



## Brilliant, indeed!

**D**r. Murray Brilliant, Professor of Pediatrics at the University of Arizona, and his research team are working on developing a novel gene therapy approach that will direct genomic rearrangements in living organisms. This approach will make it possible to correct genetic mutations which prevent the cells of the eye from making pigment.

Simply explained, we all have two copies of every gene. People with albinism have an alteration (mutation or deletion) in both copies of a gene necessary to produce pigment. This pigment is necessary for proper functioning of the retina (the back part of the eye). Without it, a person would have decreased visual acuity, light sensitivity and nystagmus (involuntary eye movements).

Last September, The Vision for Tomorrow Foundation began funding this research project. Dr. Brilliant and his team have produced scissors (enzymes) which are able to cut the DNA at

very specific places, such as between the two altered sites. The cells then repair themselves by

and have produced some pigmented cells. They have also been able to produce many additional



*Above: (l-r) Leslie Zucker and Susan Ballis (second & third from l) meet the team: Todd Camenisch, Dr. Brilliant, Elaine Forbes and Christine Klassen.*

recombining the DNA. In this process, the DNA strands often switch, restoring normal gene function, allowing production of pigment. Since receiving funding from Vision for Tomorrow last September, Dr. Brilliant and his team have succeeded in introducing these enzymes into retinal cells

enzymes and are optimizing the cell cultures. With these findings, Dr. Brilliant now has sufficient data to submit an application to the NIH (National Institutes of Health) for further funding of this exciting project. Leslie Zucker and Susan Ballis traveled to Tucson in April to meet with Dr. Brilliant and his team. "Although the results of the research by Dr. Brilliant's team are preliminary, they're very encouraging," comments Susan.

## Digital Wedding Forum helps VFT

**M**ore than 700 members of the Digital Wedding Forum (DWF), an online network for professional event photographers, met in Las Vegas from March 26th - 29th for an annual conference which featured key industry



*Mark Zucker and Jeff Caplan.*

speakers and notable photographers. At the event, mentoring sessions were offered for a minimum donation of \$25. Jeff Caplan, founder of DWF, selected the Vision for Tomorrow Foundation as the recipient of these funds which amounted to \$3,905. Thank you to Jeff Caplan, the mentors and participants for their support.

## Thanks! And more thanks!

Our letter writing campaigns in 2006 and 2007 raised more than \$150,000! Highland Park High School's Lean on Me student organization presented VFT with a check for \$2,500.

## Dear Friends,

**A**lmost ten years have gone by since my younger son, David, was born and subsequently diagnosed with oculocutaneous albinism. In an instant, we were thrown into a world of medical terms, educational acronyms, disability advocacy and, yes, plenty of sunscreen and lots of sunglasses. David is doing extremely well and adapts to his environment - we work on reinforcing his sense of self advocacy and understanding his condition.

The Vision for Tomorrow Foundation was created just last May by Susan Ballis and me, and our husbands, with the mission to empower those with low vision to have the confidence and

ability to achieve their dreams. Shortly after, we asked Wendy Baum to join our Board.

The foundation has a three-pronged vision: to raise funds for research initiatives, to provide educational resources and to increase public awareness of albinism and aniridia. In this short period of time, we've been able to develop a wonderful website and begin funding an albinism research project at the University of Arizona, in Tucson, led by Dr. Murray Brilliant.

Parenting a child is always challenging. Raising a child with a visual impairment magnifies this truth. Though we would prefer our son not have these additional challenges in his life, our lives have definitely been enriched

by these experiences and the people whom we've come to know.

Through the work of our Foundation, we hope to provide other families with the tools and resources to navigate the world of visual impairments.

We greatly appreciate your generosity and support. Please share this newsletter with your family and friends. We look forward to sharing more information on the Foundation's progress through future newsletters and through continued updates to the website. We welcome your comments and suggestions - please contact us at [info@visionfortomorrow.org](mailto:info@visionfortomorrow.org).

Leslie Zucker  
*Co-Founder*

## Accomplishments/Goals

### Accomplishments:

- Raised more than \$150,000
- Created a first-class website
- Funded Dr. Brilliant's research project
- Supported and networked with several other organizations:
  - ◆ AFI - Aniridia Foundation International
  - ◆ Hadassah/ Michaelson Rehabilitation Institute

### Goals:

- To develop educational materials
- To fund new research projects
- Begin networking with educators and medical professionals to increase awareness
- Begin corporate fundraising campaign
- Continue to raise funds to support these and other projects
- Hold one-year anniversary celebration event in the fall

## Board Members

Susan Ballis, M.D., *Co-Founder*

Jon Ballis

Wendy Baum

Leslie Zucker, *Co-Founder*

Mark Zucker

### Scientific Advisor

Dr. Richard King, M.D., Ph.D.

## Our Mission

The Vision for Tomorrow Foundation seeks to empower people with low vision to have the confidence and ability to achieve their dreams.

## Our Vision

Our goal is to provide funding for research initiatives, support and create educational resources and public awareness projects – and to be recognized as the "go-to" source of information for those seeking to learn more about non-degenerative retinal disorders causing low vision at birth.

## AFI

The Aniridia Foundation International (AFI) will hold their 2007 Medical Conference in Memphis, Tennessee July 25-29, 2007. For more information, please visit their website at [www.aniridia.net](http://www.aniridia.net).

## NOAH Conference Scheduled

The National Organization for Albinism and Hypopigmentation (NOAH), a volunteer self-help organization based in New Hampshire, has announced that their national conference will be held at The Riviera Hotel in Las Vegas July 11-13, 2008. For more detailed information, visit their website at [www.albinism.org](http://www.albinism.org) or call 800-473-2310.

## Irv Silverman A profile of perseverance

**W**arren G. Harding was the President of the United States. The first Miss America, Margaret Gorman was crowned in Atlantic City and Franklin Roosevelt fell ill with polio. It was 1921 and on the lower east side of Manhattan, the Silvermans welcomed their fifth and final child, Irving.

The boy was born with white hair, a telltale sign of albinism. But, who knew about albinism in the early 20th century? They soon realized that he was very visually impaired, as to a lesser degree, were his two blond sisters. Irv's two older brothers had black hair and were unaffected.

The mainstream school was unequipped to offer Irv an education, so he was sent to Sight Conservation, a special New York City elementary school.

Even at this special school, learning wasn't easy, but many teachers helped him along the way. Margaret McGoey is one whom he still holds dear. "I stayed in touch

with her for the next 50 years. I got as good an education as anyone in a mainstream school," comments Irv. And he also got the school's Medal of Perseverance at the end of 8th grade.

The medal was (and still is) important to Irv.

But then Irv was stopped in his tracks by the principal of the high school who informed Irv that he could not go to the public high

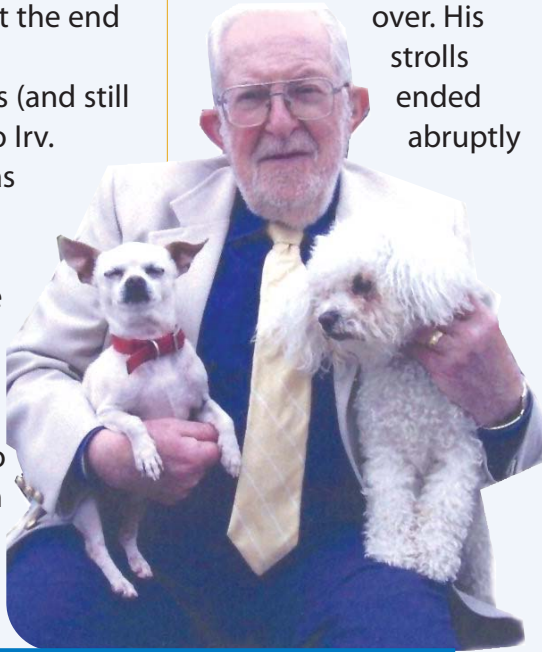
*Irv Silverman*

school. At that time in New York state, every child was legally required to stay in school until the age of 16. So Irv was forced to attend a vocational high school. There, too, was a problem. He couldn't see well enough for the typical male vocational classes like fixing cars and radios, so they put him in a home economics class.

"That was when I became probably the first Jewish truant," muses Irv. For the

next three weeks, he left home "for school" with his lunch and headed straight for Chinatown where he wandered the streets until

"school" was over. His strolls ended abruptly



with a tap on his shoulder. "Aren't you a student in my school?" asked the tapper. Irv spun around and came face-to-face with the school principal. Irv dissolved into tears.

Back at school, the nurse asked why he wasn't in a regular high school. When she discovered his vision problem, she sent him to her sister who just happened to be an optometrist specializing in low vision. (Who said there are no

happy accidents?)

The optometrist put Irv through a series of exercises to strengthen his eye muscles. They didn't work but he persevered.

In high school, he found teachers who were truly concerned about their students. "I soon overcame being embarrassed," says Irv referring to his vision problems. "Right then and there I decided, 'You are what you are.'"

He did, however, encounter one not so compassionate teacher when he attempted to enter an essay contest on The Flag. She quickly dismissed the idea stating, "I don't think you should enter this contest. There's an extensive amount of work and research."

Luckily, his history teacher encouraged him to enter and helped him with his research. Of course, Irv won the \$20 first prize!

He went on to graduate from high school in 1937.

For the continuation of this story, please visit our website at [www.visionfortomorrow.org](http://www.visionfortomorrow.org).

# Sunglasses at Night

It was April 21– a beautiful balmy night. The Madron Art Gallery setting was perfect. The food was divine, the wine sublime and the desserts delicious. More than 200 people were ready to party!

The event, "Sunglasses at Night," (to underline the critical need for sunglasses outdoors for those who have low vision), was sponsored by Ariel Hadassah, the north suburban division of the Chicago Chapter of Hadassah a worldwide non-profit organization, and the Vision for

Tomorrow Foundation. More than 100 North Shore businesses and

collectible items from Chicago Bears linebacker Brian Urlacher and

Chicago Cubs first baseman Derrek Lee.

Guests also brought sunglasses to be donated to those affected by low vision.

The event raised \$25,000,

which will be donated to the Michaelson Institute for Rehabilitation of Low Vision at Hadassah



(l-r) Debbie Solomon, Wendy Baum, Aimee Krupp, Susan Ballis and Leslie Zucker.

individuals donated items for the evening's raffle and silent auction, which also included signed

Hospital in Israel. Dr. Irene Anteby is Director of the Center for Pediatric Ophthalmology at Israel's Michaelson Institute, recipient of the proceeds of Sunglasses at Night. The Institute specializes in low vision and over the years has become Israel's center of albinism research.

**Current work:** Their genetics laboratory is working on identifying genes causing hereditary conditions with low vision, such as albinism and aniridia.

**Goal:** To enable those with impaired vision to learn to use their remaining vision in the best possible way.

## The Vision for Tomorrow Foundation

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VFT Co-Founders Leslie Zucker and Susan Ballis "Kicked off" an event with Hadassah President Aimee Krupp.