

# VISIONS 2008

## Conference Highlights



At the opening of the 2008 VISIONS Conference in Washington, DC, William Schmidt, FFB's Chief Executive Officer, set a determined and purposeful tone when he said, "Washington is such an exciting destination with all its history. But regardless of what turns history may take in the coming months and years, we are here to make blinding retinal diseases history."

The annual, three-day conference hosted by the Foundation Fighting Blindness brought together more than 500 people from across the country to learn about the latest in retinal degenerative disease clinical trials, laboratory research, coping strategies, and adaptive technologies.

### Into the Clinic and Out to the People

"We have entered a golden era of new treatments," declared Dr. Mort Goldberg to a conference hall packed with hundreds of enthusiastic attendees who came to hear his informative presentation on clinical advancements. Dr. Goldberg, the Chairman of the National Neurovision Research Institute, FFB's clinical support organization, was one of two dozen retinal physicians and scientists who reported on the promising news coming from the clinical front lines and research labs around the world. Dr. Goldberg reviewed clinical trials of a gene therapy that is restoring some sight in young adults who were nearly blind, a tiny capsule that holds promise for saving sight in people with a variety of conditions, and a cell transplantation treatment that's improving vision. More than 10 treatments in clinical trials were reported on at VISIONS.



*VISIONS attendees enjoyed learning about the latest clinical advancements from top retinal researchers.*



*Interpretive services enabled people with vision and hearing loss to play an active role.*

### Attendees Get Answers at “Doctor Is In” Sessions

For many attendees, the “Doctor Is In” sessions are a big draw, because they give people the opportunity to pose questions about their condition, one-on-one, to some of the world’s top retinal researchers and physicians. Steven Frank of Rockville, Maryland, said, “It was a thrill to meet leading Usher syndrome researchers such as Dr. William Kimberling, who was not only an expert, but friendly, approachable, and answered my questions. Also, the terrific team of sign language and tactile interpreters made the conference accessible.”

### Coping Sessions Provide Useful Tools and Strategies

Internet technologies. ADA rights. Sports and fitness. Educational resources. Those were a few of the many coping sessions offered during VISIONS. Attendees greatly valued the opportunity to learn about the tools and resources available

to people with low vision. The session titled, “Emotional Adjustment to Vision Loss: An Attitude for Success,” was very well attended and received, because the subject matter is highly relevant to virtually everyone with a retinal degenerative diseases, as well as their family and loved ones.

### Vendors Market the Latest Services and Technologies

The vendor exhibit hall was also popular with attendees. Thirty vendors were on hand to discuss and demonstrate a variety of products and services including: CCTV video magnifiers, computer access software, guide dog training, scanners, and Braille jewelry. The exhibit hall reception, which provided early-evening treats and a raffle drawing, was well-attended.



*The exhibit hall was a popular destination.*

### Laughing and Dancing the Night Away

While fighting blindness is usually serious business, the Saturday evening dinner-dance gave people a chance to let their hair down and enjoy laugh-out-loud comedy from television actor Jon Wellner, who emceed the evening. Dinner guests also enjoyed a great set of music from 14-year-old Brooke Pernice, who is blind from Leber congenital amaurosis. Brooke’s commanding voice and her band’s toe-tapping numbers inspired guests to purchase dozens of her CDs, and all of those proceeds went to FFB.

For Jon, who has retinitis pigmentosa and plays a neurotic forensic scientist on the hit television show CSI, this was his first-ever FFB event. He said, “I’ve done stand-up comedy before but this was

the first time people have come up to me afterwards and thanked me for putting into words what they've been thinking and feeling. We can't take ourselves too seriously and I feel like laughter is some of the best medicine out there...along with 15,000 units of Vitamin A Palmitate!"

No one at the dinner will ever forget Jon's story about showing up for a Doritos commercial audition clad in skimpy underwear, or "manties" as he called them, when the role called for boxer shorts. Jon lamented that fact that four years later, he is still waiting to hear if he passed the audition.



*Comedian Jon Wellner*



*Pete Sessions, Estelle Condra, David Condra, Nancy Kerrigan, Bill Schmidt*

### Prominent Figures Tell Their Inspiring Stories

The opening luncheon also provided attendees with some entertaining and inspiring celebrity encounters. Congressman Pete Sessions (R-TX), who has a family member affected by a retinal disease, spoke of the tremendous need for more research funding at the National Eye Institute. Olympic figure skating champion Nancy Kerrigan talked about how her mother missed much of Nancy's development as a skater, because of her blindness. Author and motivational speaker Estelle Condra, an adventurous traveler with retinitis pigmentosa, spoke about the funny and ironic twists that living with RP added to her journeys and encounters around the globe.

And though David Chisum is an actor in the popular daytime drama "One Life to Live," he told a very real and heartfelt story about his father and sister who have lost their vision to a retinal degenerative disease. David made it clear that he is on board with the Foundation's fight against blindness. "I am also here to say that I am one of your soldiers. I pledge to you my dedication in bringing awareness and research dollars to our quest. I know in my soul that there is a cure...One day our worries will subside and blinding diseases will be no more."

### Leading the Way

In recent years, chapter and event growth have been key elements in the overall growth of FFB. Chapter and event leaders convened at VISIONS to discuss strategies for moving their initiatives forward in the coming year. More than 50 chapter and event leaders attended leadership sessions held on Thursday and



*Actor David Chisum*



***Jane Gardner, Raleigh-Durham Chapter President***

Friday. Presenting leaders included: Jane Gardner (Raleigh), Linda Becker (Orange County, California), Rhonda Timko (Atlanta), Jean Vogel (Washington, DC), Judy Kahl (Southwest Florida), John Corneille (Chicago), Peter Wallsten (Los Angeles), and FFB Board Director Joel Davis (Washington, DC).

Bill Carty, President of the Northern Virginia Chapter, opened and closed the Thursday leadership meeting. He said, “The sessions created a forum for chapter leaders and FFB staff from across the country to share best practices, interact, and form lasting relationships. It fostered the creation of a team atmosphere among the regions and chapters that will be a key to success as we work together to achieve our goals.”

Before the Saturday evening dinner-dance, FFB Chairman Gordon Gund held a special reception for the Foundation’s Visionary Council — a group of the Foundation’s most committed donors. Approximately 65 Council members were in attendance. In appreciation of the Council, Gordon remarked, “The Foundation’s growth is nothing short of incredible. We will invest nearly \$27 million in research and public education in fiscal 2009, and we are doubling our annual budget from about \$19 million in 2006 to almost \$38 million in 2009. Our success would not have been possible without your hard work and generosity.”

### **Closing Session Features Reports on Clinical Trials**

The Conference’s closing session featured details of many of the clinical trials underway, and included a presentation by Dr. Jean Bennett who is leading a landmark human study of gene therapy at Children’s Hospital of Philadelphia that has restored some vision in three young adults who were nearly blind from Leber congenital amaurosis. Dr. Bennett and her colleagues recently treated three more people with a higher dose of the therapy and will report results on these patients in the coming months. She noted that a total of nine people and three doses will be studied in the Phase I clinical study.

Dr. Shalesh Kaushal of the University of Florida discussed a similar gene therapy treatment, and the delicate surgery involved in delivering it, that is in clinical studies at the University of Pennsylvania and the University of Florida. He, too, will be reporting trial results shortly.



***Attendees had many questions for the experts.***

Dr. David Birch of the Retina Foundation of the Southwest and Dr. J. Jill Hopkins of Retina Vitreous Associates in Los Angeles provided details of three clinical trials of encapsulated cellular technology, which is being developed by Neurotech. The tiny implantable capsule, which releases a vision-saving protein, is implanted in the eyes of more than 150 people around the country. A key benefit of the device is that it holds promise for treating a wide range of retinal conditions including: dry age-related macular degeneration, retinitis pigmentosa, Usher syndrome, and choroideremia.



*J. Jill Hopkins, M.D.*



*Larry Hall talks about his experience as a participant in the Neurotech trial.*

Closing session attendees also enjoyed compelling remarks from Larry Hall, a participant in the first Neurotech trial, who has choroideremia. Because he signed up for the Phase I study, Larry knew that the main objective was to evaluate safety rather than vision stability and improvement. After careful consideration, Larry decided to do it for the benefit of the science and to move the technology to the next level. “If no one volunteers now, there will never be a treatment,” he said.

Larry had the capsule implanted for six months, and after it was removed, the researchers told him that his treated eye had improved from 20/120 to 20/50. A year later, the vision in that eye remained at 20/50. Needless to say, Larry was a happy guy.

And now, thanks to the courage of Larry and nine other Phase I participants, Phase II/III studies are underway and evaluating the device’s affect on vision.

Jim Minow, FFB’s Chief Development Officer, took the closing session as an opportunity to graciously thank attendees for their generosity and hard work — efforts that are making the great news on the research front possible. He said, “Our research budget has increased at an annual rate of 30 percent over the last several years, and you are the ones making all of that happen.” He noted the innumerable ways that people get involved in driving research, including the efforts of Judy Kahl, who’s “FFBee” jewelry and letter-writing campaign has been a unique and effective approach to raising money and awareness.



*Attendees enjoyed a good laugh.*

Gordon Gund, Chairman and Co-Founder of the Foundation, provided inspiring concluding remarks for the conference. Though he noted that a lot of work remains to be done to move treatments into and through clinical trials, he also made it clear that the Foundation and its researchers and constituents are on the right path, and that the progress being made is very exciting. He said, “I can’t think of anything more exciting or energizing to talk about than clinical trials — especially ones that seem to be working so well.”



*Gordon Gund*

Gordon also reflected on earlier years when treatments like gene therapy were nothing more than ideas and hopes. “Fifteen years ago, Dr. Jean Bennett and Dr. Al Maguire asked themselves, ‘Can we cure a retinal disease by delivering a normal gene to the retina?’ Through their vision, brilliance, hard work and perseverance, it looks like the answer to that question is a resounding ‘yes!’”

Gordon also applauded attendees and the nationwide community of FFB supporters for their spirit and critical role in advancing treatments and cures. “When you came to DC a few days ago, you came with a pioneer spirit. You had a desire to make a difference and be part of the solution. You came with a vision of a time when there wouldn’t be blindness from these diseases. You, like the researchers, are pioneers in this fight against blindness. Thank you for lighting the way.”

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The Foundation Fighting Blindness is grateful for the generous support of the 2008 Visions Conference from:

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11435 Cronhill Drive  
Owings Mills, MD 21117  
800-683-5555  
[www.FightBlindness.org](http://www.FightBlindness.org)

# Conference Snapshots

