back.

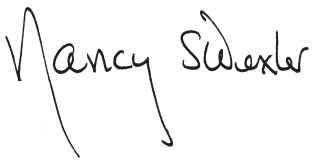
When Brandon and his family learned of his diagnosis with juvenile Huntington's disease, they were devastated, shocked and terrified! How could this be? And gradually, Brandon learned to accept his illness. Brandon and his family struggled to create the best that life could be. Brandon, Burton, Dedee and John bring to life a passion for living, a passion for joy, a passion to make the best of each day they have together, a passion to bring health to conquer sickness, a passion for laughter, a passion for hugs, and a passion for making the best out of life.

Brandon accepted and lived with Huntington's disease with equanimity and grace that is an inspiration to us all.

On September 7, 2010, Huntington's disease got the better of Brandon and he slipped away.

Each day, the memory of the many friends we have lost gives us renewed inspiration and enthusiasm to reach our goals.

Yours,



The Leslie Gehry Brenner Prize for Innovation in Science

The Hereditary Disease Foundation created *The Leslie Gehry Brenner Prize for Innovation in Science* to honor Leslie's memory. This annual prize of $100,000 reflects Leslie's many talents and gifts – originality, spontaneity, precision and rigor – all critical attributes in a scientist.

Welcome to the Hereditary Disease Foundation's 2010 Symposium and Dinner

Tonight we are celebrating the first *Leslie Gehry Brenner Prize for Innovation in Science*.

My daughter Leslie died of uterine cancer on November 16, 2008, one month after her 54th birthday. A wonderfully talented, original, free spirit, Leslie made us better by her presence and we mourn her absence. She was a gifted artist – creative with everything she touched. She drew magnificently and was an inspired painter, photographer and filmmaker. She celebrated life with joy and was extraordinarily courageous in the face of death. Leslie willed her modest estate to the Hereditary Disease Foundation.

I am pleased to congratulate David Housman, Ph.D., the first recipient of *The Leslie Gehry Brenner Prize for Innovation in Science.*

David's paradigm-breaking research – beginning in 1978 – to discover the Huntington's disease gene helped launch the Human Genome Project. The continuing ingenuity, originality and creativity in his work today make him the ideal first recipient of *The Leslie Gehry Brenner Prize for Innovation in Science*. Most accomplishments in Huntington's disease research have depended on his breakthrough.

David's achievements honor Leslie's spirit and memory.

With thanks,

Frank Gehry

David Housman Receives the First *Leslie Gehry Brenner Prize for Innovation in Science*

Dr. David Housman is Ludwig Professor of Biology at Massachusetts Institute of Technology.

David has contributed to the mapping, identification and functional characterization of genes for many human genetic disorders, including the genes for Huntington's disease, Wilms tumor, myotonic dystrophy and familial melanoma. He also is elucidating the role of particular genes in stem cells in the blood. He is also working on genes that cause resistance to chemotherapy to explain why chemotherapy stops working. His laboratory has participated in the development of innovative genomic technologies which have played a key role in the advancement of the Human Genome Project and the discovery of genes responsible for genetically based human diseases.

His current work utilizes in vivo testing systems to find drug targets and small molecules. These can be used potentially to treat Huntington's disease and myotonic dystrophy. David is studying complex trait genetics for neurodegenerative and cardiovascular diseases.

Nancy Wexler and Frank Gehry present David Housman with The Leslie Gehry Brenner Prize for Innovation in Science

Dr. Housman is a member of both the National Academy of Sciences and the Institute of Medicine of the National Academy of Sciences. He has won awards for teaching at Massachusetts Institute of Technology and in the field of biotechnology for his innovative contributions. Dr. Housman founded Integrated Genetics in 1980, which was acquired by Genzyme in 1989. His biotechnology company brought DNA-based diagnostics into an accessible setting for clinical use, as well as developing a number of useful, biologically-based therapeutics, including recombinant human fertility hormones.

He currently has a research program jointly with **Dr. Anne B. Young** and her team at MIND, the MassGeneral Institute for Neurodegenerative Diseases, Massachusetts General Hospital, Harvard University Medical School. Together they are working to find new treatments and cures for Huntington's disease, sponsored collaboratively with the pharmaceutical company, **Novartis**.

The Leslie Gehry Brenner Prize for Innovation in Science jury selected David as the first recipient of the Prize for his stellar, creative, innovative research on Huntington's disease. In 1979, he single-handedly persuaded the Scientific Advisory Board of the Hereditary Disease Foundation to support an entirely novel approach using DNA markers to find the HD gene. That was more than three decades ago – and the rest is history! ■

Many thanks for helping to make this evening so spectacular!! We raised over $1,600,000 thanks to your generosity!!!

The evening began with a state-of-the-art science symposium. *(See page 8 for details.)*

The evening continued with a wonderful and warm performance by **Howard McGillin** – star of stage and screen – where he wowed the crowd with his mellifluous voice and his phenomenal talent!

Howard set the record for appearing on Broadway in **"The Phantom of the Opera" – over 2,550 times**!!! Howard was responsible for lines stretching down Broadway every night and twice a day for matinees.

Howard also appeared in "Sunday in the Park with George," "Anything Goes," "Kiss of the Spider Woman," and many more.

I have been very fortunate to have many special, magical experiences in my life: finding the gene for Huntington's disease, being part of Frank Gehry's architecture and listening to Howard McGillin perform!

Howard McGillin

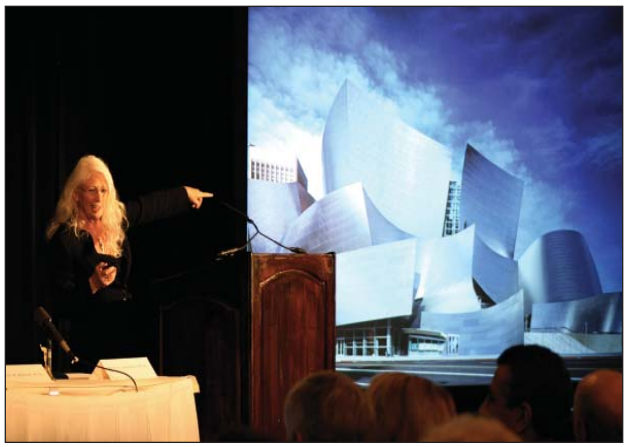
Howard helped make this special night even more magical!! Many thanks!

THE **FIRST ANNUAL**
LESLIE GEHRY BRENNER PRIZE SYMPOSIUM

March 6, 2010

Modern scientists often speak a highly technical language when they describe their experiments to their colleagues, a language difficult or impossible for most of us to understand. Yet the basic ideas behind many experiments and lines of research are usually not that difficult to comprehend, provided they can be explained in nontechnical, everyday language.

This was the idea behind the **Science Symposium** organized by the Hereditary Disease Foundation on March 6, 2010 at the Casa Del Mar in Santa Monica, CA. The Symposium was an integral part of a very special evening to award our first *Leslie Gehry Brenner Prize for Innovation in Science*. This Prize was presented to **David E. Housman, Ph.D.**, Ludwig Professor of Biology, Massachusetts Institute of Technology.



Nancy Wexler illustrates a DNA marker as Frank Gehry's Walt Disney Concert Hall in LA.

Along with David, the Symposium featured **X. William Yang, M.D., Ph.D.**, Associate Professor, Center for Neurobehavioral Genetics, Neuropsychiatric Institute, Department of Psychiatry and Biobehavioral Sciences, Brain Research Institute/Neurogenetics Affinity Group, Mental Retardation Research Center, David Geffen School of Medicine at UCLA; **Anne B. Young, M.D., Ph.D.**, Chief of the Neurology Service at Massachusetts General Hospital, Julieanne Dorn Professor of Neurology at Harvard Medical School, Founder and Scientific Director of MassGeneral Institute for Neurodegenerative Disease (MIND); and **Leslie M. Thompson, Ph.D.**, Professor, Director, Interdepartmental Neuroscience Program, Departments of Psychiatry and Human Behavior, Neurobiology and Behavior, and Biological Chemistry, University of California, Irvine. Our own **Carl D. Johnson, Ph.D.**, Executive Director for Science of the Hereditary Disease Foundation, served as moderator. Besides being brilliant researchers, all of these scientists are skilled at explaining their work to us lay folks, in language we can comprehend!! All of them are part of the Hereditary Disease Foundation family and have been on our Scientific Advisory Board for decades. Much of the amazing work they described has been supported by the Hereditary Disease Foundation, thanks to your generosity over the years. *(Their talks are available on request.)*

Carl Johnson, Leslie Thompson, David Housman, Nancy Wexler, X. William Yang, Anne Young

Nancy S. Wexler, Ph.D., Higgins Professor of Neuropsychology, Departments of Neurology and Psychiatry, Columbia University and President, Hereditary Disease Foundation, set the stage by describing her research trips to the Lake Maracaibo region of Venezuela, home to hundreds of affected families and several thousand individuals with Huntington's disease or carrying the genetic abnormality but not yet showing symptoms.

Nancy and her team gathered the family trees of over 18,000 people, dating back to the early 1800s. They also gathered medical information about the families. David said that without these families, finding the HD gene would not have been possible.

David Housman then described how he developed the basic conceptual approach that led, in an astonishingly short time, to identification of the genetic abnormality associated with Huntington's disease. The key element was the Venezuelan HD

Continued on next page

The Leslie Gehry Brenner Prize Symposium

continued from previous page

Carl Johnson and David Housman

community. David believed, back in the late 1970s, that newly-discovered variations in the DNA of different individuals – called RFLPs or Restriction Fragment-Length Polymorphisms – could be used to help find human disease genes. But it was not until he met Nancy and learned about the large Venezuelan HD families that he really became convinced it might be possible. At least it was worth a very good try!! He still feels, even today, that his participation in locating the HD gene, on chromosome four, which happened in 1983, and then identifying the HD gene itself, in 1993, were the highlights of his scientific life. These discoveries helped launch the Human Genome Project.

Leslie Thompson and Anne Young

David also told how, for him, finding the gene was just a beginning. He is still passionate about finding treatments and cures! He gave us a glimpse of his continuing work on so-called "genetic modifiers." These are other genes that may interact with the Huntington's disease gene to slow down or speed up or otherwise modify its effects. David feels frustrated that there are still no effective drugs to prevent, delay or reverse the onset of the disease. But he is gratified to know that, thanks to his identification of the HD gene and to another new technology called preimplantation genetic diagnosis (PGD), it is now possible for those carrying the abnormal version of the HD gene, as well as persons at 50% risk, to have children who are free of inheriting the disease.

While David showed us innovations as to how to make a healthy human baby, **William Yang** showed us how he used the same techniques to make both healthy mice and ones with HD. He explained how his team created a switch – basically another molecule – which he attached in his mice at the beginning of their HD protein. Thanks to William's inventive skill, these mice have the human HD protein in their mice genome. They develop abnormal movements and have behavioral disturbances. They also develop characteristic clumps in their brain cells. When William "flipped the switch" on these mice – they were cured!!! Even more astonishingly, the clumps did not appear!!!! Attaching the switch is much easier in mice than in men, of course. William's team is testing the safety and efficacy of this approach in mice, as preparation for clinical trials in humans!

With her usual flair for straight, understandable and inspiring talk, **Anne Young** laid out some of her work on possible drug treatment interventions for HD. She described the work of her team at the MIND at Massachusetts General Hospital, collaborating with the pharmaceutical giant, **Novartis**. There are wonderful advantages to working together with Novartis. It is a very sophisticated, expert company which has experience finding treatments and cures for genetic diseases. She explained that they have huge "libraries" or collections of molecules that might be useful to treat Huntington's. With the resources of a large company, Novartis can use a process called "high throughput screening" to see which of these millions of molecules target Huntington's disease and might be a possible new treatment. She described one such molecule that her team has identified, which they are pursuing as a promising lead. Anne has seen more patients with Huntington's than most neurologists anywhere in the world,

Anne Young's diagram of a cell shows both the normal and abnormal huntingtin protein.

Continued on next page

The Leslie Gehry Brenner Symposium

continued from previous page

but even she was surprised, she said, by one ninety-year-old woman with Huntington's. This woman, whom she showed us in a video, could easily have escaped diagnosis, except for the fact that her son developed symptoms much earlier in life. In the video the woman, who had extremely slight choreic movements, was crocheting! If only we could discover her secret!!

Anne Young is a hard act to follow, but **Leslie Thompson** rose to the challenge.

Leslie Thompson

Leslie sketched out one of the hottest new approaches in research on genetic disease, which has been greatly advanced by the establishment of the **California Institute for Regenerative Medicine** (CIRM), also known as the stem cell institute. Stem cells are those basic cells of the body that can essentially develop into any kind of cell, even a brain cell!! Stem cells are incredibly useful for testing drugs for both efficacy and safety. Leslie has been developing models of Huntington's in two different types of stem cells.

One type are called *embryonic stem (ES) cells*, derived from human embryos. Some of these embryos have the abnormal version of the HD gene in them. They have very generously been donated for precisely this kind of research by couples using "preimplantation genetic diagnosis" described by David earlier. Couples implant

Background: Anne Young's slide illustrate her drug discovery collaboration with Novartis to find cures.

embryos that have the normal version of the HD gene. Many also donate the embryos carrying the abnormal version of the gene for stem cell research. Even though some parents may go on to develop HD in the future, these brave parents are changing the course of history through their children and through research.

The other type of stem cells are known as *induced pluripotent (iPS) cells*. They are derived from skin cells that have been genetically engineered to convert them to stem cells. Stem cells from a person with either the abnormal or the normal versions of the Huntington's gene can be used to test drugs.

Leslie Thompson describes her multimillion dollar ideas for stem cells.

Leslie talked about using stem cells as a "disease in a dish" to look for new treatments. They could potentially be used to deliver drugs or as gene therapy, as stem cell and transplantation technologies develop.

Leslie's work is so important that she has garnered two prestigious grants – one for **$3.8 million** from the California Institute for Regenerative Medicine (CIRM), and the other, a **$1.4 million** grant from the National Institute of Neurological Disorders and Stroke (NINDS) of the National Institutes of Health (NIH) as part of the National American Recovery & Reinvestment Act. Leslie is the Principal Investigator (PI) - or team leader - for the CIRM grant and coordinating PI of the multi-investigator NINDS Consortium grant - both very big honors and trust in her work!!!!

From Maracaibo and Mass General to genetic modifiers and molecular switches to high-throughput screening and stem cells – the Symposium covered an array of exciting approaches, leaving everyone hungry for treatments and cures – and a sumptuous and delicious dinner!!! ■

LESLIE GEHRY BRENNER PRIZE FOR INNOVATION IN SCIENCE

Thank you so much for making this magical event such a success!!

Alice and Nancy Wexler

Jodie Evans, Frank Gehry, and Sally Kellerman

Back row: Alejandro Gehry, Carrie Jenkins, Anand Devarajan
Front row: Doreen Nelson, Joyce Shin, and Samuel Gehry

Joan Steffan, Leslie Thompson, and Tacie & Sandy Fox

Carrie Jenkins, Miriam Wosk,
Frank Gehry, and Alejandro Gehry

Nancy Wexler and John Roberts

Ed Moses

Please turn page for more Photo Highlights

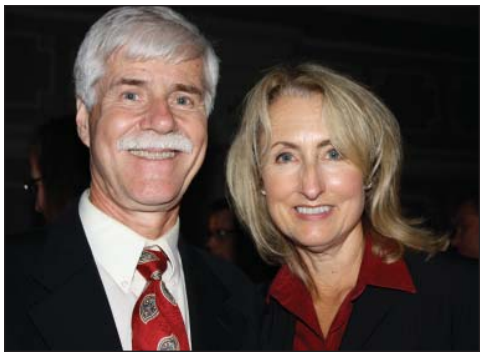
LESLIE GEHRY BRENNER PRIZE FOR INNOVATION IN SCIENCE

Bernie Moran and Susan Curtis

Nancy Wexler and Dawn Walker

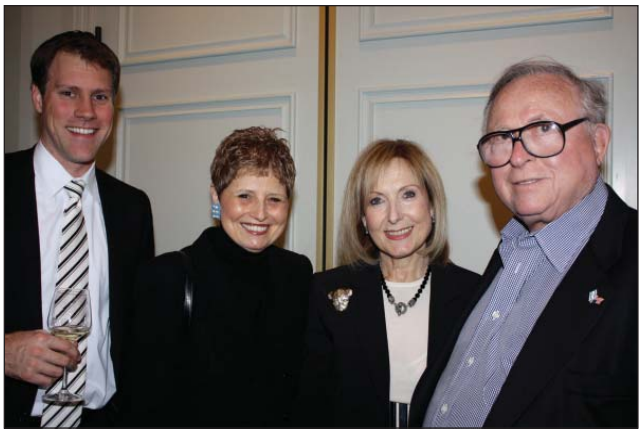
John Mazziotta, Nancy Wexler, Jonathan Guest, and Richard Samson

Paul Patterson and Ali Khoshnan



Bill & Joan Steffan

Jonathan Guest and Anne Young



Chad Smith, Deborah Borda, Rivka Seiden, and Larry Field

Please turn page for more Photo Highlights

LESLIE GEHRY BRENNER PRIZE FOR INNOVATION IN SCIENCE

Jodie Evans, Sally Kellerman and Jonathan Krane

X. William & Yue Peng Yang, Ai Yamamoto and Gian Mario Favalli

Barbara Isenberg and Frank Gehry

Jill Auerbach, Paul Muchowski, David Housman, and Lisa Masser

David Housman and Michael Andresen

Leslie Thompson and Sandy Fox

Carl Johnson and Richard Samson

Rebecca Marder and Tony & Helen Berlandt

Please turn page for more Photo Highlights

LESLIE GEHRY BRENNER PRIZE FOR INNOVATION IN SCIENCE

Elaine Attias and Alice Wexler

Miriam Wosk, May Carol Rudin, Patricia Glaser, Kerry Garvis Wright, and Jodie Evans

Back row: Carl Johnson, Susan Curtis
Front row: Illene & Michael Levine

Doreen Nelson and Frank Gehry

Nancy Wexler, Howard McGillin, and Deborah Borda

Carlos Portera and Yvette Bordelon

Chuck Arnoldi

LESLIE GEHRY BRENNER PRIZE FOR INNOVATION IN SCIENCE

Bobby & Dawn Walker

Howard McGillin (front) & Joe Thalken

Alice Wexler, Noriko Fujinami, and Paul Moore

Jodie Evans and Nancy Wexler

Joe Thalken, Howard McGillin, and Richard Samson

Arvind Sreedharan and Nancy Wexler

Michael Howard, Barbara Brownstein and Bruce Ricci

Report by Marina Chicurel

Macdara ("Mac") Mullin has trouble eating. His arms and legs move uncontrollably, almost constantly. His face twitches and his speech is often difficult to understand. Mac Mullin is only 45 years old, but he lives in a nursing home. He never married nor had children. Fourteen years ago, at the age of 31, he was diagnosed with Huntington's disease (HD).

Sharing his experiences at the meeting "**HD2010: The Milton Wexler Celebration of Life**," Mac Mullin powerfully motivated the scientists who gathered in Cambridge, Massachusetts on August 4-7. Nearly 200 presentations on HD were delivered to a bustling crowd of over 350 participants.

Researchers presented new findings, tools, and ideas to advance our understanding of HD. In contrast to meetings from years past, many of this year's presentations helped extend and strengthen established lines of research, in addition to exposing new, uncharted areas of study. *More than ever before, there was a sense of HD research reaching a new level of maturity and promise – one that is giving rise to a more solid foundation for the development of new therapies.*

One of the topics that showed encouraging signs of maturation, for example, was the use of gene silencing as a potential therapy for Huntington's disease. **Gene silencing** is a technique in which a particular gene is blocked from producing the protein it makes. In this case, the abnormal form of huntingtin is not produced, rescuing the cell. Ever since our earliest workshops in this area – and our grant support – nearly a decade ago, researchers have been collecting evidence that this strategy can rescue mice carrying an abnormal huntingtin gene which produces HD-like symptoms.


Nancy and Alice Wexler

At the 2010 meeting, several participants described progress in resolving the many technical issues associated with this ambitious treatment plan. Particularly exciting were observations from two research groups – working with mice – showed that the benefits of huntingtin gene silencing persist for weeks after stopping the silencing treatment. *These findings suggest that reducing levels of mutant huntingtin – even for a fairly short time – can have long-lived health benefits.* The group discussed an idea proposed by Carl Johnson, Executive Director for Science, Hereditary Disease Foundation, of using "Huntington's Holidays."In people, this treatment might entail giving the therapies at intervals to reduce toxicity.The research teams also reported that the silencing molecules were effective in reducing HD's symptoms and brain damage, even when they were given to mice that had already developed HD-like symptoms. *This suggests that the damage caused by the huntingtin protein is not necessarily permanent. Impairments can be reversed and repaired, when given a chance.*

There is still work to be done before gene silencing can be safely tested in people, but the technique has come a long way in ten years.And with the growing number of researchers tackling the challenges that remain, many participants were hopeful that testing in humans will soon be possible.

Another example of exciting progress presented at the meeting was the description of **new ways to track the effects caused by HD**, even in individuals who are not yet experiencing symptoms and have not been diagnosed. Because HD develops slowly over many years and often causes different symptoms in different people, tracking HD is not easy. Being able to carefully monitor the effects of HD over time is very important. *It is especially critical in designing clinical trials to see if*


Nancy Wexler and Gillian Bates

Continued on next page

continued from previous page

new treatments are effective. Being able to more rapidly determine if treatments work is good for patients and families.

For many years, researchers have been searching for indicators—known as **biomarkers**—of HD's progression, that are reliable, consistent, and can be measured without causing much discomfort.

Findings presented at the meeting suggest that several such biomarkers may soon be available. For example, meeting participants described changes in the brain. Sometimes these can be detected using extremely **sensitive brain imaging techniques**. These changes can sometimes be identified decades before people develop symptoms. Some of these differences are noticeable in brain scans across the span of a single year. These changes in brain scans promise to be helpful in documenting how well a treatment works. They also may be helpful in giving treatments to individuals even before they are diagnosed. Sometimes giving therapies preventively can be very effective.

Investigators also described changes in molecules that can be detected in blood as potential biomarkers. Some molecules reflect changes in the gut. These molecules can even be found in feces! All these different molecules appear to be excellent indicators of HD's effects. *These early, sensitive biomarkers should help researchers more easily assess whether a potential new treatment is beneficial.*

New exciting discoveries were presented revealing extraordinary insights into how the abnormal huntingtin protein causes symptoms. Even more critically, plans were laid out for thwarting the culprit in its tracks! Several participants used new "high throughput" techniques in which the effects of hundreds or thousands of molecules can be tested

David Housman and Sir Michael Rawlins

at once. The data emerging from these studies point to several proteins in the body that could possibly be modified with drugs to treat HD. Some of these proteins are targeted by drugs that are already being developed to treat other diseases, such as cancer. This means that, if the benefits of these drugs are confirmed, they could be available for medical use relatively quickly.

Participants also provided new evidence on **how the abnormal huntingtin protein behaves under different conditions,** suggesting new ways in which its harmful effects could be stifled. For example, some researchers showed how chemically modifying the abnormal protein, through a naturally occurring process called phosphorylation, changes the way it clumps inside cells. Being able to regulate the clumping, or aggregation, of huntingtin is of potential medical value. We are learning increasingly from HD experts that these clumps can be either good or bad for the cell – depending on their structure and location.

Participants were also excited about tools that promises to help accelerate the screening of drugs for treating HD. *New techniques are enabling scientists to obtain human stem cells – cells that can reproduce in a dish and be coaxed into making different types of cells, including brain cells. Stem cells can be derived from tissues of people with HD, allowing scientists to study safely the effects of different drugs – before testing them in people.* Stem cells can be used like a "**disease in a dish**"! Since human stem cells have our human proteins – both the abnormal and normal versions – they are wonderful professors to teach us about Huntington's. These professors also give us new leads on finding drugs.

In addition to discussing ways to halt or eliminate the abnormal huntingtin protein's negative effects, researchers at the meeting discussed ways to **manage better HD's symptoms**. For example, one researcher showed that when the sleeping and eating schedules of mice carrying the HD gene are normalized, their HD-like symptoms improve significantly. HD mice, like HD patients, have disrupted sleep-wake cycles. However, when they are given a drug to make them sleepy during the day (mice normally sleep during the daytime) and a drug to keep them awake at night, they perform better on tests that assess the severity of their HD-like symptoms, including tests of their mental skills. Also, putting these mice on a regular feeding schedule improved their health, particularly enhancing their liver function.

Findings like these illustrate the maturation and excitement of HD research – an especially welcome event considering the struggle of individuals suffering with HD like Mac Mullin. Mr. Mullin urged participants to keep up their efforts to develop a cure for the next generation. "It's a pain to your heart, and you can't take it away," said Mr. Mullin as he described receiving the news of his HD diagnosis. **Judging from the advances presented at the "HD2010: Milton Wexler Celebration of Life Symposium, it won't be too long before there will be much better medical options to lessen, if not remove, such dreadful pain.** ■

2010 Funding

Hereditary Disease Foundation grants, postdoctoral fellowships and research contracts are helping identify routes to the development of cures and treatments for Huntington's disease and other similar hereditary disorders. The HDF's Scientific Advisory Board, comprised of world-renowned experts in genetics, neurology, neuroscience, and therapy development, approves funding for groundbreaking research. The following projects received over $800,000 in funding in 2010.

SPECIAL AWARD

David Housman, Massachusetts Institute of Technology. ***First Recipient of the Leslie Gehry Prize for Innovation in Science.***

RESEARCH GRANTS

Mate Dobrossy, Cardiff University. Characterizing BAC transgenic mice lines expressing GFP under the control of D2 and M4 promoters corresponding to the striatal indirect and direct pathways, respectively.

Martin Duennwald, Boston Biomedical Research Institute. The immuno proteasome as a potential new therapeutic target in Huntington's disease.

Michelle Gray, University of Alabama at Birmingham. Conditional inactivation of full length mutant huntingtin expression in glial cells of BACHD mice.

Jodi McBride, Oregon Health & Science University. Systemic delivery of RNA interference using AAV9: pushing the envelope for a global delivery strategy to treat Huntington's disease.

Daniel Offen, Tel Aviv University. Mesenchymal stem cell secreting neurotrophic factors: a potential new therapy for Huntington's disease.

POSTDOCTORAL FELLOWSHIPS

Ismael Al-Ramahi, Baylor College of Medicine, Mentor: Juan Botas. Screen of genes involved in Ca2+ homeostasis and signaling to identify genetic modifiers and potential targets for HD treatment.

Rebecca Aron, Gladstone Institute of Neurological Disease, University of California, San Francisco, Mentor: Paul Muchowski. Validation of potential genetic modifiers of Huntington's disease in neuronal cell and mouse models.

Nicholas Franich, David Geffen School of Medicine at UCLA, Mentor: Marie-Francoise Chesselet. Direct comparison of CAG 140 and CAG150 knock-in mouse models of Huntington's disease: neuropathological and behavioral analysis.

Geraldine T. Gomez, Children's Hospital Boston, Harvard Medical School, Mentor; Paul Rosenberg. The role of cell-type specific expression of GLT1 in the pathogenesis of Huntington's disease.

Raphael Hourez, Harvard Medical School, Mentor: Alfred Goldberg. Can puromycin-sensitive aminopeptidase (PSA) help protect against polyglutamine-induced neurodegeneration?

Shulin Ju, Brandeis University, Mentor: Gregory Petsko. Structural and functional characterization of the Huntington's disease-associated protein huntingtin: identification of interacting proteins using yeast two hybrid screen and structure determination by x-ray crystallography.

Jane E. Lauckner, Stanford University, Mentor: Ron Kopito. Characterization of the infectious transmission of polyglutamine aggregates in the pathogenesis of Huntington's disease.

Amanda Lumsden, Massachusetts General Hospital, Harvard University, Mentor: James Gusella. Investigating the normal function of huntingtin in *Dictyostelium discoideum*.

Antonio Valencia, Massachusetts General Hospital, Harvard University, Mentor: Marian DiFiglia. Role of lipid rafts in the AKT dependent survival pathway in Huntington's disease.

RESEARCH CONTRACTS

Beverly Davidson, University of Iowa. Preclinical development of a gene therapy for Huntington's disease via RNA interference.

Christian Neri, INSERM, France. Accelerating data integration for the prioritization of HD high-quality neuroprotective targets and releasing information.

Leslie Thompson, University of California, Irvine. Cure HD Initiative: Transcription Project; Investigating Gene Expression Profiles in HD *Drosophilia* Project.

EXCITING NEWS - BREAKTHROUGH IN HUNTINGTON'S DISEASE FEATURED ON THE NBC NIGHTLY NEWS!

Aired Monday, May 10, 2010 on the NBC Nightly News with Brian Williams, ***Robert Bazell****, Chief Science Correspondent, interviewed Hereditary Disease Foundation President* ***Nancy S. Wexler****, Ph.D., as well as longtime Hereditary Disease Foundation-supported researcher* ***X. William Yang****, M.D., Ph.D., about Yang's recent and exciting research findings on Huntington's disease at UCLA!*

Mapping Huntington's Disease

By Robert Bazell, NBC's chief science and health correspondent

Tonight we report on a story we have been following for almost three decades. Huntington's disease is a hereditary condition that destroys parts of the brain that control movement, intellect and emotions. In other words, it wreaks a horrible destruction of both the mind and the body. About 30,000 people in the U.S. suffer the condition, which is usually fatal within a few years of onset.

Huntington's disease (HD) gets far less attention and resources than many other deadly conditions, one reason being that other than the folk singer Woody Guthrie, no celebrities have suffered its fate. But in the world of science, HD gets a lot of attention, because research on the disease has led to many critical firsts that could prove useful for HD as well as other better known genetic and brain disorders. Much of this effort can be traced to Dr. **Nancy Wexler** of Columbia University Medical Center, whom we profile tonight. Soon after Nancy graduated from college, she learned her mother suffered from Huntington's. Because Huntington's is caused by a single dominant gene, that meant Nancy and her sister Alice each have a 50 percent chance of acquiring the disease themselves.

Their father, **Dr. Milton Wexler**, a well-known Beverly Hills psychoanalyst, set up a foundation to focus as many of the world's top scientists as possible on the quest for a cure. Starting in 1979, Nancy and a long string of collaborators began working with the residents of Maracaibo, Venezuela, a very poor fishing community with an unusually high incidence of HD. With blood samples from Maracaibo, scientists first found the approximate position of the HD gene. This led to a blood test to determine who is a carrier and who is not. It was among the first genetic tests to raise some of the profound ethical dilemmas that often come with genetic testing.

In 1993, the scientists isolated the gene and went on to discern how it destroys the mind. In tonight's report, we describe how **Dr. X. William Yang** of UCLA has used that information to genetically manipulate mice with the condition and eliminate the disease. Genetic manipulation of mice is not a cure, but the story illustrates both the difficulties and exhilaration of medical research.

For excellent accounts for the search for a cure, I recommend **Alice Wexler's** two books: *"Mapping Fate: A Memoir of Family, Risk, and Genetic Research"* (1996) and *"The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease"* (2010). Both are available in paperback.

More specifics about X. William Yang's research:

X. William Yang, M.D., Ph.D., is Associate Professor, Semel Institute and Department of Psychiatry & Biobehavioral Sciences at the David Geffen School of Medicine at UCLA. He has made many critical contributions to solving the Huntington's disease puzzle!

William created the first "Bacterial Artificial Chromosomes" (BAC) transgenic mouse model of HD. This mouse expresses the entire human, abnormal HD gene. These mice show multiple behavioral and brain changes, similar to people with HD. His BACHD model is now widely used internationally to better understand the illness. It is also used to test candidate therapies for Huntington's disease.

William pioneered a series of Huntington's disease mouse models in which the expression of the abnormal huntingtin protein can be switched on or off in different cell types in the brain. Using these models, he showed that the abnormal huntingtin protein, expressed in one type of nerve cells, can make their neighbors sick.

In a recently published study, using yet another set of BACHD mouse models, William's group demonstrated a molecular switch which lies in the very end of the abnormal huntingtin protein. William and his colleagues found that by modifying – or "flipping" – that switch, they can prevent the appearance of HD symptoms in these mice.

To demonstrate this, William and his colleagues genetically engineered mice expressing the abnormal huntingtin protein, with subtle changes. In one group of mice, he mimicked a chemical tag, called "phosphorylation." These mice were cured of the disease and did not develop any symptoms.

In another group of mice, he engineered the mice to resist such chemical tagging. These mice got sick with HD symptoms.

William's group showed that, in mice, mimicking phoshorylation can prevent the onset of the disease. His study demonstrates the vital importance of discovering new HD treatments that can work through this neuroprotective molecular switch. ■

BBC

On the Hereditary Disease Foundation website, you can read, watch and listen to various print, TV, and radio pieces, skillfully and sensitively reported by Will Grant of BBC.

Venezuelan village key in search for Huntington's cure

By Will Grant
Published August 19, 2010

The village of Barranquitas in Venezuela has the highest concentration of Huntington's disease, a devastating brain condition, in the world. The BBC's Will Grant accompanies a US scientist there as she continues her life's work to find a cure.

Dr Nancy Wexler has been coming to Barranquitas for many years

Dr. Nancy Wexler has been coming to Barranquitas for many years.

Angela staggers across Barranquitas under the blistering sun to reach the children's lunch hall, her matchstick-thin legs struggling to support her frail frame.
Although it is a small village, it is hard work crossing it when your limbs won't do what you tell them to.
But Angela is determined to make the effort because an old friend has just arrived.

That friend, American scientist Nancy Wexler, has been travelling to Barranquitas for more than 30 years. She is sure it holds the key to an answer she has been looking for her entire adult life: a cure for Huntington's disease (HD).
For Dr Wexler this is more than an academic pursuit or a career goal, it's a family obsession.

"My mother died of Huntington's and she was a scientist. My father was a scientist too, and so we said 'let's find a cure'," said Dr Wexler. "And we still say that. You can't get up in the morning without having hope and confidence that the cure is just around the corner."

As the daughter of an HD sufferer, she has a one-in-two chance of carrying the fatal genetic flaw herself.
Huntington's is an incurable and fatal hereditary disease which causes the sufferer to lose control of their muscles.

It develops into serious problems with swallowing and many patients die from choking or malnutrition. Beyond the physical symptoms, deep depression can often take hold.

It affects 1 in 10,000 people, but in Barranquitas, a remote location where over the years there has been much inter-marrying between few families, the rate is more like 1 in 10.
Some 1,000 villagers already have fully-blown Huntington's; many more carry the gene.

Such a high concentration of Huntington's patients made it the backbone of Dr Wexler's research.
Her research in Venezuela was crucial for the breakthrough in 1993 when the abnormality that causes HD was identified: a single defective gene on chromosome 4.

HUNTINGTON'S DISEASE

- Hereditary neurological disorder
- Causes progressive degeneration of cells in brain
- Slowly impairs ability to walk, talk, think, or reason
- Symptoms usually appear between age 30 and 50
- Person has 50% change of inheriting the gene if a parent has HD
- No cure to date

Ciro Soto is one of the villagers whose DNA and family history helped that discovery.

Dr Wexler met Mr Soto when he was just eight years old. Now almost 40, his body twitches uncontrollably from the disease. "Ciro was a wonderful drummer, very athletic, a beautiful fisherman," said Dr Wexler.

"Both of Ciro's parents had Huntington's," she explained. "There were 14 siblings and 10... have Huntington's. Some of them have

Continued on next page

Venezuelan Village Key to Cure

continued from previous page

unfortunately already died of the disease."

Tough life

Despite the breakthrough, the team had not been back to Venezuela since 2002 given the strained ties between the Bush administration and President Hugo Chavez.

There is still no formal protocol with the Venezuelan government for removing the DNA samples Dr Wexler needs.

But in a positive development, the Venezuelan Health Ministry sent a representative to Barranquitas to meet her.

"I think Dr Wexler's persistence has been admirable," said Dr Federico Savinon.

While acknowledging there been some "difficulties in working together", Dr Savinon said that "the ministry and the health minister herself, Col Eugenia Sader, are completely disposed to reopening a space for joint work with Dr Wexler". However, Dr Wexler and the people of Barranquitas have heard such promises before.

Successive health ministers have voiced support for the research, but the New York-based team are yet to see any serious progress on the signing of the protocol for the research.

Life in Barranquitas is tough. The government has provided new housing for some families, including Ciro's.

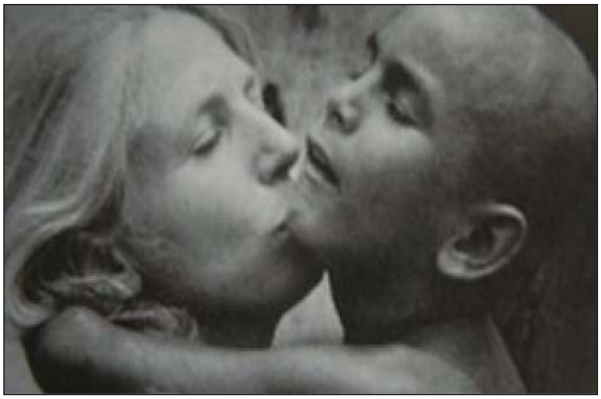
But most Huntington's sufferers still live in deep poverty while simultaneously trying to deal with the fatal illness.

Casa Hogar is a care home looking after some 50 people.

In 1999, Dr Wexler co-founded a care home for HD patients outside the state capital, Maracaibo.

Built on the site of the "roughest bar in town", the Casa Hogar is a haven for more than 50 people whose families can no longer cope. Everyone who works there has relatives with Huntington's sufferers. Many of them don't know if one day they may develop the disease too. Dr Wexler's long association with Barranquitas gives her hope.

The Casa Hogar is facing a chronic lack of funding, possibly even closure. Still, Dr Wexler remains confident that one day it won't be needed. "We never know when some miraculous discovery is going to be made," she said.



"There are science breakthroughs on the horizon and happening now so I am very hopeful about the cure in the near future."

When Angela made it to the lunch-hall, she was greeted with a huge hug by Dr Wexler.

Despite the setbacks, Dr Wexler is optimistic that Angela's grandson, who is also at risk of the disease, will have more of a chance at a cure than she did. ■

Benedict Mander of The Financial Times *has written thoughtfully about the families suffering from Huntington's disease in the village of Barranquitas, Venezuela. He was able to expertly capture the dignity of these wonderful people and the tragedy of their circumstances.*

Venezuela village holds cure for hereditary illness

Excerpted from Benedict Mander in Barranquitas
Published August 17, 2010

It does not take long to realise that there is something wrong in Barranquitas. Some of the villagers wander around aimlessly, looking confused and frightened. Many are grotesquely emaciated. Their limbs jerk erratically.

A grim fate awaits many of the inhabitants of this isolated village on the south western shores of Lake Maracaibo in Venezuela, even those who appear perfectly healthy.

About half of the roughly 10,000-strong population of Barranquitas either has, or is at risk of developing, Huntington's disease (HD), a fatal hereditary illness that gradually kills brain cells and causes the body to waste away.

This remote area has the highest concentration of HD in the world, which is why Professor Nancy Wexler has come here almost every year since 1979. It was her research, far away from the cutting-edge laboratories of the developed world, that was the key to a discovery that pushed back the boundaries of science.

"It was this family here that launched the Human Genome Project," says Prof Wexler, her arm affectionately around the shoulders of a young man called Siros. "Siros's family proved that we had the gene," she explains, from a dingy concrete room in Siros's home in Barranquitas.

By studying the blood samples from Siros's family, which has been afflicted with a uniquely large number of cases of HD through several generations (both of Siros's parents suffered from the disease, as did 10 of their 14 children), Prof Wexler and her collaborators isolated the gene that carries the disease.

Nancy greets Siros, whose family was crucial in helping towards the discovery of the location of the Huntington's gene, which also triggered the start of the Human Genome Project.

"They said it would be like trying to find a needle in a haystack. Actually, it's more like trying to find a particular bit of hay in a haystack," says Prof Wexler. She said that most scientists ridiculed her quest, while even the "believers" warned that the project could take anything from 50 to 100 years.

But she was determined: when Prof Wexler was in her early 20s her mother was diagnosed with HD, meaning that she herself has a one-in-two chance of developing the disease.

Prof Wexler's research, which included painstakingly piecing together family relations in Barranquitas and a nearby village called Laguneta, enabled the discovery of the gene that causes HD.

Her ground-breaking methods proved that it was possible to do the same with all genes, heralding the beginning of the Human Genome Project. "It was mind-blowing," she said. The discovery of the HD gene also meant that accurate tests could be made to determine whether or not humans, including foetuses, would develop the disease.

Prof Wexler decided not to take the test herself. "What's the point of finding out whether I have the disease if there's no cure?" she asks.

So far a cure has remained elusive. Not only would it change the lives of a huge number of people around the world – HD occurs in 5-10 people per 100,000 – but it is also believed that a cure for HD might help in finding a cure for other more complex neurodegenerative disorders such as Parkinson's and Alzheimer's.

So Prof Wexler keeps returning to Barranquitas, where she has become known as the "blonde angel". Now, wherever she goes in this rundown, forgotten place, she is greeted with smiles, hugs and cheers, and attracts large crowds that follow her around its muddy streets.

"She's like the Pied Piper," remarked the former British Ambassador to Venezuela, Catherine Royle, who has closely supported Prof Wexler's work.

A Barranquitas local, María Luisa Hernández, a local who cares for children in danger of developing HD, says, "Nancy Wexler has given more than just professional help but her love, her life." ■

FT.com FINANCIAL TIMES

In Memoriam

We mourn the loss of wonderful friends. They have been critical supporters of the Hereditary Disease Foundation family. They have played inspirational roles to the world as well.

They understood the importance of the novel, creative and cutting-edge science we support. Their belief and support in us made it possible.

***Jennifer Jones Simon, Harry Lieberman and Max Palevsky**, longtime friends and Founding Trustees of the Hereditary Disease Foundation—we all miss and love you!*

JENNIFER JONES

March 2, 1919 - December 17, 2009
By Claudia Luther

Hans Edinger/
Associated Press

Jennifer Jones, the actress who won an Academy Award for her luminous performance in the 1943 film "The Song of Bernadette" and who was married to two legendary men—producer David O. Selznick and industrialist and art collector Norton Simon—has died. She was 90.

Jones died Thursday of natural causes at her home in Malibu, according to Leslie C. Denk, a spokeswoman for the Norton Simon Museum in Pasadena.

Jones had an influential role at the art museum, becoming chairwoman of the Norton Simon Foundation Board after her husband's death in 1993 and overseeing a $3-million renovation of the museum's interior and gardens that was completed in 1999.

But she was best known for her movie career. In all, she starred in more than two dozen films, playing opposite such A-list actors as William Holden, Joseph Cotten and Gregory Peck.

In addition to her best-actress win for "Bernadette," Jones was nominated for an Academy Award for leading roles in three other films: "Love Letters" (1945), a melodrama in which an amnesiac is cured through the love of a man, played by Cotten; the western epic "Duel in the Sun" (1946), with Peck; and "Love Is a Many-Splendored Thing" (1955), in which she played Dr. Han Suyin opposite Holden. She was also nominated as best supporting actress for "Since You Went Away" (1944), in which she starred with her first husband, Robert Walker.

The tall, sensitive Jones might never have risen to stardom but for Selznick, who was the first to see something special in the beautiful "big-eyed girl" named Phylis Isley who showed up in his New York office to test—although not very well—for the part of Claudia in the 1943 film of the same name. (Dorothy McGuire won the role.)

After seeing her second test, he decided she was "the best sure-fire female star to come along since Leigh and Bergman"—referring to Vivien Leigh and Ingrid Bergman, both then under contract to the producer.

He found the young actress a new name and began grooming her for stardom, finding Jones her first big role in "Bernadette" and, afterward, producing or choosing most of her films. He endlessly pestered Hollywood with his memos about her makeup, her camera angles, her costumes. She was his protege, his obsession, his crusade, eventually his lover and, finally, his wife.

His adoration of her, said film critic David Thomson, shaped the rest of his life and fueled "one of the great gossip-column melodramas of the time."

"She was an ardent young actress before she met Selznick," Thomson wrote in "The New Biographical Dictionary of Film." "But it is hard now to be sure whether we would know her if his great wind had not picked her up like a leaf."

Jones was born in Tulsa, Okla., on March 2, 1919, the daughter of the owners and stars of Isley Stock Co., a tent show that toured the Midwest. She became interested in acting during her school years and eventually studied at Northwestern University and the American Academy of Dramatic Arts in New York.

It was at the academy that she met Walker, whom she married in 1939 and with whom she had two sons, Robert Walker Jr. and Michael Walker.

Continued on next page

continued from previous page

After several failed attempts to break into Hollywood, the two actors settled in New York City, and Jones finally got her chance for a screen test with Selznick.

By that time, Selznick was almost 40 and had already produced the epic "Gone With the Wind" and a string of popular and important films, including "David Copperfield," "A Tale of Two Cities" and "Rebecca." He was looking for another "GWTW"—and another star to discover.

"The Song of Bernadette," a 20th Century Fox film directed by Henry King, was the vehicle Selznick picked to introduce Jones to the American public.

It was, everyone agreed, perfect casting. Jones, who was Catholic and had gone to a convent school, had the kind of wide-eyed innocence that made her believable as Bernadette Soubirous, the French peasant girl who saw a vision of the Virgin Mary in a grotto.

"I cried all the way through 'Bernadette' because Jennifer was so moving and because I realized then I had lost the award," said Ingrid Bergman, who was nominated for an Oscar for her role in "For Whom the Bell Tolls" the same year Jones won.

At the time, Jones was a wife and mother, but even that tame image was not what the studio wanted for the actress it had playing a virginal mystic. For months, Jones was asked to hide her family life and present herself as a real-life Bernadette.

That changed after Selznick arranged for Jones and Walker to play opposite each other in Jones' second starring film, the World War II tear-jerker "Since You Went Away" from 1944. To promote that film, publicity stories were churned out about "Mr. and Mrs. Cinderella" and their contented home life with their children.

By then, however, the relationship was frayed, and the couple divorced in 1945. Walker, who had starred in "See Here, Private Hargrove," "Strangers on a Train" and opposite Judy Garland in "The Clock," died in 1951.

In 1948, Selznick divorced his wife, Irene Mayer, daughter of MGM mogul Louis B. Mayer. Selznick, 47, and Jones, 30, were married in 1949 on a yacht off the Italian Riviera.

More than 30 years later, Jones told the Washington Post of her relationship with Selznick: "I felt appreciated right from the beginning. I felt totally at ease. I don't know whether that's love at first sight."

But she said the stories of Selznick's domination were overblown.

"I had good roles, and I had David to guide me," Jones said.

Selznick's "Duel in the Sun" a 1946 western, earned Jones one of her best-actress Oscar nominations.

Selznick intended "Duel" as a sweeping epic in the tradition of his greatest triumph, "Gone With the Wind."

But the film, in which Jones played a woman of mixed race caught between two brothers (Peck and Cotten), ran into publicity problems when the Catholic Church issued a statement saying the story "tends to throw audience sympathy on the side of sin" and that Jones "is unduly, if not indecently, exposed." The Egyptian Theatre in Hollywood removed posters of her that showed cleavage, and much was made of the difference between Jones' role in "Duel" and her role as the innocent in "Bernadette."

"Duel," although a box-office hit, today is remembered with some humor by critics. Leonard Maltin, writing in his movie guide, called "Duel" a "big, brawling, engrossing, often stupid sex-western."

Among Jones' other major roles were "Portrait of Jennie" (1948), "Madame Bovary" (1949) and, in the 1950s, "Carrie," "Beat the Devil," "Ruby Gentry," "The Man in the Gray Flannel Suit," "Good Morning, Miss Dove," "The Barretts of Wimpole Street" and "A Farewell to Arms." She played Nicole Diver in 1962's "Tender Is the Night."

Starting in the mid-1960s, Jones went through a bleak period. Her film career was on the wane and, in 1965, Selznick died. Two years later, on the day her good friend Charles Bickford died at the age of 78, Jones attempted suicide. She was found by sheriff's deputies in the surf in Malibu, where she had collapsed after taking sleeping pills and, it appeared from evidence at the scene, drinking wine.

"I don't think I wanted to die," she told the Washington Post several years later. "These accidents happen."

Jones' penultimate film, "Angel, Angel, Down We Go" (1969), was so bad that film historian Edward Margulies, co-author of "Bad Movies We Love," referred to the film in labeling Jones "the true standout" among former Oscar winners who "slid into grade-Z trash" in their later careers.

Jones' final film role was a supporting role as Fred Astaire's love interest in the 1974 film "The Towering Inferno." But by then,

Continued on next page

continued from previous page

Jones' life had taken a turn for the better after having met Norton Simon.

He was recently divorced when they met in May 1971 at a reception in Los Angeles for a New York magazine editor. Simon was 64, and Jones was 52.

At that time, Jones had retreated from Hollywood and was raising her daughter by Selznick, Mary Jennifer.

Active for many years with mental-health and charity organizations, Jones was working with the Manhattan Project, a group of Salvation Army residential treatment facilities for young people addicted to narcotics. Simon said later that, of course, he found Jones beautiful but that they connected because of her activism.

Simon by that time had severed his last managerial ties to his business empire and was one of the world's leading art collectors, mostly of old masters. By the end of May, the couple had embarked on a trip to Paris, stopping over in London, where they decided to get married.

Jones said that she had considered museums boring until she met Simon. She changed her mind on a trip to Siena, Italy, with her husband.

Jones, in turn, opened Simon's mind to other cultures. According to Times arts reporter Suzanne Muchnic's 1998 biography of Simon, "Odd Man In," it was Jones, a longtime yoga practitioner, who persuaded Simon to take his first trip to India, where he was "smitten by the art of regions he had scarcely considered before." Simon became a major force in the Indian and Southeast Asian art market.

Jones eventually became an important part of Simon's art empire. When he became incapacitated by Guillain-Barré syndrome, he named his wife president of the Norton Simon Museum. As chairwoman of the Norton Simon Foundation Board, she oversaw the renovation in the late '90s of the museum's interior, designed by museum trustee Frank Gehry, and the gardens, by landscape designer Nancy Goslee Power. She was given emeritus status in 2003.

Jones herself was surprised at the many turns her life had taken.

"Actually," she told the Washington Post in 1977, "every time I stop to think about it, I'm really amazed. I think I've had an extraordinary life. And lots of times I can hardly believe it's me."

Jones is survived by her son Robert Walker Jr., eight grandchildren and four great-grandchildren. Her son Michael Walker died in 2007. In 1975, her daughter with Selznick, Mary Jennifer, committed suicide. ■

Luther is a former Times staff writer.

HARRY A. LIEBERMAN
1921 – February 10, 2010

Eulogy for Harry Lieberman, *given by his daughter,* Debbie Fine at his funeral on February 12, 2010:

Today we can dwell on the sadness. Surely this feels like a very sad day.

Or we can use this day to do something else. We can reflect on the positives of my dad's life. And there were certainly a lot of positives.

First of all, he was 89 years old – by any measurement, that's a long life.

And, until recently, it was a healthy, happy and extremely productive life.

But it was much more than that. It was a life that embraced responsibility. To accomplish as much as he did required intelligence, strength of character and the ability to convince others to follow his lead. It's a power that he's still using – amazingly – even today. I'm sure we can all picture him smiling at the thought that so many of his friends and family came here from places as far away and as warm as California and Florida – and here we are, all gathered in this chapel surrounded by about 3 feet of snow. You have to admit, he's a powerful force.

He was also very bright. He could discuss almost any subject – law, politics, business, technology or the economy. But by far his favorite subject was his family. He loved spending time with and taking care of his family.

Like when my sisters and I were very young – probably starting in

Continued on next page

continued from previous page

5th grade and all through high school - he made sure that we always had his famous French toast for breakfast. It was famous because he didn't just make French toast – he created French toast. He had his own, very special recipe and his own very special method. He always used challah and soaked it forever so the inside was soft while the outside got crisp and crunchy. Then he sprinkled it with cinnamon and sugar as it cooked. The French toast was sweet even before we poured on the syrup. He wasn't a big fan of French toast for himself – he just loved making it for us and then sitting down to watch us enjoy it. I don't think I ever eat French toast without comparing it to his.

He also loved taking his grandchildren on fishing trips. Because his company did so much business with DuPont, they let him use their boat. In order to keep the kids interested, he created contests, which became the highlight of the trip. There was one for the first fish. The biggest fish. The last fish. The smallest fish. The ugliest fish. He kept inventing contests until every grandchild won. Once, Andy won for catching the most unusual fish because even though they were in the ocean, Andy defied the laws of nature when he snared a freshwater rainbow trout. On the same trip, Oscar won for catching the most avian fish. You may not be familiar with 'avian fish' but apparently catching them requires a skill that only Oscar possesses. Difficult as it may seem, Oscar was able to hook a bird – not once, not twice, but three times – as he tossed out his fishing line. You'll be happy to know that even though Oscar kept his prize, all of the birds were taken off the hook and flew away safely.

My father thought it was important to teach as well as to entertain. Which is why, in 1981, he took Matthew and Emily to see the film, "The History of the World, Part One." He felt it would be a good jumping off point for a discussion about history. As some of you may remember, "The History of the World, Part One" was a Mel Brooks film, filled with all sorts of inappropriate jokes about sex and drugs. However, my father didn't know that and by the time he realized that the content wasn't exactly what he had anticipated, the kids were already having too good a time. So he let them stay and enjoy the film. Fortunately, they had no idea what they were laughing at.

Because he placed such importance on education, he paid for all of his children and grandchildren to go college. When the tuition bill was due and they needed to sign up for next year, he made them each come to have a talk with him. He always wanted to know how they were doing and what courses they were taking the next year. Of course, he was checking up on them, but it was more his way of staying involved in their lives. He always promised the grandchildren that he would take care of the bill, as along as they took care of their studies. That, he believed, was their job.

He was also a remarkably attentive and adoring great grandfather. Here's a perfect example. Recently, my grandson, Adam, told him about a geography assignment. So my father bought him an atlas. Then he showed Adam how to use it. Together they found Vladavostock, the city in Russia where my dad was born. The next day he called to have Adam and Evan, Adam's brother, find another city. But because they were at school, he left a message – asking them to call him when they found it on the map. That started a pattern. From then on, every day, while boys were at school, he called and left the name of another city. And every day, they came home with great excitement, waiting to learn about the new city they needed to locate. For Adam and Evan, it was a great game and a lot of fun. But, just as my father intended, it instilled them with a lifelong interest in geography.

I mentioned before that my father had a strong sense of family and that he liked all of us to be together – especially at important events. This is certainly one of those times. And I know he is happy that we are all together, not just to mourn his passing but also to celebrate his wonderful life. ■

MAX PALEVSKY
July 24, 1924 - May 5, 2010
By Elaine Woo

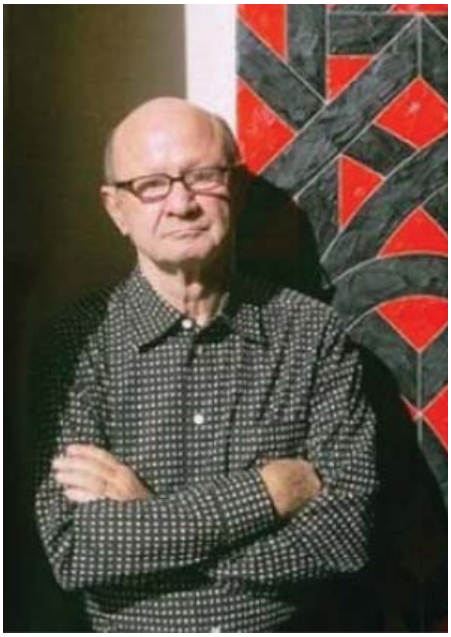
A founder of Intel, the billionaire donated lavishly to political causes and the arts as well as to other eclectic pursuits. He was a key backer of L.A.'s first black mayor, Tom Bradley.

But his portfolio resembled a conglomerate's. A baron of the early computer industry, he helped found the world's largest chipmaker, Intel. He came up with the cash to save a fledgling magazine called Rolling Stone and bankrolled movies. And he used his immense wealth to build notable art collections that turned the Los Angeles County Museum of Art into a destination for lovers of the Arts and Crafts movement.

Continued on next page

In Memoriam

continued from previous page



Ringo H.W. Chiu/The Times
December 4, 2008

Palevsky, 85, died of heart failure at his Beverly Hills home, said his wife, Jodie Evans.

"I'm not sure the average person knows him," said television producer Norman Lear, a longtime friend, "but anybody interested in the arts has Max to thank for the way he supported arts in this town … and, if you cared for his politics, for who he supported. He was a very unique soul."

The noted art collector and philanthropist gained prominence in the 1960s when he turned Scientific Data Systems, a builder of mainframe computers, into a hugely lucrative business that he sold to Xerox in 1969 for $1 billion. He went on to serve as a director and chairman of Xerox's executive committee before becoming a founder and director of Intel Corp.

He left the corporate world during the 1970s to produce movies, bolster the coffers of Rolling Stone and delve into politics.

He was an early supporter of George McGovern during his ill-fated 1972 presidential campaign, then ran Bradley's successful 1973 bid for mayor. He also was a major backer of Robert F. Kennedy and Jimmy Carter during their presidential bids, and various campaigns of former Gov. Gray Davis. And, with Lear, he was a member of the "Malibu Mafia," a loose alliance of extremely wealthy Westside Democrats who used their influence to promote liberal causes and candidates.

In later years, Palevsky soured on politics and concentrated more of his attention on art. He built important collections of Arts and Crafts movement furniture and Japanese woodblock prints, which have been featured in shows at LACMA.

He made a dramatic reentry into the political fray in 2000 when he wrote a $1-million check to the campaign finance reform initiative co-authored by Ron Unz, a conservative Silicon Valley tycoon.

The contribution — the largest political donation Palevsky had ever made — shocked state Democratic leaders, who opposed the ultimately unsuccessful measure. But Palevsky, saying that he was sickened by the "corruption of the electoral process," announced that he made the contribution "in hopes that I will never again legally be allowed to write huge checks to California political candidates."

Palevsky got his first taste of politics in the 1960s. In 1966, he supported Tom Braden, a newspaper publisher, for California's lieutenant governor. In 1967, he was a regional leader of the antiwar group Business Executives Move for Vietnam Peace. Those experiences led to his involvement in Kennedy's 1968 presidential campaign and the tumultuous Chicago Democratic National Convention, where he met McGovern.

"In some way, I guess, I tasted blood in the '68 campaign. I really saw what it was all about," he told the New York Times in 1972.

He jumped on the McGovern bandwagon before the South Dakota senator's stunning upset in the Wisconsin primary. "Max was his most important early contributor," said Frank Mankiewicz, McGovern's campaign director.

According to "The Power and the Glitter," a 1990 book about the interplay between Hollywood and Washington by former Los Angeles Times political writer Ronald Brownstein, Palevsky donated more than $319,000, which financed McGovern's successful direct-mail operation. He also raised money from others, represented McGovern at a meeting with Vietcong negotiators in Paris, and advised him on issues.

He abruptly left McGovern's side during the 1972 Democratic convention in Miami when he realized that his advice, particularly about the organization of the campaign, was being ignored.

"My role in the campaign wasn't that significant," he told The Times in 1973. "At a certain point I just found it all very boring and I just got up one day and said . . . 'Son, I don't see much point in staying around.'"

He did not stay out of politics for long, however. The following year he was the top advisor in then-Los Angeles City Councilman Bradley's mayoral campaign. He made

Continued on next page

continued from previous page

Gray Davis the campaign's chief fundraiser, which launched Davis into politics. Bradley, who had lost his first bid for mayor to Sam Yorty in 1969, became the city's first African American mayor in 1973. He was reelected four times, an unprecedented run that ended with his retirement in 1993.

The 1970s were a heady time for Palevsky, who had joined forces with the Malibu Mafia, a group so named because some of its members, such as Lear, lived in the exclusive Malibu Colony.

But by the end of the decade, he was withdrawing from politics and turning his attention back to the business world. According to Brownstein, the reason was that changes in campaign finance laws were limiting the huge donations that gave clout to wealthy contributors like Palevsky.

Twenty years later, the computer baron-turned-political benefactor was still disenchanted with politics. But this time, his unhappiness stemmed from his conclusion that so-called fat cats, as he had been, had corrupted the political process. He became the biggest backer of Proposition 25, the initiative on the 2000 statewide ballot that sought to limit individual contributions, ban corporate donations and require overnight disclosure of any contributions over $1,000.

Palevsky's massive support of Proposition 25 came a day after news reports that then-Gov. Davis, who had received $150,000 from Palevsky for his political ventures over the years, had launched an aggressive effort to defeat the initiative by soliciting contributions from business interests. But it was, perhaps, too late: The state Democratic Party countered with a $500,000 donation to the anti-Proposition 25 forces; voters a week later soundly defeated the measure.

Palevsky felt so strongly about campaign finance reform that for the first time in his life he raised money for a Republican, U.S. Sen. John McCain (R-Ariz.), who spoke out strongly on the issue during his 2000 candidacy for the Republican nomination for president.

The son of Polish Jewish immigrants, Palevsky was born July 24, 1924, and grew up in Chicago during the Depression. His father was a house painter and his mother a homemaker; neither spoke much English.

During World War II, he served as an electronics officer in the Army Air Forces. Afterward, he studied at the University of Chicago, where he majored in mathematics and philosophy. He earned his bachelor's degree in 1948, then undertook postgraduate work at UC Berkeley and UCLA.

An expert in symbolic logic, he planned on an academic career. But Palevsky became fascinated by computers, which the public in the early 1950s considered science fiction. Palevsky saw the possibilities in the emerging technology and in 1951 left academia to stake his claim.

He worked in the computer division of Bendix Corp. and for Packard Bell before launching Scientific Data Systems with 11 other scientists in 1961. Over the next several years, sales for the company, which focused on an untapped market for small mainframe machines, soared.

He sold the Santa Monica-based company to Xerox in 1969, a time, he later joked, "when $1 billion meant something." His 10% share meant he pocketed $100 million.

Palevsky, whose fortune later earned him a spot in the Forbes 400, went on to serve as chairman or chief executive of Xerox's executive committee, Silicon Systems and Daisy Systems Corp. He was one of the first major investors in Intel.

By the time he sold Scientific Data Systems, he was already interested in politics. But as that passion waned, his commitment to art collecting deepened.

Palevsky amassed one of the world's premier collections of the American Arts and Crafts movement, including numerous pieces by Gustav Stickley.

In 1990, he gave 32 pieces of Arts and Crafts furniture to the Los Angeles County Museum of Art; three years later, he added an additional 42 pieces to his gift. In 2000, he donated $2 million to LACMA for Arts and Crafts works. He supplied about a third of the 300 objects displayed in a 2004-05 LACMA exhibit, "The Arts and Crafts Movement in Europe and America: 1880-1920." Last year, the museum presented "The Arts and Crafts Movement: Masterworks From the Max Palevsky and Jodie Evans Collection."

His Japanese prints included many works by 18th century masters Katsushika Hokusai and Kitagawa Utamaro. Palevsky loaned 44 of the 50 prints in his tightly monitored collection to LACMA for a show in 2001.

His passion for art embroiled Palevsky in controversy in the 1980s when he withdrew a $1-million pledge to help build a permanent

Continued on next page

continued from previous page

downtown home for the Los Angeles Museum of Contemporary Art.

Claiming that the then-fledgling museum reneged on a promise to give him architectural control of its new complex on Bunker Hill, he filed a lawsuit in 1984 to recoup $500,000 he had already given the museum and excuse himself from paying the other half million.

The museum ultimately settled the dispute with "an amount exceeding the sum [$500,000] paid to the museum," but less than the total amount he had originally pledged. He subsequently promised his art holdings to LACMA.

He could be unpleasantly controlling and admitted as much during an interview with The Times a few years ago.

When a reporter observed how he could not set down a book without carefully aligning its edges with the sides of a table, or how he meticulously arrayed six pairs of eyeglasses in a row next to six different decorative cases, Palevsky, who married and divorced five times, acknowledged, "I know it's all a little obsessive. I should have been an architect."

In addition to Evans, he leaves a daughter, Madeleine Moskowitz; four sons, Nicholas, Alexander, Jonathan and Matthew; a stepson, Jan Krajewski III; a sister, Helen Futterman; and four grandchildren.

In his last years, he increased his philanthropic efforts, giving $20 million in 2000 to his alma mater, the University of Chicago.

He professed little involvement in business affairs, having turned over the management of his finances to others. The man who had played a major role in creating today's computer-obsessed society also confessed that he no longer had much interest in technology. In fact, he had begun to disparage the revolution he helped spawn, believing that computers and the Internet had become "substitutes for interaction with the real world."

"I haven't touched a computer, watched TV or used a credit card in 15 years. I am," he told the Times in 2001, "a Luddite." ■

BRANDON LEE ROBERTS
April 7, 1975 – September 10, 2010

Brandon was born in Williamsburg, Va., April 7, 1975. He passed away peacefully, September 7, 2010, knowing that he was so loved by his family and friends.

He is survived by his parents John and Dedee Roberts of Austin, his brother Burton Roberts of Santa Monica, California, and his many friends from across the country.

Brandon grew up in St. Louis, Missouri and attended Saint Louis Country Day School. He then attended Western State College in Gunnison, Colorado and loved the years he spent there close to the mountains. The incredible friends he made in each school remain dear friends today.

Brandon's young life was shortened by Huntington's disease, but he packed so much into the time he had on this earth. He was the adventuresome rock-climber, hiker and back-packer, the strong youth camp counselor, the athlete, the amazing artist and creative writer, the best friend you could ever have, greatest brother and son there could be and a true "lover of life." He has taught all who have met him how to live and love unconditionally. He lived the life of grace. Brandon and his hugs will be greatly missed by all.

The family's sincere thanks and gratitude go to the staff and owners of CORE Health Care who have cared for Brandon so lovingly, Hospice Austin, and Christopher House who have made these difficult times bearable.

Memorial contributions can be made in Brandon's name to: The Hereditary Disease Foundation, 3960 Broadway, 6th Floor, New York, N.Y. 10032 (hdfoundation.org), where the scientists are working tirelessly to find a cure for Huntington's disease. ■

Hereditary Disease Foundation Leadership

Board of Directors

Gerald Aronson, M.D.
Robi Blumenstein
Bruce Donaldson
Jodie Evans
Sandy Fox
Berta A. Gehry, Treasurer
Frank O. Gehry, Vice-President
David Gerstenhaber
Kelly Posner Gerstenhaber, Ph.D.
Arthur Golding, M.D.
Jonathan Guest
David Housman, Ph.D.
Jonathan Matz
Herbert Pardes, M.D.
Alice Wexler, Ph.D., Secretary
Nancy S. Wexler, Ph.D., President
Anne B. Young, M.D., Ph.D.

Lifetime Directors

Julie Andrews
Elaine Attias
James Blanchard
Deborah Blethen
Betty Borman
Burton Borman
Carol Burnett
Jean Hale Coleman
Blake Edwards
Peter Falk
Marjorie Fasman
Peter Feibleman
Susan Feibleman
Carrie Fisher
Dewanna Golding
Kiyo Higashi
Robert Higashi, CPA
Arnold Klein, M.D.
Elaine May
Shelby Modell
John Moorhouse
Virginia Moorhouse
Edward C. Moses
Joyce Ostin
Michael Ostin
Morris Ostin
Steven Perez
Vincente Perez
Patricia Phelps, Ph.D.
Marisa Pouw
Alison Rubinson
Joel Rubinson
Jack Rudin
Mary Carol Rudin
Susan Rudin
David Shea
Jennifer Shea
Susan I. Spivak
Billie Milam Weisman
Luanne Wells

Hereditary Disease Foundation Scientific Advisory Board

An All Party Parliamentary Group (APPG) for Huntington's disease was launched on June 30, 2010 at the Houses of Parliament in London.

APPGs are groups of Parliamentarians drawn from all political parties formed to support particular causes.

The APPG for Huntington's disease has been established to promote research and to increase services and care for people with Huntington's disease and their families.

Over 600 family members came from all parts of the UK to the House of Commons to make our cause visible. They were greeted by over 60 MPs, who were moved to action. Over 70 members of the House of Commons and the House of Lords are giving their active support. ■

Visit the Hereditary Disease Foundation website: www.hdfoundation.org to read more about the latest news and research and find out how you can contribute.

Hereditary Disease Foundation
3960 Broadway, 6th Floor
New York, NY 10032
Phone: (212) 928-2121
Fax: (212) 928-2172
Email: cures@hdfoundation.org

Ways of Giving

There are many creative ways of giving to the Hereditary Disease Foundation to help us find treatments and cures for Huntington's disease and other hereditary illnesses. Your gift will serve as a catalyst for other donors to contribute, and will help ensure the continued success of the Foundation.

You can make a gift of cash or appreciated securities, or include the HDF in your estate planning. You can make a beques to HDF simply by asking your attorney to include HDF in your will or codicil.

For more information about making a donation or how your legacy gift today can fund the discoveries of tomorrow, call Karen Dean, Controller, at 212.928.0420 or email her at karendean@hdfoundation.org.

For more information about Ways of Giving, please visit our website – www.hdfoundation.org.

The Hereditary Disease Foundation is a non-profit 501(c)(3) organization. ■