

# The National Organization for Albinism and Hypopigmentation

The Albinism Community

*Coming Together*



# NOAH

S a n F r a n c i s c o

2 0 0 2

*9th National Conference*

July 18-21, 2002  
Concord, California



*The National Organization  
for Albinism & Hypopigmentation  
welcomes you to  
San Francisco  
and*

*“The Albinism Community Coming Together”*

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**Jerrilyn & Gregg Ankenman**

*Danville, California*

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**Jesse Kain**

Registration Chairperson

*Santa Fe, New Mexico*



**Jeannine Joyce**  
Vendor Coordinator

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Merchandise Coordinator

**NOAH** gratefully acknowledges **Rose Blie** for her design of the conference logo.



# NOAH 2002 National Conference - Program At-A-Glance



## Wednesday July 17, 2002

7:00 pm- 9:00 pm NOAH People of Color Meeting *Hospitality Suite*

## Thursday July 18, 2002

4:00 pm- 8:00 pm Registration, T-shirt sales, membership, etc. *Club Room 1*  
 6:00 pm- 9:00 pm Albinism Town Square/Positive Exposure *Club Room 2*  
 5:30 pm- 7:00 pm Welcome Reception *Foyer*  
 6:30 pm- 9:00 pm Child Care Available  
     Ages 0-4 *Seminar 2*  
     Ages 5 and up *Seminar 4*  
 7:00 pm Opening Session *Ballroom C*  
 7:30 pm Keynote Presentation *Ballroom C*  
 9:00 pm Social Hour *Hospitality Suite*

## Friday July 19, 2002

7:30 am - 8:30 am First Timer's Continental Breakfast *Ballroom E*  
 7:30 am - 8:30 am Continental Breakfast *Foyer*  
 8:00 am - 4:00 pm Registration, T-shirt sales, membership, etc. *Club Room 1*  
 8:30 am - 4:30 pm Albinism Town Square/Positive Exposure *Club Room 2*  
 8:30 am - 4:30 pm Exhibitors / Vendors *Foyer*  
 8:30 am - 4:30 pm Child Care Available  
     Ages 0-4 *Seminar 2*  
     Ages 5 and up *Seminar 4*  
 8:30 am - 4:30 pm Teen Activities Ages 14-16 *Hospitality 2*  
 9:00 am - 10:15 am General Session *Ballroom CDE*  
 Morning Keynote  
 Current Issues in Albinism Research  
 10:45am - 11:45 am Concurrent Sessions  
 A. Ask The Doctors *Ballroom C*  
 B. Funding for Assistive Technology *Ballroom D*  
 C. NPOC Panel *Ballroom E*  
 D. Parenting Concerns for  
     People with Albinism *The Parkroom*  
 E. Positive Exposure *ATS/Club 2*  
 12:00pm - 1:30 pm Lunch *Ballroom A&B*  
 1:30 pm - 2:30 pm Concurrent Sessions  
 A. Albinism and the Eye *Ballroom C*  
 B. IEP / Education Issues *Ballroom D*  
 C. What to Expect from a  
     Low Vision Exam *Ballroom E*  
 D. A Modern Overview of  
     Ocular Albinism *The Parkroom*

3:00 pm - 4:30 pm	<b>DISCUSSION GROUPS</b>	
	A. Adults with Albinism	<i>Ballroom D&amp;E</i>
	B. Parents of children with Albinism	<i>Ballroom C</i>
	C. Families & Friends of people with Albinism	<i>The Parkroom</i>
	D. Teens with Albinism	<i>Seminar 4</i>
5:00 pm - 6:00 pm	NOAH General Business Meeting	<i>The Parkroom</i>
	Dinner on your own	
7:00 pm - 9:00 pm	AWA Meeting	<i>Hospitality 2</i>
7:00 pm - 9:00 pm	NPOC Meeting	<i>Baldwin</i>
8:30 pm	Hospitality Room Open	<i>Hospitality 1</i>

**Saturday July 20, 2002**

7:30 am - 8:30 am	Chapter & Contact Person Breakfast	<i>Ballroom E</i>
7:30 am - 8:30 am	Continental Breakfast	<i>Foyer</i>
8:00 am - 4:00 pm	Registration, T-shirt sales, membership, etc.	<i>Club Room 1</i>
8:30 am - 4:30 pm	Albinism Town Square/Positive Exposure	<i>Club Room 2</i>
8:30 am - 4:30 pm	Exhibitors / Vendors	<i>Foyer</i>
8:30 am - 4:30 pm	Child Care Available Ages 0-4	<i>Seminar 2</i>
	Ages 5 and up	<i>Seminar 4</i>
8:30 am - 12:00 pm	Teen Activities Ages 14-16	<i>Hospitality 2</i>
9:00 am - 10:15 am	General Session	<i>Ballroom C, D, E</i>
	Housekeeping/Announcements	
	Morning Keynote: <i>The Albinism Experiences Panel</i>	
10:45 am - 11:45 am	<b>CONCURRENT SESSIONS</b>	
	A. Low Vision Driving Panel	<i>Ballroom C</i>
	B. Careers Panel	<i>Ballroom D</i>
	C. Handling Negative Issues	<i>Ballroom E</i>
	D. Employment Rights/ADA	<i>The Parkroom</i>
	E. Positive Exposure	<i>ATS/Club2</i>
12:00 pm - 1:30 pm	Lunch	<i>Ballroom A&amp;B</i>
1:30 pm - 2:30 pm	<b>CONCURRENT SESSIONS</b>	
	A. The Process of Obtaining and Advocating for the Bioptic Driving Privilege	<i>Ballroom C</i>
	B. Albinism in the Cinema	<i>Ballroom D</i>
	C. The ABC's of Skin Care and Glamour	<i>Ballroom E</i>
	D. Albinism in Later Life	<i>Seminar 4</i>
	E. The Relationship Challenge	<i>The Parkroom</i>
3:00 pm - 4:30 pm	<b>DISCUSSION GROUPS</b>	
	A. West Coast	<i>Ballroom C</i>
	B. Midwest	<i>Ballroom D&amp;E</i>
	C. South	<i>The Parkroom</i>
	D. East Coast	<i>Seminar 4</i>

**Saturday July 20, 2002 (continued)**

5:00 pm- 6:00 pm

NOAH Photo  
Dinner on your own

*Ballroom C*

7:00 pm

Entertainment  
Silent Auction/Raffles

*The Parkroom*

**Sunday July 21, 2002**

8:30 am- 12:00 pm

T-shirt sales, Membership, etc.

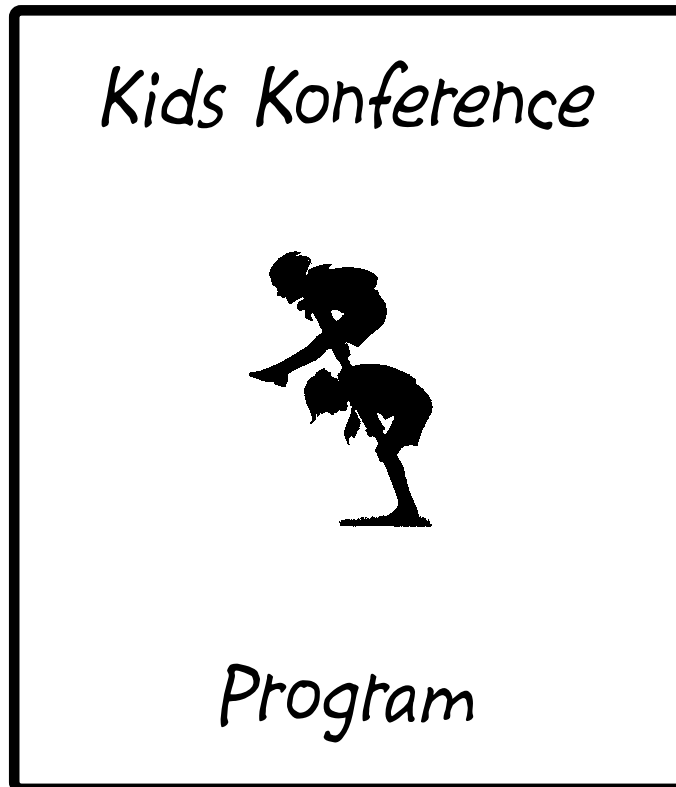
*Club Room 1*

9:00 am- 11:30 am

General Session  
Housekeeping/General Announcements  
Group Breakfast  
Closing Ceremony  
Video Presentation of Conference

*Ballroom A&B*

Children's activities are detailed in the special...





## Friday July 19, 2002

7:30 am - 8:30 am	<b>First Timer's Continental Breakfast</b>	<i>Ballroom E</i>
All those who are attending a NOAH Conference <b>for the first time</b> are invited to a special breakfast in your honor. Meet the NOAH Board members and others from all over the world who are experiencing their first NOAH conference.		
7:30 am - 8:30 am	Continental Breakfast	<i>Foyer</i>
8:00 am - 4:00 pm	Registration, T-shirt sales, membership, etc.	<i>Club Room 1</i>
8:30 am - 4:30 pm	Albinism Town Square/Positive Exposure	<i>Club Room 2</i>
8:30 am - 4:30 pm	Exhibitors / Vendors	<i>Foyer</i>
8:30 am - 4:30 pm	Child Care Available Ages 0-4	<i>Seminar 2</i>
	Ages 5 and up	<i>Seminar 4</i>
8:30 am - 4:30 pm	Teen Activities Ages 14-16	<i>Hospitality 2</i>
9:00 am - 10:15 am	<b>GENERAL SESSION</b>	<i>Ballroom C, D, E</i>

Housekeeping/General Announcements

### **MORNING KEYNOTE**

#### **Current Issues in Albinism Research**

Richard King, M.D. - University of Minnesota

From the International Albinism Center in Minneapolis, Minnesota, the latest in research studies of albinism, what has been done and what is in store for the future.

#### **Hermansky-Pudlak Syndromes: Clinical and Molecular Aspects**

William Gahl, M.D. - National Institutes of Health

Dr. Gahl will introduce Hermansky-Pudlak Syndrome as a type of OCA and discuss a screening program for this diagnosis.

### 10:45 am - 11:45 am **CONCURRENT SESSIONS**

#### **A. Ask The Doctors**

*Ballroom C*

Murray Brilliant, Ph.D. - University of Arizona

William Gahl, M.D. - National Institutes of Health

Richard A. King, M.D. - University of Minnesota

Richard A. Lewis, M.D. - Baylor College of Medicine

## **Friday July 19, 2002** *(continued)*

Moderators - Mike McGowan - Chicago, IL  
Vicky Vaught - Conway, SC

A panel discussion by the top scientists in the field of albinism research. Bring your questions and thirst for knowledge!

### **B. Funding for Assistive Technology**

*Ballroom D*

Janice Knuth - Philadelphia, PA

Assistive technology is devices and related services that enable people with disabilities to do things or to do things more easily. The presenter will briefly discuss assistive technology for persons with low vision. She will also discuss funding sources and other resources for helping people of all ages to access assistive technology.

### **C. NPOC Panel**

*Ballroom E*

Lee G. Edwards - Atlanta, GA

Francia Malone - Flint, MI

Kathy Widefoot DeLaRosa - Pinion, AZ

Moderator - Debbie Wilson - Flint, MI

People of color with albinism face the same challenges that Caucasians with albinism face with regard to low vision and sun protection, but they also face additional challenges related to race and identity. This panel will share their experiences, challenges and successes.

### **D. Parenting Concerns for People with Albinism** *The Parkroom*

June Waugh - Albany, CA

How does albinism impact the decision to have children and the ability to raise them? Together we will discuss support systems, healthy parenting, and the great joys and sorrows of childrearing with a twist of visual impairment.

## Friday July 19, 2002 (*continued*)

### **E. Positive Exposure**

*ATS/Club2*

Rick Guidotti - New York, NY

Positive Exposure is an innovative program that challenge the stigma associated with difference and celebrates the richness of genetic variation with positive images and powerful life stories. Utilizing photography and video interviews, Positive Exposure investigates the social and psychological experiences of people living with genetic, physical and mental health conditions of all ages and ethnocultural heritages.

Rick Guidotti will share some of his fabulous photographs and talk about the Positive Exposure project. He'll discuss his travels around the world photographing and interviewing people with albinism and share the details of his experiences in Fiji, Puerto Rico and with Navajo and Zuni American Indians. Rick will also open up the session for discussion about future ideas for the development of Positive Exposure.

12:00pm- 1:30 pm Lunch *Ballroom A&B*

1:30 pm- 2:30 pm **CONCURRENT SESSIONS**

#### **A. Albinism and the Eye**

*Ballroom C*

Derrald Taylor, O.D. - Mokena, IL

An overview of the visual system and how it is affected by albinism. Simple techniques for assessing vision function and all the basics to explain vision issues in layman's terms.

#### **B. IEP / Education Issues**

*Ballroom D*

Linda Wurzbach - Danville, CA

Angela Bau - University of California, Berkeley

Cynthia Towers - Seattle, WA

Moderator - Janice Knuth - Philadelphia, PA

Your child's education is a high priority in their early life. Their success now will lead them down a path towards independence and self sufficiency. This panel discussion will help you determine how to navigate the challenges and work with your child's education team to insure the success you desire.

## Friday July 19, 2002 (continued)

- C. What to Expect from a Low Vision Exam** *Ballroom E*  
Patsy Harvey, O.D., M.P.H. - UC Berkeley

This presentation will discuss the tests that should be included in a low vision evaluation. Low vision aids and environmental modifications to help people at school, work, and for sports and driving will be demonstrated. Facts vs myths about vision problems will be discussed.

- D. A Modern Overview of Ocular Albinism:** *The Parkroom*  
**What is it, where did it come from, and what happens now?**  
Richard A. Lewis, M.D. - Baylor College of Medicine Houston, TX

A review of the history of the Nettleship-Falls X-linked Ocular Albinism, its distinctive features, the ways to make the diagnosis and separate it from other forms of albinism, the inheritance pattern, the implications for family planning, the importance of carrier examination, and the hopes for the future.

- 3:00 pm- 4:30 pm            **DISCUSSION GROUPS**
- A. Adults with Albinism** *Ballroom D&E*
  - B. Parents of children with Albinism** *Ballroom C*
  - C. Families & Friends of people with Albinism** *The Parkroom*
  - D. Teens with Albinism** *Seminar 4*
- 5:00 pm- 6:00 pm            **NOAH -General Business Meeting** *Baldwin, Chabot*  
All conference attendees are welcome.
- Dinner on your own**
- 7:00 pm- 9:00 pm            **Albinism World Alliance Meeting** *Hospitality Suite*
- 7:00 pm- 9:00 pm            **NOAH People of Color Meeting** *Baldwin*
- 8:30 pm                        **Hospitality Room Open** *Hospitality 1*

## Saturday July 20, 2002

7:30 am - 8:30 am	Chapter/Contact Person Cont. Breakfast	<i>Ballroom E</i>
7:30 am - 8:30 am	Continental Breakfast	<i>Foyer</i>
8:00 am - 4:00 pm	Registration, T-shirt sales, membership, etc.	<i>Club Room 1</i>
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8:30 am - 4:30 pm	Child Care Available Ages 0-4	<i>Seminar 2</i>
	Ages 5 and up	<i>Seminar 4</i>
8:30 am - 12:00 pm	Teen Activities Ages 14-16	<i>Hospitality 2</i>
9:00 am - 10:15 am	<b>GENERAL SESSION</b>	<i>Ballroom C, D, E</i>

Housekeeping/General Announcements

### **Morning Keynote: The Albinism Experiences Panel**

Margaret Mary Campbell - Scranton, PA

Jesse Kain - Santa Fe, NM

Ali This - Brea, CA

Lee G. Edwards - Atlanta, GA

Moderator - Mike McGowan - Chicago, IL

Mike McGowan will facilitate this very popular panel discussion, where a diverse panel of individuals with albinism will be presented with questions relating to their lives and their personal experiences with albinism. There will be time included for an open questions and answer period.

### 10:45am - 11:45 am **CONCURRENT SESSIONS**

#### **A. Low Vision Driving**

*Ballroom C*

Derrald, Taylor, O.D. - Mokena, IL

Raimond Vazira - CA

Joe Williams - Clayton, CA

Brendan Cosgrove - Columbia, MO

A brief summary of current driving issues and research followed by the sharing of experiences and concerns of a variety of persons with albinism.

## Saturday July 20, 2002 (*continued*)

### **B. Careers Panel**

*Ballroom D*

Heidi Brown - Nashville, TN  
Sam Herron - Goodlettsville, TN  
Steven Garrison - San Francisco, CA  
Connie Curry - Saratoga, CA  
Moderator - TBA

A panel discussion with people with albinism in different careers. How did they choose their careers? What did it take to get there? Does their vision affect what they do? What accommodations do they use? There are many factors that go into choosing a career, learn about the choices these people made.

### **C. Coping with the Pain of Albinism:**

*Ballroom E*

#### **Making Lemonade When Lemons are Offered**

June Waugh - Albany, CA

This workshop will explore how to handle the negative experiences that often accompany albinism. How we cope and transform those experiences is vitally important. We will offer experience, ideas, and a model to think about in how to change those lemons into lemonade.

### **D. Know Your Rights in Employment:**

*The Parkroom*

#### **Low Vision and the ADA**

Brian Dimmick - Oakland, CA

This session will be presented by Brian Dimmick of Disability Rights Advocates. DRA is a non-profit legal center dedicated to protecting the civil and human rights of people with disabilities throughout the United States and the world. Their mission is to ensure dignity, equality, and opportunity for people with all types of disabilities in all key areas of life. Brian will address the basic issues of ADA employment rights (including requesting accommodation at work). There will be ample time for questions and answers.

12:00pm - 1:30 pm

Lunch

*Ballroom A&B*

## Saturday July 20, 2002 (continued)

1:30 pm- 2:30 pm **CONCURRENT SESSIONS**

**A. The process of Obtaining and Advocating for the Bioptic Driving Privilege** *Ballroom C*

Chuck Huss, C.O.M.S. - Institute, WV

This presentation will address the prerequisites that low vision consumers need to consider when applying for the driver license privilege and how to go about advocating for legislative change to expand your State's vision requirements for driving, including the use of bioptic telescopic lens systems.

**B. Albinism in the Cinema** *Ballroom D*

Vail Reese, M.D. - San Francisco, CA

Dermatologist Vail Reese will provide a retrospective of movie characters with albinism, emphasizing negative stereotyping. Possible reasons for the biases will be explored.

**C. The ABC's of skin care and Glamour** *Ballroom E*

Cynthia Towers - Seattle, WA

Mary-Kay Consultant and long time NOAH member, Cynthia Towers will conduct a seminar in how to look and feel your best with proper skin care and make-up application techniques.

**D. Albinism in Later Life** *Seminar 4*

Connie Curry - Saratoga, CA

Mike McGowan - Chicago, IL

Richard Thompson, O.D. - Bramalea, Ontario, Canada

Moderator - Janice Knuth - Philadelphia, PA

A panel discussion of the issues faced by older adults with albinism. Are people with albinism subject to the same need for longer arms as the rest of the general population? Should you be concerned about skin cancer? Do your motivations for career and personal success change? Join us for an active discussion.

## Saturday July 20, 2002 (*continued*)

### E. The Relationship Challenge

*The Parkroom*

Moderator - Pam Lewis - Decatur, GA

Go to any bookstore and peruse the self-help section. You will quickly see that relationships are a common difficulty in our culture. Having albinism can further complicate the process, but it doesn't mean you are condemned to a life alone. This session is for adults and will focus on the issues associated with entering and maintaining a committed relationship. Members of our community both single, and happily committed will share their relationship highs and lows.

3:00 pm-	4:30 pm	<b>DISCUSSION GROUPS</b>	
	<b>A.</b>	<b>West Coast</b>	<i>Ballroom C</i>
	<b>B.</b>	<b>Midwest</b>	<i>Ballroom D&amp;E</i>
	<b>C.</b>	<b>South</b>	<i>The Parkroom</i>
	<b>D.</b>	<b>East Coast</b>	<i>Seminar 4</i>
5:00 pm-	6:00 pm	<b>NOAH Photo - Ron Robinson</b>	<i>Ballroom C</i>
		<b>Dinner on your own</b>	
7:00 pm		Entertainment, Silent Auction/Raffles	<i>The Parkroom</i>
		<b>Club NOAH</b>	

Join us for **Club NOAH featuring Brooke Fox and Ravioli the Clown!** Ravioli the clown will kick off our festivities with a magic show that will amaze and thrill young and old. Then stay tuned for the music of Brooke Fox. Her intensely personal lyrics, soulful vocals, and earthy acoustic guitar create an intoxicating blend of music, ranging from dreamy, jazzy folk to Carly Simon-like pop to feisty, Alanis Morissette-type rock. She brings with her, a love for the craft of songwriting, and a live presence that has been hailed as "a must-see". "This young woman is a poet on fire," said Laurel Boland of *Sensored Magazine*. In between, we will be awarding our raffle and silent auction prizes! Join us for an evening with something for everyone!



## Sunday July 21, 2002

8:30 am - 12:00 pm

9:00 am - 11:30 am

Registration, T-shirt sales, etc.

### GENERAL SESSION

Housekeeping/General Announcements

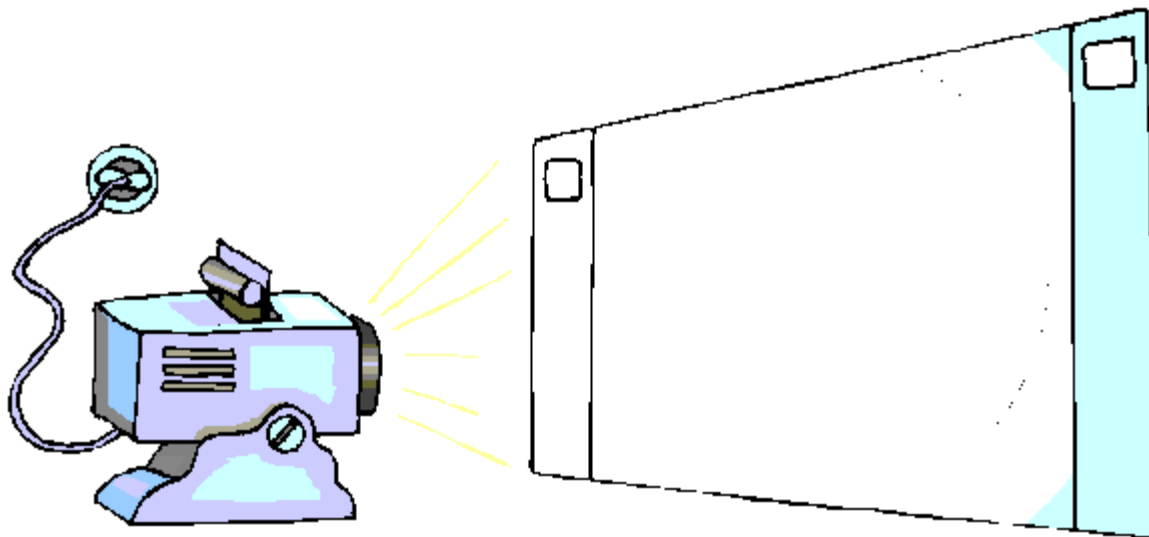
Group Breakfast

Closing Ceremony

Video Presentation of Conference

*Club Room 1*

*Ballroom A&B*



# Conference Speakers & Presenters

**Jerrilyn Ankenman, M.D.** - Jerrilyn Ankenman is the mother of Dan, a 7 year old with Oculocutaneous Albinism. She attended medical school at the University Of Utah, did her residency at Children's Hospital Oakland, and is a board certified pediatrician practicing in The Bay Area. She lives in Danville with her husband Gregg, and their kids Colette and Dan.

**Matthew Bailey** - So far, two small events have dramatically determined the direction of Matt's life. The first happened when Matt was three. "My dad brought me home a little black transistor radio -- I was instantly hooked." Matt's worked as a radio air personality - if you can call that work - for six years, playing everything from oldies to country and soft rock to 80s. Matt currently writes radio commercials and is on the air for a radio station in Atlanta.

That other event happened shortly after Matt graduated from college. "I called NOAH's 800 number hoping for some info on driving with bioptics, and when I heard they had a website, I decided to check it out. That was at 2:30 in the afternoon - I didn't log off the webboards until 2 the next morning! That experience totally changed my attitude about albinism. When you hear people making fun of you for it, you start believing it's bad and so I often outright denied having albinism. The webboards showed me just how cool, smart, funny, fun loving, and amazing folks with albinism actually are. I suddenly realized, "if this genetic phenomenon gets me into this club, I'm pretty lucky!" Matt's been on NOAH's board of directors since 2000, hoping someday soon everyone with albinism will know how amazing they are.

**Angela Bau** - Angela received her M.Ed. from Boston College. She has been in the field of visual impairment for over 20 years. Currently, she is an Education/ Rehabilitation Specialist as well as Low Vision Services Coordinator at the Low Vision Clinic in the School of Optometry at U.C. Berkeley. She also works an O&M instructor and supervises student teachers in the VI program at S.F. State University. In the past, she has been a Teacher of the Visually Impaired. Ms. Bau also teaches English as Second Language. She has an interest in facilitating cultural competence in teaching and rehabilitation work.

**Heidi Brown** - Heidi graduated from the University of Wisconsin – Green Bay with a Bachelor’s Degree in Psychology and Human Development. Currently, Heidi is a Women’s Advocate working at a domestic violence shelter for women and children

**David Buhl** - David is from Rockford Illinois. He is a graduate of Northern Illinois University. He holds a bachelor’s degree in Special Education and a Master’s degree in Orientation and Mobility. He’s an avid outdoorsman and loves to fishing and boating.

**Murray Brilliant, Ph.D.** - A Lindholm Professor of Mammalian Genetics in the Department of Pediatrics, of the Molecular Biology and Genetics Graduate Program at the University of Arizona in Tucson, Dr. Brilliant, has been conducting research on genetics and albinism for over 20 years. He obtained his graduate education at the University of Colorado, and other research experiences at The Jackson Laboratory in Maine and the Institute for Cancer Research in Philadelphia.

**Margaret Mary Campbell** - Margaret Mary Campbell says she is retired, but don’t believe her! She still volunteers for the school where she taught. She has been certified as an elementary level “peer mediator” and works as a mentor to other teachers. One of her proudest moments came when she completed a complicated ropes course as part of teacher leadership training. She was the first legally blind person to complete the course. She volunteers her time at the St. Joseph’s home for children and at Christmas gladly plays the role of Mrs. Claus. She has been married to Jack for more that 16 years and they live in Scranton, PA.

**Brendan Cosgrove** - Brendan Cosgrove, 22, has been around NOAH in some form or another since around 1984 (or so his parents tell him). He even got the chance to serve on the NOAH Board of Directors from 1998 to 2000. Brendan earned his bachelors degree in journalism and history from the University of Missouri in Columbia, MO. He is currently a producer for News/Talk 1400 KFRU in Columbia where he reports and anchors news, books guests for the local talk shows, and is responsible making sure the station's programming runs smoothly. On the weekends you can find Brendan driving all over the Midwest usually in his quest to visit all the major league and most minor league baseball parks.

**Connie Curry** - Connie Curry has a masters degree in Education and is the owner of Balloonatics, a balloon decorating company that she founded 21 years ago. She enjoys teaching at the International Balloon Arts Convention. At age 63, Connie is proud to be competing in a national figure skating competition this September. Connie lives in Saratoga, California with her wonderful husband of 33 years, Tom Lawrence. She is a Past President of NOAH.

**Kathleen Widefoot DeLaRosa** - Kathleen Widefoot DeLaRosa is a Native American Indian of the Navajo Tribe and lives in Pinon Arizona. She is the youngest of six children and the only one born with albinism. Kathy is the mother of a child with disabilities. She is active in her community with many organizations including acting as a PALS (Parents Are Liaisons to Schools) Representative for her School District. Her first conference was in Boston in 2000. She hasn't stopped talking about NOAH since.

**Brian Dimmick** - Brian Dimmick is an attorney with Disability Rights Advocates, ("DRA"), a national and international non-profit law center headquartered in Oakland, California. He is a graduate of Stanford Law School. Brian works primarily on employment discrimination cases at DRA, and is currently working on a project funded by the Skadden Fellowship Program to improve access to employment for people with vision and hearing disabilities. Brian is currently working on a DRA case against UPS on behalf of deaf workers and applicants around the country, and is also working on guides to employers and employees concerning their rights and responsibilities under the ADA and California law.

**Lee G. Edwards** - Lee is a 1992 graduate of the University of Alabama at Birmingham with a Bachelor of Science degree in Human Resource Management. He has faced the difficulty of living with albinism in the black community. Lee co-founded Dayton Area Persons with Albinism in 1987 and in June of 2000 he founded the Atlanta Area Persons with Albinism. As the Author of *Too White to be Black and too Black to be White*, Lee has had the opportunity to discuss the subject of albinism on radio talk shows in Ohio and Alabama.

**Brooke Fox** - Brooke Fox is a Northern California native. Her musical career has taken her from Boston, to Nashville and most recently New York City. Her intensely personal lyrics, soulful vocals, and earthy acoustic guitar create an

intoxicating blend of music, ranging from dreamy, jazzy folk to Carly Simon-like pop to feisty, Alanis Morissette-type rock. She brings with her, a love for the craft of songwriting, and a live presence that has been hailed as “a must-see”, “This young woman is a poet on fire,” said Laurel Boland of *Sensored Magazine*. For more information see [www.BrookeFox.com](http://www.BrookeFox.com).

**William A. Gahl, M.D., Ph.D.** - Dr. Gahl has recently assumed the position of Clinical Director of the National Human Genome Research Institute, and is also director of the intramural portion of the Office of Rare Diseases. For the past 8 years, he has studied Hermansky-Pudlak Syndrome, and has been involved in the discovery of two of the genes responsible for this disease. He has also characterized the different HPS subtypes by personally seeing more than 110 HPS patients at the National Institutes of Health.

**Steven Garrison** - Mr. Garrison comes to Riverstone Networks with more than 15 years experience in developing sales and marketing programs for emerging technology companies. He is currently responsible for corporate and solutions marketing at Riverstone. Mr. Garrison has authored and co-authored numerous presentations and papers on the data, wireless communications, and semiconductor industries and has received four U.S. patents. He earned an MS in Materials Science and Engineering from M.I.T. in 1986 and a B.S. in Ceramic Science from Alfred University in 1983.

**Rick Guidotti** - After completing his education in photography and filmmaking, at New York's School of Visual Arts Rick Guidotti established a studio in Manhattan, specializing in portraiture and fashion photography for fifteen years. During that period, Rick also worked in Milan, Paris, and London for commercial and editorial clients including L'Oreal, Revlon, ELLE, HARPER'S BAZAAR and LIFE magazine.

Since 1998, Rick has been devoted full-time to completing POSITIVE EXPOSURE. Through the combination of grants and personal funds Rick has been able to travel extensively throughout the US, Canada, the South Pacific, Panama, and England, photographing and interviewing people with albinism in their communities. He was honored by The Genetic Alliance in 1998 with "Art of Reporting" award for his "Redefining Beauty" photo essay in LIFE magazine.

**Victor Gurganious** - Victor attended Cape Fear Technical Institute in Wilmington, NC where he received a trade diploma in Wooden Boat construction and commercial fisheries with an Associates Degree in Marine Technology. He worked as a commercial fisherman to pay the bills while in school. Upon graduation in 1982 Victor moved to New Orleans to find a job in the oil industry where he didn't have any luck. He then moved back to North Carolina where he learned the construction business from scratch, working as a laborer in various jobs until 1988 where he started his own construction company. The company grew steadily, ultimately securing government contracts at the local, state and federal levels. In April of 2002, he sold the roofing portion of his business in preparation of returning to school in August. He will be attending classes in Business Administration and Restaurant Management.

**Patsy Harvey, O.D., M.P.H.** - Patsy Harvey is a nationally recognized public speaker. She has been a professor at UC Berkeley School of Optometry Low Vision Clinic for 18 years and is Director of Children's Vision Programs. She also acts as a Consultant for Department of Managed Health Care.

**Samuel Herron** - Sam decided to become a meteorologist at age 12 after studying weather in a school science class. He earned a B.S. in Atmospheric Science from the University of North Carolina at Ashville in 1993. Since then, Sam has worked as a meteorologist with the National Weather Service in Michigan, South Dakota, and Tennessee. Sam resides in Nashville, Tennessee.

**Chuck Huss, C.O.M.S.** - Chuck Huss is nationally know for his work and experience in the area of formalized low vision driver training and assessment – having coordinated and served as one of the principal researchers for the West Virginia Low Vision Driving Study, 1985-1995. He has been employed as an AER Certified Orientation and Mobility Specialist, (COMS) for the past 26 years. He received his Master of Arts degree in Orientation and Mobility from Western Michigan University in 1976.

**Jesse Kain** - Jesse Kain lives in Santa Fe New Mexico and works as an independent computer consultant. His interest includes computers, hiking, racquetball, skiing, ice skating, attending movies and theater and listening to music. Over the years Jessie's studies have included computer science, music, massage therapy, and

hypnotherapy. Jesse has been a member of NOAH for eight years and a board member for four years. “Through being a member of NOAH I have learned greater acceptance of myself and others.”

**Richard A. King, M.D.**- Dr. King is a professor in genetics at the University of Minnesota. He has been a very important part of NOAH’s National Conferences for many years, sharing the latest information on his research in albinism. He has the degree of M.D. in internal medicine, a Ph.D. in genetics and has been conducting albinism research for over twenty years.

**Janice Knuth** - Janice Knuth is one of 7 founders of NOAH. She served as president of NOAH for its first eleven years and continued on the Executive Committee for four more years. Jan has a master's degree in social work. She currently works as Assistive Technology Training Coordinator at the Institute on Disabilities at Temple University in Philadelphia. She lives in Center City Philadelphia and enjoys teaching and serving in other leadership positions in her church, cooking, and going to operas and other cultural events and movies.

**Dan Lee** - Dan Lee spent thirty years as a plant engineer for the YMCA of Metropolitan Chicago ascending to the position of Corporate Director of Purchasing and Building Services. He was actively involved in the development of the low vision closed circuit TV system and became the first representative for Visualek along with his wife Barbara.

Dan was member of the Board of Directors for the Chicago Lighthouse For People Who Are Blind or Visually Impaired for 19 years and served as Board Chairman for two years. He served as Senior Director of Industries for seven years before retirement and currently works as a consultant for the Lighthouse. Dan serves as First Vice President of NOAH.

**Pamela Goldstein Lewis** - Pamela Goldstein Lewis, MA, MFT is a graduate of University of California, Santa Barbara and Pepperdine University. As a marriage and family therapist, she worked both in private practice and for the County of Los Angeles where she focused on families, children, and parenting skills. She served on the Board of Directors of the Cincinnati Association for the Blind. At present, she resides in Atlanta, GA, and volunteers at Oak Grove Elementary School where

her twins Arielle (a child with albinism) and Sarah are students. Her husband, William, is a Professor at Emory University School of Medicine.

**Richard A. Lewis, M.D.**- Dr. Richard A. Lewis is one of the foremost researchers in the subject of ocular albinism. He is a tenured professor at the Baylor College of Medicine in the departments of Ophthalmology, Pediatrics, Medicine and Molecular and Human Genetics. His research has led to a test that can screen families for the OA 1 gene (the gene that causes most cases of OA). Dr. Lewis lives with his wife in Houston Texas.

**Francia D. Malone** - Francia is a 30 year old, native of Flint, Michigan. She has been visually impaired since birth and was diagnosed with Ocular Albinism in 2000. She graduated from Charles Stewart Mott Community College in 1994 with an associates degree in liberal arts. She founded Francia's Home Care Service in 2001. The business is dedicated to the memory of her parents Linnie and John Malone. In December 2001, Francia received the "Client Achievement/ Rehabilitation of the Year Award" from the Michigan Commission For the Blind and as a result was featured in her local newspaper and television news. Earlier this year, she was selected to be an honorary chairman for the Small Business Advisory Council in Washington, D.C.. Francia is very active in her community promoting Albinism awareness and education and mentoring individuals with disabilities.

**Michael McGowan** - President of NOAH, Mike is the Director of Information Services Office of the Chief Judge of the Circuit Court of Cook County, Illinois. He has been instrumental in successful fundraising efforts for Northern Illinois NOAH and the NOAH National Conferences.

**Vail Reese, M.D.** - Born and raised in Berkeley, California, Dr. Reese attended medical school at UC San Francisco. He received his college degree and dermatology training at Brown University in Providence, Rhode Island. In private practice in San Francisco, with a clinical faculty position at UCSF, Dr. Reese maintains the dermatology in the cinema web site, [www.skinema.com](http://www.skinema.com).

**Derrald, Taylor, O.D.** - Dr. Taylor has been a friend, consultant and supporter of NOAH for many years. On the faculty of the Illinois College of Optometry since

1972, he is also a Diplomate in the Low Vision Section of the American Academy of Optometry and holds a master's degree in vocational rehabilitation. For 18 years he served on the Advisory Council of the Illinois School for Visually Impaired.

**Richard Thompson, O.D.** - Dr. Rick Thompson is a fourth generation optometrist who graduated from the University of Waterloo, Ontario, Canada in 1979. He earned his fellowship at the American Academy of Optometry in 1982. In 1985 his interest in children's vision led him to study developmental and behavioral optometry with the Optometric Extension Program and the College of Syntonic Optometry. At this time he started offering in-office vision therapy to his patients as well as the traditional diagnostic and treatment options offered by optometrists. This led him into a specialized area of diagnosis and treatment called neuro-optometry. In his private practice in Brampton, Ontario, Canada. He now offers low vision services in his practice to both children and adults. In 1993 he and his wife Trish became proud parents of their fourth child, Lee-Anne. Her OCA (oculo-cutaneous albinism) led the Thompson's to NOAH. In 2000 Rick was elected to NOAH's Board of Directors. At this time he chairs the Albinism Awareness Committee.

**Cynthia Towers** - Cynthia Towers is a 20-year veteran of the classroom. She has worked in Special Education, elementary 4th and 5th grade and just completed her first year as a middle school math teacher. She has a Master's Degree in Education from the University of Washington and has served on a number of local and state educational committees. She also teaches teachers in the area of classroom management. Cynthia has been with the Mary Kay Corporation for four years. Although this is a part time venture, she receives full time satisfaction in being able to assist other women in the area of helping them to look and feel better about themselves. Her most rewarding community service is to go into retirement centers to conduct facial classes. Cynthia has a range of customers from fully sighted to totally blind.

**June Waugh** - June Waugh has been involved in the field of Special Education for the Visually Impaired since 1973. In addition she is a Marriage and Family Therapist since 1992. She is Coordinator of Low Vision Services at California School for the Blind and is in charge of the school based Low Vision Clinic with

the University of California Berkeley School of Optometry. She is the North American/Caribbean representative to the World Blind Union Children's Committee and on the WBU Working Group for Low Vision. She has been involved with NOAH since 1987.

**Debbie Wilson** -Debbie Lynn Wilson is a 43 year old, woman with albinism. She was born in Muskegon MI and currently reside in Flint Michigan. Debbie holds a Masters of Social Work degree from Western Michigan University and works as a Rehabilitation Counselor for the Michigan Commission for the Blind. She has 3 siblings with albinism. She is a member of the National Association of Social Workers, Lion's Club, National Rehabilitation Association, and Delta Sigma Theta Sorority- Flint Alumni Chapter, Board member of Visually Impaired Center. Debbie serves as the NOAH contact person for the state of Michigan.

**Lisa Williams** - Lisa Williams is a wife and mother. She has been married to her husband Joe for 18 years and has one daughter Natalie, aged 6. Lisa and Joe home school their daughter Natalie who will begin 3rd grade in September. Lisa also works with Joe in their home-based training consulting business. Lisa, Joe and Natalie live in Clayton, California.

**Joe Williams** - Joe Williams is a native Californian and although he has had albinism all his life, he rarely thinks about it. Growing up in San Diego, the land of sun and fun, did tend to make him stick out. As a kid at the beach, most people thought he was from back East. As a long time resident of the Bay Area though, he finds that the "tan" thing is not such a big deal. Life these days is mostly about being a good husband and father, working to pay the bills and helping make life better for others.

**Linda Wurzbach** - Linda Wurzbach is Adjunct faculty at Saint Mary's College in Moraga California. She is a former School Board Trustee for the San Ramon Valley Unified School District. She is currently a family/child advocate for children with special education needs, and a parent of a child with special needs.

## *Exhibitors and Information Tables*

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*Donna Appell*

National Organization for Albinism and Hypopigmentation (NOAH)

*Dan Lee*

NPR Healthcare (Particle Sciences)

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