

# NOAH CON 2024

Conference Program



**NOAH's 20th National Conference**

**July 11-14, 2024**

**GARDEN GROVE, CA**  
**[albinism.org/noahcon](http://albinism.org/noahcon)**  
**#NOAHCon24**



**MISSION:** NOAH’s mission is to act as a conduit for accurate and authoritative information about all aspects of living with albinism and to provide a place where people with albinism and their families in the U.S. and Canada can find acceptance, support, and fellowship.

**VISION:** NOAH envisions a world where people with albinism are empowered to be fully functioning members of society, where barriers and the stigma of difference no longer exist, and where people with albinism have a quality of life that is rewarding, dignified, and fulfilling.

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**NOAH New Parent Program**

Megan Pitt, LMHC  
 Program Coordinator

**NOAHCon24  
 is Online**

Keep up with the latest NOAH Conference news and information by following the action on Facebook, Twitter and Instagram. Use #NOAHCon24 and @NOAHAlbinism when posting to social media. Upload those priceless photos and you may see them in the closing session slideshow.

**You will also be eligible to win a NOAH prize pack for sharing on social!**



The National Organization for Albinism & Hypopigmentation

# WELCOMES YOU to Garden Grove, CA

It's time for *"Take Two!"*

Although this year's theme is a nod to the film industry and our long-anticipated screening of "Jasmine is a Star", it is also a reference to NOAH's second attempt at hosting a conference in Orange County.

We ask you to join us in extending our gratitude to the staff here at the Hyatt Regency Orange County for their amazing partnership and unprecedented support through the 2020 cancellation due to the pandemic.

## Log on to NOAHCon!

Navigate to

[www.albinism.org/orange-county](http://www.albinism.org/orange-county)  
password: star

for digital conference information including:  
speaker bios, digital program and much more!



JOIN US at the Opening Session

Thursday, July 11th  
at 7:30 PM

Grand Ballroom A – D



NOAH will honor the late Dr. C. Gail Summers and her contributions to the albinism community.

# THANK YOU TO ALL OUR GENEROUS SUPPORTERS!

## Thank You



Thanks to Delta Gamma Foundation for supporting NOAH's personal grant program.



Thanks to Parker Hannifin Foundation for supporting NOAH's iPad Program

### Thanks to Our Sponsors

Epstein Ostrove  
Jonathan's Cleaners  
Under the Same Sun

Thanks to the following NOAH Toolkit Donors:

**Ainslee Jones Girl Scouts Silver Award Project**



**Rebekah's Readers**



## A Very Special Thanks



NOAH's Board of Directors would like to express sincere appreciation for NOAH's biggest conference benefactor, Beverly Kaiser. Throughout the years, Beverly's generosity and benevolence have had an immeasurable impact on the albinism community and have brought dozens of families to NOAH events. Her donation to the 2024 Conference was \$25,000, which went toward personal grants to fund individuals and families who otherwise would not have been able to attend the conference and for other conference expenses. Beverly's selfless actions and giving nature continue to help bring the albinism community together.

### Exhibitor List

Advanced Ocular Imaging Program

American Printing House for the Blind

Anthony's Adventures  
Author, Brenda Mitchell

Described and Captioned Media Program

Designs for Vision, Inc.

eyeGENE®

HPS Network

LightHouse for the Blind and Visually Impaired

Lighthouse Guild

Ocutech

Positive Exposure

ShadeSuits, Inc.

The International Academy of Low Vision Specialists

Under The Same Sun

The Vision of Children Foundation

## Conference Statement

NOAH's mission is to provide authoritative and accurate information to the albinism community. NOAH strives to make the biennial national conference the town square of the albinism community. Our goal is to create a safe, comfortable, engaging place where people with albinism, the parents of children with albinism as well as other interested family members, friends and professionals can freely come together to foster fellowship and to share information, opinions and ideas.

The Conference Program Committee endeavors to gather relevant and interesting information for presentation in the educational sessions, during discussion groups and at the exhibits. The committee's goal is to present a balanced view of albinism encompassing various perspectives. Inclusion or exclusion of a topic, presenter or exhibitor does not represent a positive or negative opinion by NOAH of a product, the person making the presentation or the views that he or she may express. NOAH hopes that the information provided at conferences will empower attendees in making their individual, private decisions concerning living with albinism.



## 2024 NOAH Conference Committee

It takes dozens of volunteers to hold a NOAH conference. Thanks to all who pitched in to make the stars align. Special thanks go to the committee members who took the lead to plan and execute NOAH's 20th National Conference.

### Kids' Program Leads

#### Rising Stars: 6 mos – K

Beth Cope  
Kelly Huizdos

#### SuperStars: 1st – 6th

Tricia Thomas  
Angela Adamo

#### Directors & Producers: 7th – 9th & 10th – 12th

Kimberly Paglia  
Tony Paglia

### Marketing and Communications

Lori Aubrey  
Marleena Barber  
Karen Bly  
Ethan Cohen  
Hershula Davis  
Casey Greer  
Cris Plant  
Emily Silva  
Sarah Venn

### Conference Nurse

Alix Laughlin

### Educational Program

Kathi Garza, MEd, TVI  
Erika Evans  
Nick Smith  
Rebecca Smith

### Audio Visual

Matthew Hernandez

### Local Support

André Bullock  
Grace Khalifa  
Dana Warenski

### NOAH PWA Choir

Marleena Barber

### Silent Auction/Raffle

Chris Kramer  
Joni Vella

### Social Activities

Marleena Barber

### Vendor/Sponsor Coordination

Lee Laughlin

### Volunteer Coordination

Sheila Adamo  
Michelle O'Connor

### Young Adult Programming

Cassandra Mendez

# ★ ★ CONFERENCE SCHEDULE ★ ★

for Thursday, July 11th

3:00 PM – 8:00 PM

**Check in, Preorder Pickup,  
Merchandise Sales**  
Grand Rotunda

7:30 PM – 9:00 PM

**Opening Session,  
Sponsored by Epstein Ostrove, LLC**  
Grand Ballroom A–D

3:00 PM – 7:30 PM

**Silent Auction Item Drop-off  
and Sun Gear Drop-off** (see Page 7)  
Grand Rotunda

9:00 PM – 10:00 PM

**Welcome Reception,  
Sponsored by Epstein Ostrove, LLC**  
Light snacks, soft drinks, cash bar –  
(for registered conference attendees)  
Grand Ballroom A–D

**Dinner**

**On Your Own**

5:00 PM – 5:30 PM

**First Timers Session**  
Grand E & F

**See insert for Friday and Saturday  
Adult Education Program and  
information about onsite  
Research Opportunities**

5:30 PM – 6:00 PM

**Young Adult Orientation**  
Grand G

5:30 PM – 7:00 PM

**Producers and Directors  
T Shirt pick up**  
Harbor

5:45 PM – 6:15 PM

**Rising Stars  
Parent Orientation**  
Salon VII & VIII

6:15 PM – 6:45 PM

**SuperStars  
Parent Orientation**  
Salon VII & VIII

## **NOAH Game Night (Adults 18+)**

**Cost: Free!**

**Friday, July 12th**

**10:00 PM – 11:00 PM**

**Grand A**



An improv-style game night where YOU are the entertainment! Try your luck at “Password,” “Let’s Make a Deal,” “Family Feud,” and more, or sit back and watch your friends for some laughs. This adults only (18+) comedy game night will be hosted by the hilarious, **Dennis Hurley**, a PWA actor-comedian who has appeared on NBC’s Superstore, Comedy Central’s The Daily Show, Justin Timberlake’s 2016 Can’t Stop The Feeling music video, and the internationally acclaimed The Albino Code, a parody of The DaVinci Code that he wrote and starred in.

**[www.dennis-hurley.com](http://www.dennis-hurley.com)**

# ★ ★ CONFERENCE SCHEDULE ★ ★

for Sunday, July 14th

9:00 AM – 10:30 AM

## Breakfast

(for registered conference attendees)  
Grand Ballroom A–D

9:30 AM

## Closing Session:

Retrospective Conference  
Slide Show

NOAH PWA Choir Performance

NOAH Event Announcements



Photo courtesy of Positive Exposure, Rick Guidotti

## Sun Protective Gear Swap

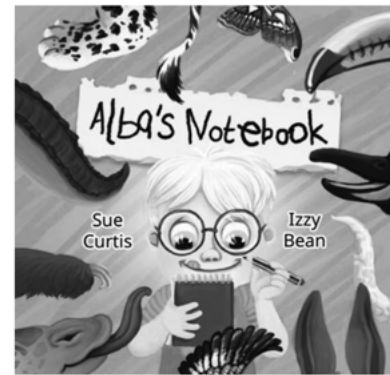
**Drop Off** – If you brought sun-protective clothing, hats, sunglasses, goggles, or other helpful items that are gently used, clean and in good condition to share with other families, please drop off during the swap:

**Thursday 3:00 – 7:30 PM**  
and  
**Friday 8:00 AM**  
at the registration table

**Sun Gear Swap Meet** – Those interested in used sun gear should meet for the swap, **Friday 8:00 – 8:45 AM** in the Grand Ballroom Foyer.

A second swap meet may be held if necessary **Saturday 8:00 – 8:45 AM**.

*Leftovers will be donated.*



**Published 8<sup>th</sup> May 2024**

Their bags are packed, the tents are ready and the pages of Alba's notebook are waiting to be filled.

Every night Alba gets out his notebook. But what does he write inside? Join Alba, who has albinism, and his friends on their animal adventure.

This book stars a main character thriving with albinism.

**Reading age: 3 - 7 years**  
**Available on Amazon**  
[www.suecurtisbooks.co.uk](http://www.suecurtisbooks.co.uk)  
**Instagram - suecurtisbooks**



# RISING STARS SCHEDULE



(for Kids 6 Months – Entering Kindergarten)  
North Tower - Second Floor - Salon I-V

## Friday, July 12th

8:00 AM – 8:45 AM

**Check in**  
Salon Foyer

9:00 AM

**Puppet Show**  
**Interactive STEM Program**  
**LUNCH in room**  
**Story Time**  
**Naps/quiet time**

3:15 PM

**Check out**

## Saturday, July 13th

8:00 AM – 8:45 AM

**Check in**  
Salon Foyer

9:00 AM

**Baby Yoga**  
**Music with Ranger Jack**  
**LUNCH in room**  
**Naps/quiet time**  
**Bubbles**

**Make 2024 NOAH Conference Bears**

3:15 PM

**Check out**

Each day, the Rising Stars will enjoy age-appropriate play time. Activities planned include crafts, dancing scarves, music and movement, bubbles, cars, coloring and more. We will have a gross motor area that includes riding toys, plus a ball pit and tunnel for children one to three years old!

We can't wait to meet our Rising Stars!



Photo courtesy of Positive Exposure, Rick Guidotti





# SUPERSTARS SCHEDULE



(for Kids Entering 1st Grade – 6th Grade)  
North Tower - First Floor - Garden 1-4

**Friday, July 12th**

## **1st & 2nd Grades – Red SuperStars**

8:30 AM

**Check in**  
Garden Foyer

9:00 AM

**“Adventures of the Lost Treasure” STEM**  
**Space BINGO**  
**Drama Games with Casey!**  
**LUNCH in room**  
**Treasure Hunt Game**  
**Magic Show**

3:15 PM

**Check out**

## **5th & 6th Grades – Blue SuperStars**

8:30 AM

**Check in**  
Garden Foyer

9:00 AM

**Collaborative Geometric Canvas**  
**Harry Potter Game Show**  
**LUNCH in room**  
**Make 2024 NOAHCon Bears for**  
**Preschool (BLUE group is NOT**  
**getting bears to take home.)**  
**Ask an Adult with Albinism**

3:15 PM

**Check out**

## **3rd & 4th Grades – Yellow SuperStars**

8:30 AM

**Check in**  
Garden Foyer

9:00 AM

**Pokemon Game Show**  
**Quilt Squares**  
**LUNCH in room**  
**Summer Fun Bingo**  
**Make 2024 NOAH**  
**Conference Bears**

3:15 PM

**Check out**



Photo courtesy of Megan Pitt



# SUPERSTARS SCHEDULE



(for Kids Entering 1st Grade – 6th Grade)  
North Tower - First Floor - Garden 1-4

**Saturday, July 13th**

## 1st & 2nd Grades – Red SuperStars

8:30 AM

**Check in**  
Garden Foyer

9:00 AM

**“I am” Collage**

**Yoga**

**Space Trivia**

**LUNCH in room**

**Make 2024 NOAH Conference Bears**

**Puppet Show**

**Sun Protection**

3:15 PM

**Check out**

## 3rd & 4th Grades – Yellow SuperStars

8:30 AM

**Check in**  
Garden Foyer

9:00 AM

**Yoga**

**Craft – Attitude is Everything Poster**

**Ask a Teen with Albinism**

**Sun Protection**

**LUNCH in room**

**Power – UP Program**

3:15 PM

**Check out**

## 5th & 6th Grades – Blue SuperStars

8:30 AM

**Check in**  
Garden Foyer

9:00 AM

**Cooperative Chaos Competition**

**Orientation & Mobility Lesson**

**Walk to Coco’s Bakery for Lunch Out**

**Cup Stacking Contest**

3:15 PM

**Check out**



Photo courtesy of Terri Nigro



# DIRECTORS SCHEDULE



(for Kids Entering 7th Grade – 9th Grade)  
North Tower - Second Floor - Pacific and Harbor  
Friday the 12th and Saturday the 13th

## Friday, July 12th

8:45 AM – 9:00 AM

**Check in**  
Pacific

9:00 AM – 10:00 AM

**KEYNOTE -**  
“What is YOUR Story?”

10:00 AM – 10:45 AM

**Orientation & Mobility - “Going Mobile”**

10:45 AM – 11:30 AM

**Improv Games**

11:30 AM – 12:00 PM

**Visit Exhibit area**

12:00 PM – 1:00 PM

**LUNCH in room**

1:00 PM – 2:00 PM

**Drum Circle**

2:00 PM – 3:15 PM

**“Telling Our Stories”**  
**PWA Panel Discussion**

3:15 PM

**Wrap up and check out**  
Pacific

## Saturday, July 13th

8:45 AM – 9:00 AM

**Check in**  
Pacific

9:00 AM – 9:45 AM

**My Life in Comics**

9:45 AM – 10:30 AM

**“Shine Bright with Confidence”**  
hosted by Rare with Flair

10:30 AM – 11:00 AM

**O&M - Restaurant Skills**

11:00 AM – 3:00 PM

**Bus to Anaheim GardenWalk**

**LUNCH out**

**GooseChase Scavenger Hunt**

**Bus to Hyatt**

**Self Portraits**

3:15 PM

**Wrap up and check out**  
Pacific



Photo courtesy of Carolyn Budd

## Exhibitor Showcase!

Friday, July 12th

12:45 PM – 1:45 PM

Meet in in Grand B – D

Stop by for a one-stop shop  
where attendees can hear from  
all of the conference vendors  
in one place.



# PRODUCERS SCHEDULE



(for Kids Entering 10th Grade – 12th Grade)  
North Tower - Second Floor - Pacific and Harbor

## Friday, July 12th

8:45 AM – 9:00 AM

**Check in**  
Harbor

9:00 AM – 10:00 AM

**KEYNOTE - “What is YOUR Story?”**

10:00 AM – 10:45 AM

**Improv Games**

10:45 AM – 11:30 AM

**Orientation & Mobility - “Going Mobile”**

11:30 AM – 12:30 PM

**LUNCH in room**

12:30 PM – 1:00 PM

**Visit Exhibit area**

1:00 PM – 2:00 PM

**Drum Circle**

2:00 PM – 3:15 PM

**“Telling Our Stories” PWA Panel  
Discussion**

3:15 PM

**Check out**  
Harbor

## Saturday, July 13th

8:45 AM – 9:00 AM

**Check in**  
Harbor

9:00 AM – 9:45 AM

**“Shine Bright with Confidence”  
hosted by Rare with Flair**

9:45 AM – 10:30 AM

**My Life in Comics**

10:30 AM – 11:00 AM

**O&M - Restaurant Skills**

11:00 AM – 12:30 PM

**LUNCH out - walk to Red Robin**

12:30 PM – 1:30 PM

**Self Portraits**

1:30 PM – 2:00 PM

**Let’s Talk**

2:00 PM – 3:00 PM

**Adult Program Option:**

**“Red Carpet Ready”**

**“Star Search - NOAH Fundraising  
& Fellowship”**

**“Bioptic Driving Panel Discussion”**

3:15 PM

**Check out**  
Harbor



Photo courtesy of Elizabeth Drury

# ★ ★ YOUNG ADULT SCHEDULE ★ ★

As recent “graduates” from the NOAH Kids’ Conference begin to navigate their path to adulthood, NOAH understands that adult conference attendees join us with a wide range of needs and expectations for programming. In addition to the educational programs being offered in the Adult Program Schedule, check out some of these social and educational opportunities for the 18–30 demographic!

## Thursday, July 11th

5:30 PM – 6:00 PM

### **Young Adult Orientation**

Consider this “Freshman Orientation” for 18 to 30(ish) adults who may be looking for session suggestions to get the most from their conference experience.

Grand G

9:30 PM

### **PWA Young Adult Connections IRL (“In Real Life”) Meet-Up**

Whether you’ve been networking with your young adult NOAH pals on zoom or want to join others for the first time, we can’t wait to hang out IN PERSON! (**Note** We will gather in Grand Ballroom E for about 15 minutes before moving on to another location to continue the fun.)

Grand E

## Friday, July 12th

8:00 AM – 5:00 PM

### **NOAH Exchange**

Be sure to take some time to visit this year’s NOAHCon Exhibitors (see page 4)

Grand Ballroom Foyer



Photo courtesy of Bellhouse\*\*

2:00 PM – 3:00 PM

### **Young Adults with Albinism Forum**

Join us for a lively chat about day-to-day living, navigating your world, and how to dive into the social scene or your a new job! This is an excellent place for networking and engagement among the 18–30 year-old crowd.

Laguna Suite

3:15 PM – 4:00 PM

### **Conquering Your Career Panel**

Join us for an informative panel discussion where adults with albinism will discuss their career paths and goals, how their path has changed over time, and what advice they have for others with albinism wishing to pursue a similar career path. Audience members are encouraged to engage and ask questions of the panelists as well!

Grand A

## Saturday, July 13th

2:00 PM – 3:00 PM

### **Unleashing the Adventurer Within**

Adventure can be profoundly beneficial for both children and adults with albinism. These social connections offer emotional support, encouragement, and camaraderie, enriching lives and enhancing overall well-being.

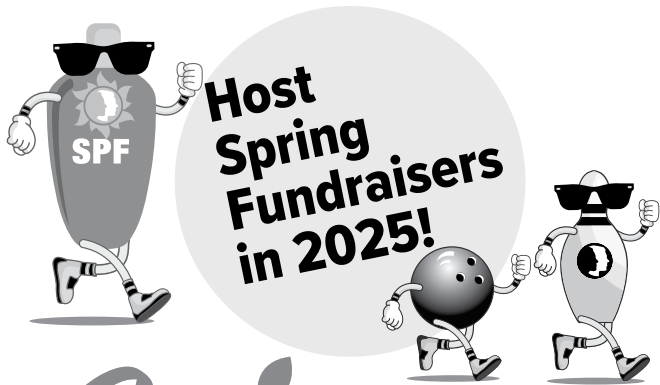
Salon VII

3:15 PM – 4:00 PM

### **Group Mixedfit**

Mixedfit is a people-inspired fitness program that combines explosive dance movements and body weight toning. It’s nothing fancy; just a fun time to dance!

Salon VII



# Spring for NOAH<sup>SM</sup>

Annual Bowl-a-thon & Community Fundraisers

Visit: [albinism.org/fundraisers](http://albinism.org/fundraisers) or contact [fundraise@albinism.org](mailto:fundraise@albinism.org) to get started!



## Try-It Technology Fair

Friday, July 12th  
3:30 PM – 5:00 PM  
Grand G

This interactive session targets parents, kids, and teachers and includes hands-on access to technology for home, school, and community use. Technology facilitators will provide experiences with Apple and Android apps used for travel, iPad apps used to support access to school and home tasks, and a virtual reality simulation tool developed by EdPlus at Arizona State University. Come join the fun, and bring your devices to get immediate access to what's new and cool in our community!

**Protect.  
Empower.  
Advocate.**

Progress update on Albinism in Africa.



Join our session to learn about our life saving work to end deadly discrimination against people with albinism.

-- [underthesamesun.com](http://underthesamesun.com) --





# CONFERENCE SCHEDULE



## Thursday Night Meet-ups

9:30 PM

### Drinks with Dads

Meet-up at OC Brewhouse lobby bar

### Young Adult Connections

#### “In Real Life” Meet-up

Grand Ballroom E

### Adult Connections “In Real Life” Meet-Up

Grand Ballroom F

### First Timers’ Meet-up

Grand Ballroom G

**\*NO TEEN OR TWEEN ROOMS TONIGHT\***

## Friday, July 12, 2024

7:30 AM – 8:30 AM

### Friday Grab-n-Go Breakfast

**\*Optional Meal - Purchase Required\***

Grand Ballroom B

8:00 AM – 8:30 AM

### Yoga - Salon VIII

### Silent Auction Drop-off - Grand Rotunda

### Sun Gear Drop-off / Swap - Ballroom Foyer

8:00 AM – 5:00 PM

### NOAH Exchange - Exhibits Open

Grand Ballroom Foyer

9:00 AM – 9:30 AM

### Keynote Address - Community

Grand Ballroom A

9:45 AM – 11:30 AM

### Latest Research in Albinism

Grand Ballroom A

### PWA Canvas Paint - **\*\*pre-registration required\*\*** - Salon VI

### Connecting Assessments to Services

Grand Ballroom F

11:30 AM – 12:45 PM

### Friday Lunch - Grand Ballroom B–D

12:45 PM – 1:45 PM

### Ask the Doctors for PWAs

Grand Ballroom A

### Employment Skills Should Start Young

Grand Ballroom E

### Bioptic Driving Training, Testing, and Licensure: Similarities and Differences Across the United States

Grand Ballroom G

### Exhibitors Showcase

Meet in Grand Ballroom B–D

### Parents of Newly Diagnosed Children and Young Children with Albinism - Salon VII

### My MO for O&M - Grand Ballroom F

### Writing from Memory: A Creative Writing Workshop - Salon VI

2:00 PM – 3:00 PM

### Ask the Doctors for Parents and Families

Grand Ballroom A

### Young Adults with Albinism Forum

Laguna Suite

### Ask an Educator - Grand Ballroom F

### How Do We Navigate this Thing Called Mid-Life and Beyond? - Salon VII

### Dealing with Comments & Questions (for family members) - Grand Ballroom G

### Navigating the Expanded Core Curriculum in School: Advocacy, Assessment, Services, and Opportunities

Grand Ballroom E

3:15 PM – 4:00 PM

### Conquering Your Career Panel

Grand Ballroom A

**PWA Book Club** - Salon VI

**The Man Cave - PWA Guys  
Forum** Salon VIII

3:15 PM – 5:00 PM

**Out & About with O&M**

Meet at the Registration Table

**Office Hours with Dr. Anne Corn**

Laguna Suite

**Try-It Technology Fair**

Grand Ballroom G

4:00 PM – 5:00 PM

**NOAH PWA Choir Rehearsal** - Salon VII

5:00 PM – 9:00 PM

**(Off-Site Outing) Jasmine is a Star  
Movie Screening at Frida Cinema**

Off-Site – Frida Cinema

**(Off-Site Outing) Huntington Beach  
at Sunset Trip**

Off-Site – Huntington Beach

9:00 PM – 11:00 PM

**Teen /Tween Room - Karaoke Party**

Pacific Room and Harbor Room

10:00 PM – 11:00 PM

**NOAH Game Night (18+)** - Grand Ballroom A

## Saturday, July 13, 2024

7:30 AM – 8:30 AM

**Saturday Grab-n-Go Breakfast**

**\*Optional Meal - Purchase Required\***

Grand Ballroom B

8:00 AM – 8:30 AM

**Silent Auction Drop-off** - Grand Rotunda

**Sun Gear Swap (if necessary)**

Grand Ballroom Foyer

9:00 AM – 10:00 AM

**Jasmine is a Star Panel Discussion**

Grand Ballroom A

**Hermansky-Pudlak Syndrome -**

**Diagnosis and Management** - Salon VII

**Around Town, Around the World**

Grand Ballroom E

**Understanding and Supporting the  
Psychosocial well-being of Children  
& Adolescents with Albinism from a  
Developmental Perspective**

Grand Ballroom F

**The Power of Networking: Albinism  
Advocacy Around the World**

Grand Ballroom G

**Adoptive Families Forum**

Laguna Suite

**In Stitches (PWA Crafting)**

Salon VI

10:15 AM – 11:30 AM

**Panel Discussion for Newly Diagnosed  
Parents, Grandparents and Caregivers  
(1st Time Conference Attendees)**

Grand Ballroom A

**Protect. Empower. Advocate: Progress on  
Albinism in Africa (UTSS and AAN)**

Grand Ballroom G

**Enhancing Learning through**

**Accessible Media** - Grand Ballroom F

**Supporting People with Albinism in**

**Sport & Physical Activity** - Grand Ballroom E

**Grandparent Forum**

Laguna Suite

**A Closer Look at Legos** - \*\*pre-registration  
required\*\* - Salon VI

11:30 AM – 12:45 PM

**Saturday Lunch**

Grand Ballroom B-D

12:45 PM – 1:45 PM

**Genetics of Albinism for Beginners**

Grand Ballroom F

**How PWAs See - Investigating  
Facial Recognition**

Grand Ballroom A

*Continued on next page*



# ADA Jeopardy

Saturday, July 13th

12:45 PM – 1:45 PM

Grand Ballroom E

This interactive lecture will use a game-show format to explore key provisions of the Americans with Disabilities Act (ADA), spotlighting how it addresses accessibility, discrimination, and accommodation in both public and private sectors.

## Parenting Without Pigment Forum

Grand Ballroom G

## PWA Gal Pals Forum

Salon VIII

## Black PWAs Forum

Laguna Suite

## Writing from Memory:

### A Creative Writing Workshop

Salon VI

2:00 PM – 3:00 PM

## Low Vision/Bioptic Driving Panel

### Discussion Session

Grand Ballroom A

## Parents of Children with Albinism Forum

Salon VIII

## Unleashing the Adventurer Within

Salon VII

## Star Search NOAH Fundraising and Fellowship

Grand Ballroom G

## Building Self-Reliance in a Supportive Environment for Parents and Caregivers

Grand Ballroom E

## Red Carpet Ready

Grand Ballroom F

3:15 PM – 4:00 PM

## Group Mixedfit

Salon VIII

## NOAH Town Hall:

### Meet the NOAH Board & Staff

Grand Ballroom G

## GRAND Ideas for Orientation & Mobility:

### O&M is Everything and Everything is O&M!

Grand Ballroom E

3:15 PM – 5:00 PM

## Minute to Win-It

Grand Ballroom B-D

4:00 PM – 5:00 PM

## NOAH PWA Choir Rehearsal

Salon VII

5:30 PM – 7:30 PM

## NOAH Pizza Party \*Optional Meal - Purchase Required\*

Garden 3

7:30 PM – 10:00 PM

## Dessert Reception/Dance Party and NOAH Silent Auction

Royal Ballroom, South Tower

10:00 PM – 11:00 PM

## NOAH Karaoke Party (18+)

Royal Ballroom, South Tower

10:00 PM – 12:00 AM

## NOAH Teen / Tween Rooms

Harbor Room and Pacific Room

## Sunday, July 14, 2024

8:15 AM – 8:45 PM

## NOAH PWA Choir Dress Rehearsal and Photo

Grand Ballroom A–D

9:00 AM – 10:30 AM

## Farewell Breakfast/Closing with NOAH PWA Choir Performance

Grand Ballroom A–D

# NOAH is thrilled to provide NOAHCon 2024 attendees with Onsite Research Opportunities!

Please visit the Terrace Rooms (*South Tower - see map below*) to find out more about albinism research opportunities with:

**Medical College of Wisconsin** in Terrace A  
(see flyer insert for more details)

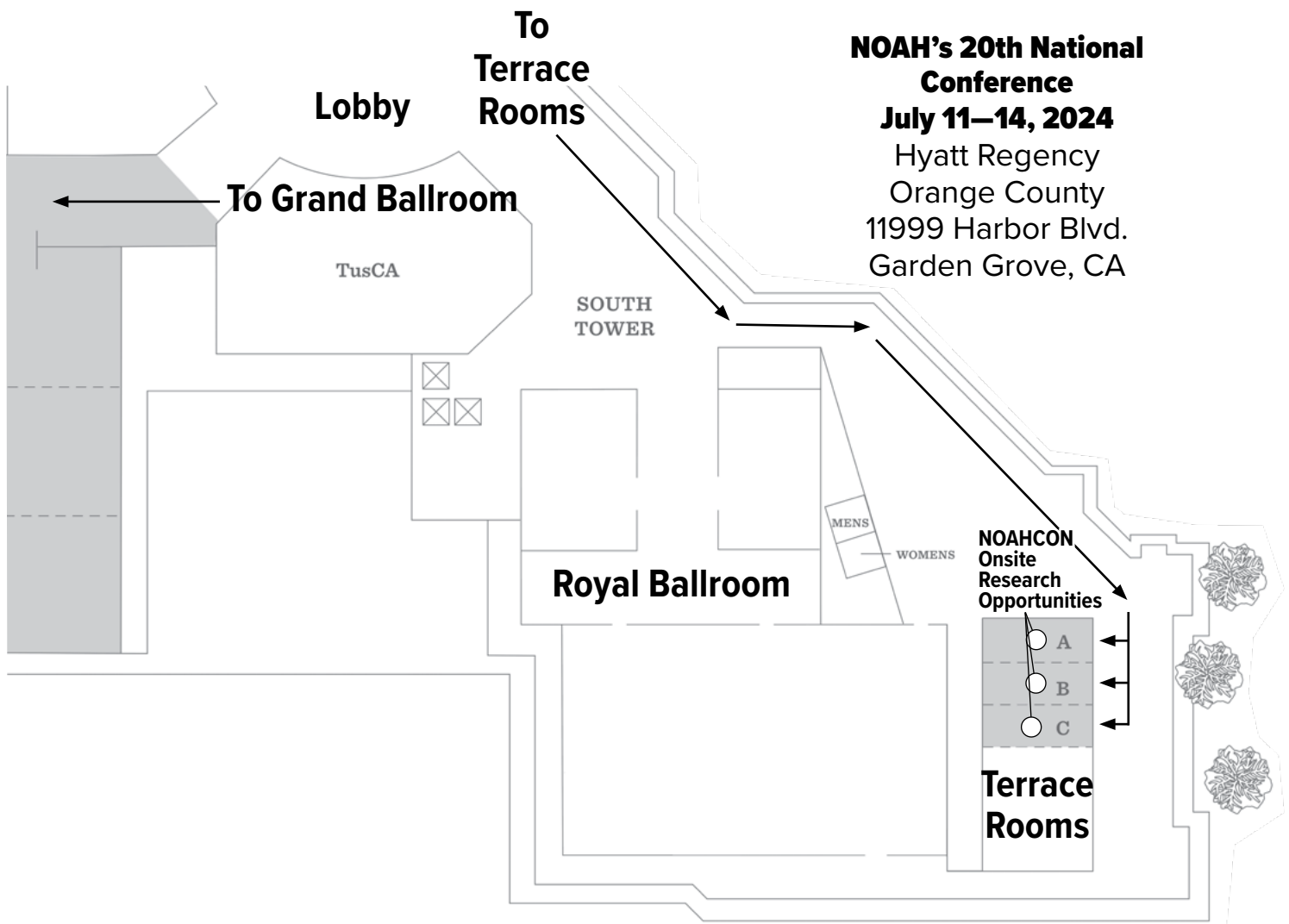
**Albinism International Databank** in Terrace B  
(see flyer insert for more details)

**eyeGENE®** in Terrace C

The National Ophthalmic Disease Genotyping and Phenotyping Network (eyeGENE®) is a genomic medicine initiative created by the National Eye Institute (NEI), part of the National Institutes of Health (NIH). The core mission of eyeGENE® is to facilitate research into the causes and mechanisms of rare inherited eye diseases and accelerate pathways to treatments. eyeGENE® collects genetic testing, clinical information, and imaging from participants.

<https://eyegene.nih.gov>

**Onsite Research Opportunities will be available Friday, July 12th and Saturday, July 13th from 8:00 AM to 11:00 AM and 12:15 PM to 5:00 PM.** Representatives will also have information available in the NOAH Exchange throughout the weekend. Please stop by and find out more!





# ADULT EDUCATION Programs



See insert for dates and times!

## Adoptive Families Forum

This peer-to-peer discussion session gives adoptive parents of kids with albinism the chance to express their concerns, ask questions and learn. Bring your burning questions, come to share your thoughts or just listen. This is a safe place for parents to be with others who have walked in your shoes.

## Adult Connections “In Real Life” Meet-Up

Change out of your pajama pants, and get ready for some REAL LIFE fun with your adult NOAH pals. Whether you’ve been networking with us on zoom or want to join others for the first time, we can’t wait to hang out IN PERSON!

**\*\*Note\*\*** We will gather in Grand Ballroom F for about 15 minutes before moving on to another location to continue the fun.

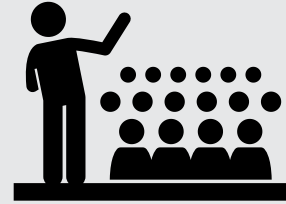
## Around Town, Around the World

Cindy Bachofer, PhD, CLVT;  
Marjie Wood, TVI, COMS

Picture your child as a young adult confidently and independently traveling across town, on a college campus, or to visit grandparents in another state. What skills are needed for these travel scenarios to play out? No matter your child’s current age, as



Photo courtesy of Christopher Ranaudo



## Keynote Address - Community

Friday, July 12th  
9:00 AM – 9:30 AM  
Grand Ballroom A

This year marks NOAH’s 20th Biennial National Conference. As we kick-off the adult education program, join us in commemorating the occasion as a community.

a parent you have an integral role in helping your child gain the confidence and independence to meet this goal. The presenters will focus on specific skills across the ages and stages of growth and activities for families to incorporate in supporting this development. The ultimate goal is to help your child become a confident and successful traveler across environments.

## Ask an Educator

Cindy Bachofer, PhD, CLVT; Anne Corn, EdD;  
Kayla Hamlin, TVI, COMS; Marjie Wood, TVI, COMS ;  
Jocelyn Leworthy, MSc, CCLS

Do you have questions about the development and implementation of your child’s IEP or 504 Plan? | Have you wondered about social development, } mental health, age-appropriate independent living skills, or post-secondary education? Parents of children with albinism of all ages are welcome and encouraged to bring their questions to this

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Photo courtesy of Positive Exposure, Rick Guidotti

question-and-answer session with professionals in the field of special education, clinical social work, and orientation and mobility. We look forward to problem-solving with you!

**Ask the Doctors for Parents and Families**

David Adams, MD, PhD; Murray Brilliant, PhD; Brian Brooks, MD, PhD; Joseph Carroll, PhD; Sasha Strul, MD; Donna Appell, RN (Facilitator)

In this session, geared to parents and families of individuals with albinism, a panel of top scientists in the field of albinism research will be available to answer your questions and satisfy your thirst for knowledge about albinism. This session is moderated by Donna Appell, RN.

**Ask the Doctors PWAs**

David Adams, MD, PhD; Murray Brilliant, PhD.; Brian Brooks, MD, PhD; Joseph Carroll, PhD; Sasha Strul, MD.; Donna Appell, RN (Facilitator)

In this session geared to adults with albinism a panel of top scientists in the field of albinism research will be available to answer your questions and satisfy your thirst for knowledge about albinism.

**Bioptic Driving Training, Testing, and Licensure: Similarities and Differences Across the United States**

Chuck Huss, COMS, Driver Rehabilitation Specialist

Between 1986 and 2020, the presenter, with members of a multi-disciplinary team of professionals from the West Virginia Division of Rehabilitation Services (WVDRS) provided eighty-four, short-term

“Understanding the Bioptic Driver” in-services to 178 professionals, representative of twenty-six states. This presentation will provide a sampling of the results of a survey questionnaire set out to determine how many states (after in-service training) went on to develop and implement their own programs of formalized bioptic driver training, testing and licensing. Color coded bar graphs will be used to emphasize the similarities and differences currently existing among certain states.

**Black PWAs Forum**

Dale Hamilton, Jr.

All too often within our communities, we are faced with the challenge of acceptance and adaptation. Together we will celebrate what it means to be who we are, dynamic individuals in the world. This panel will explore the many voices and experiences within the global albinism community.



**See YOUR name in the stars!**

Spiffy wants all of his friends to “**Be a Star for NOAH**”! Here’s how:

A generous donor has challenged Spiffy and the NOAH community to match a \$1500 gift.

For just a \$5 gift, you can add your shout-out to NOAH’s “Walk of Fame” in the Grand Ballroom Hallway.

For every \$5 donated, you earn a star and help Spiffy get closer to the goal!!

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## Jasmine is a Star Private Screening at Frida Cinema

Friday, July 12th, 5:00 PM – 9:00 PM

**This is a Ticketed event - \$25.00 per person.**  
Includes screening, small popcorn and drink,  
red carpet moments, talkback session  
with members of the cast and crew.

*Limited tickets available onsite at Registration table.*



Iyana LeShea as “Jasmine”; Jordan White as “Chris”; Jo Rochelle (Writer/Director); Anup Kulkarni (Director of Photography); Joshua Roark (Production Design / Producer); Jennifer Renée (Makeup Artist)

Join us for an exclusive, private screening of the feature film *Jasmine is a Star!*

Film synopsis: A determined sixteen-year-old with albinism makes it her mission to become a professional model

in her hometown of Minneapolis, while attempting to go unnoticed in every other aspect of her teenage life (Rated PG).

Bring your Hollywood glam, walk the red carpet and meet the director and stars of the film! Cost includes film screening, panel discussion with director and actors following the film, one small popcorn and fountain drink, and Red Carpet Photo Op.

### **Building Self-Reliance in a Supportive Environment for Parents and Caregivers**

Sheila Adamo, LCSW, CADC;  
Kathi Garza, MEd, TVI

Whether your child is beginning school for the first time or is starting their professional life, the real challenge of providing the “right” amount of support and letting natural consequences occur is difficult and can feel, at times, overwhelming and scary. In this session, we will provide tools to address your own anxiety as a parent and discuss how to best support your child with albinism with a message of confidence, encouragement and love.

### **Connecting Assessments to Services**

Anne Corn, EdD; Kayla Hamlin, TVI, COMS;  
Marjie Wood, TVI, COMS

This session will answer questions about how and when to advocate for assessments, what evaluations are appropriate, what components should be included, and who conducts each type of assessment. Presenters will explain and connect

how assessments drive an IEP or 504, how to get effective and necessary services needed to achieve desired outcomes, and what steps to take when disagreements arise between families and school teams.

### **Conquering Your Career Panel**

Nick Smith (Facilitator)

Join us for an informative panel discussion where adults with albinism will discuss their career paths and goals, how their path has changed over time, and what advice they have for others with albinism wishing to pursue a similar career path. Audience members are encouraged to engage and ask questions of the panelists as well!

### **Dealing with Comments & Questions**

(for family members)

Sheila Adamo, LCSW, CADC; Megan Pitt, LMHC

Parents will examine how to deal with comments and questions regarding albinism from others that

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Photo courtesy of Desiree Feria Smith

will include humor, sarcasm, anger and honesty. Parents will analyze their own patterns of responses to others and explore ways of responding that will both honor their own feelings and enable them to serve as a role model to their children. Looking forward to talking,

### **Drinks with Dads**

Donté Mickens, NOAH Board Chair

Join other NOAH Dads for some beverages and networking during the first night of NOAHCon in the OC Brewhouse (hotel Lobby). Start a tab and some new friendships in the community!

### **Employment Skills Should Start Young**

Cindy Camp - Described & Captioned Media Program

Employment skills are usually addressed in high school, but many important skills needed for transition are learned as children. Self-advocacy, problem solving, and flexibility are critical for job readiness. Because many children with disabilities miss out on important incidental learning opportunities, parents and teachers can help students succeed by setting realistic goals and having high expectations. This session explores the soft skills needed for successful employment and provides resources for teaching them to students of all ages who are blind and visually impaired.

### **Enhancing Learning through Accessible Media**

Cindy Camp - Described and Captioned Media Program

Research has shown that the use of multimedia is beneficial to all students. However, it is not always easy to find educational media with high quality audio description. The Described and Captioned Media Program is a federally funded program which provides accessible educational media and much more. Learn about this free resource. We'll discuss how described media can enhance learning and the classroom experience for students with visual impairments.

### **First Timers' Meet-up**

Let's meet up for some fun with other first-time NOAH Conference attendees. Find your group, have some fun, and enjoy some social time with us!

**\*\*Note\*\*** We will gather in Grand Ballroom G for about 15 minutes before moving on to another location to continue the fun.

### **First Timers' Session**

Karen Bly, NOAH Executive Director; Kathi Garza, MEd, TVI; Sheila Adamo, LCSW, CADC

Is this your FIRST NOAHCon? Join us for a quick orientation, and hear some helpful tips and tricks to make the most out of your very first NOAH Conference experience!

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## Genetics of Albinism for Beginners

Murray Brilliant, PhD

This session will delve more deeply into the genetics of albinism. Each type of albinism will be described. The differences between genotypes and phenotypes will be discussed. And the impact that the genetic changes in albinism have on how the body makes pigment will be explained.

## GRAND Ideas for Orientation & Mobility: O&M is Everything and Everything is O&M!

Marjie Wood, TVI, COMS

If you've ever wondered what O&M is and how you, as a grandparent, can play an integral part in your grandchild's growth and understanding of the world through fun activities and daily routines, then this lively interactive session is for you! Bring your questions to maximize the experience!

## Grandparent Forum

Join this session to discuss your unique role of supporting both your child in parenthood and your grandchild as they navigate life as a person with albinism. Attendees are invited to share thoughts, questions, insights, and experiences with peers.

## Group Mixedfit

Jackie Hernandez

Mixedfit is a people inspired fitness program that combines explosive dance movements and body weight toning. It's nothing fancy; just a fun time to dance. All routines can be modified up or down to match what your body feels. Come have a good time with me and your favorite NOAH people.

## Hermansky-Pudlak Syndrome Diagnosis and Management

Donna Appell, Executive Director HPS Network

This session will inform the audience of the tests available to diagnose HPS. Our discussion will include information on the different genotypes and phenotypes associated with HPS. We will also discuss the management for the care of an individual with HPS and the current research in progress for treatment.

## Canvas Paint for Adults with Albinism

Friday, July 12th  
9:45 AM – 11:30 AM  
Salon VI



It doesn't matter if you are an aspiring artist or you can't draw a straight line with a ruler...

Join your NOAH friends for a fun hands-on painting activity.

*\*Preregistration required.\**

Wristbands will be available for pickup at the NOAH Registration table for those who have paid the \$12 materials fee.

## How Do We Navigate this Thing Called Mid-Life and Beyond?

Erika Evans

As a PWA reaches the pinnacle of mid-life and beyond what should we take note of? What are other older adults with albinism facing in their day-to-day lives? What changes have you noticed in comparison to family and friends without albinism? Join us for an engaging conversation about it! Let's build a network of support for things that make me say "hmmmm" or "nobody told me it would be like this."

## How PWAs See - Investigating Facial Recognition

Elizabeth Schafer

Are you curious about how a PWA sees? Are you a PWA looking for a new tool to help describe the way you see the world? If so, this session is for you! Come experience a visual representation of what PWAs are able to see from different distances through a guided presentation. Attendees will also engage in a curated panel where PWAs will answer questions about how they see, share candid experiences, and provide tips & tricks about how they perceive and navigate the world using their vision.

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## **In Stitches (PWA Crafting)**

Joni Vella

Get your needles, thread, scrapbook paper, fabric, yarn, markers, beads, or any other project you're working on. We're turning the ballroom into a craftroom! Join avid quilter, knitter, and baker, Joni Vella for a craft-a-ganza! Bring your projects to work on or just to show off to the group. Come with your interests, your questions, and any tips and tricks you use to work through tasks. With Joni as host, you're sure to be "in stitches" as you share your experiences and common interests!



## **Huntington Beach at Sunset Off-site Trip**

**Friday, July 12th  
5:00 PM – 9:00 PM**

*\*Preregistration required.\**

Wristbands available for pickup at the NOAH Registration table for those who have paid the \$16 fee. Limited on-site sales may be available.

No vacation to Southern California is complete without a trip to the beach, and there's no better time to visit than at sunset! Huntington Beach, located about 40 minutes from the conference hotel, has fun for everyone including a boardwalk, numerous restaurants, bars, boutique shops, and plenty of outdoor activities like pickleball courts and disc golf. There are also several park areas to explore, the beautiful Secret Garden, as well as soft sand and clear Pacific waters. Grab a bite to eat and take a sunset walk on the beach.

## **Jasmine is a Star Panel Discussion**

Writer/Director - Jo Rochelle

Ilyana LeShea; Jordan White; Jennifer Renée

This "Star-studded" panel discussion will feature some of the cast and crew from the film "Jasmine is A Star." Panelists will offer their unique perspectives regarding their work in the film industry and the importance of PWA representation. People with Albinism and families will be starstruck as our panelists offer information about their individual journey and provide insight from their experiences.

## **Latest Research in Albinism**

David Adams, MD, PhD; Murray Brilliant, PhD;

Brian Brooks, MD, PhD; Joseph Carroll, PhD;

Sasha Strul, MD; Donna Appell, RN (Facilitator)

This session brings together the luminaries in the field of albinism research. The doctors will discuss recent developments in albinism research, current projects, and what is in store for the future.

## **Low Vision/Bioptic Driving Panel Discussion Session**

Chuck Huss, COMS, Driver Rehabilitation  
Specialist (Facilitator)

This panel discussion session will address questions from audience attendees using a multi-disciplinary approach consisting of professionals with backgrounds in clinical low vision, orientation and mobility, driver education training, driver licensing, current and/or former low vision/bioptic drivers.

## **My MO for O&M**

William Adams, MA, COMS

Join us for an informative panel discussion where individuals with albinism will share about how they get around. Facilitated by an Orientation & Mobility Specialist who has albinism, this panel is sure to be filled with information to help PWAs and family members understand different methods to navigating the world with low vision.

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## Teen/Tween Karaoke Party

with DJ Chris “Boston” Ranaudo

**FRIDAY, July 12th**  
**9:00 PM – 11:00 PM**  
**Pacific**

If you're a teen who loves to sing, join your pals for an awesome karaoke experience! Get up and sing solo, drag your friends onto the stage to join you in song, or hide in the audience singing your heart out! No matter how you choose to join, you'll be sure to have tunes.... I mean TONS of fun!

### **Navigating the Expanded Core Curriculum in School: Advocacy, Assessment, Services, and Opportunities**

Adrian Amandi, TVI, Director of the California Education Resource Center for the Blind and Visually Impaired - CSB  
Samantha Peterson, Low Vision Clinic and Classroom Coordinator – CSB

Delve into the pivotal role instruction in the Expanded Core Curriculum (ECC) plays in supporting children with albinism. This session explores the ECC's significance, challenges in assessments, and obtaining services. Participants will discover tools for guiding comprehensive evaluations, gain insights into pertinent laws, and learn about resources and practical ideas that can empower families to improve their children's access to school-related services and a richer, whole-child education.



Photo courtesy of Esther Rosi-Kessel

### **NOAH Town Hall – Meet the NOAH Board and Staff**

NOAH Board & Staff

This session will be your opportunity to meet the NOAH staff members and NOAH Board of Directors in person. The NOAH team will share about the organization, its finances, governance, and our many programs and services. This is your opportunity to see what NOAH has to offer and see how you can get involved. The session includes time for audience questions.

### **Office Hours with Dr. Anne Corn**

Anne Corn, EdD

Dr. Anne Corn, has graciously agreed to meet individually with parents regarding education concerns for their children. Dr. Corn has a reputation for helping parents navigate school systems and to make decisions during the school years. Please send Dr. Corn an email to sign up for a 15 minute session at: [Anne123C@gmail.com](mailto:Anne123C@gmail.com). She will also take walk-ins as time permits.

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Photo courtesy of Dennis Hurley

### **Out & About w/ O&M**

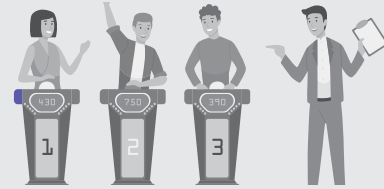
Marjie Wood, TVI, COMS

Have you ever wondered what an age-appropriate O&M lesson looks like for your child? This session provides an opportunity to observe an O&M Specialist working with your child (aged 2–21) and ask questions afterwards. Lessons will take place in and around the conference hotel, depending on weather conditions and the child’s age. Please note that children may be placed in small groups according to age depending on the number of O&M specialists available.

### **Panel Discussion for Newly Diagnosed Parents, Grandparents and Caregivers (1st Time Conference Attendees)**

Sheila Adamo, LCSW, CADC

Do you need a space to connect with others and process any emotions that joining the NOAH community can bring up? If so, this is the place to be! This session provides the time and space to meet some of NOAH’s Parent Liaisons and hear a little about their journey with NOAH. We will provide time to talk in small groups to answer questions that you may have as you enter into this new community and address any feelings you’ve experienced in the process.



## **Minute to Win-It**

**with Maria Lepore-Stevens,  
EdD, CAPE, COMS**

**SATURDAY, July 13th**

**3:15 PM – 5:00 PM**

**Grand Ballroom B–D**

End the last full day of the conference with a little friendly competition. The rules are simple – complete a task within 60 seconds, but don’t be fooled by these seemingly easy objectives. Whether you’re racing against the clock, solo, or competing head to head against friends, the thrill of victory and the agony of defeat are just seconds away!

### **Parenting Without Pigment Forum**

Jackie Hernandez

Are you a parent WITH albinism? This forum is full of fun just for you! Join the Parenting Without Pigment group, live and in person for our normal zoom meeting antics and hopefully, some new faces to share in the fun and learning. Come to talk about keeping tabs on your kids in the park, packing for a day on public transportation, and navigating all those extracurricular family activities with low vision.

### **Parents of Children with Albinism Forum**

Megan Pitt, LMHC

This peer-to-peer discussion session gives parents of kids with albinism the chance to express their concerns, ask questions and learn. Bring your burning questions, come to share your thoughts or just listen. This is a safe place for parents to be with others who have walked in your shoes.

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## **Parents of Newly Diagnosed Children and Young Children with Albinism**

Sheila Adamo, LCSW, CADC; Megan Pitt, LMHC

This session will provide an opportunity for parents whose children have been newly diagnosed, or who are still in the early years of parenting to join a community that will share and learn about adapting to the new role of a parent of a child with albinism. The workshop will provide tools and strategies that will assist parents while providing a space to discuss concerns and gain support from a community of parents that truly understand. We will discuss the common challenges and struggles parents may face and provide a guide to managing them while providing the best possible support for your child.

## **Protect. Empower. Advocate: Progress on Albinism in Africa**

Under the Same Sun (UTSS);  
African Albinism Network (AAN)

Join us for an insightful presentation as Under The Same Sun, a dedicated partner to NOAH and the global albinism community, shares highlights of our work since the last NOAH Con. Discover how our work in Tanzania has expanded across Africa through the Africa Albinism Network and how we continue to stand at the forefront of protecting and advocating for the human rights of individuals with albinism. Featuring UTSS's leadership team, hear about the impactful strides made in changing hearts and minds, addressing discrimination, stigma, and combatting attacks against people with albinism in Africa.

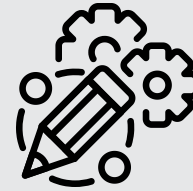
## **PWA Book Club**

Casey Greer

If you're a bookworm who loves to read, join other NOAH readers to discuss True Biz by Sara Nović - Adult Fiction (18+). The book club has been meeting on zoom for awhile, but it's time to turn those pages in person!

## **PWA Gal Pals Forum**

PWA girls, this one is for YOU! Join us for a lively chat about day-to-day living, tips and tricks for navigating your world, diving into the social scene, or share



## **Writing from Memory: A Creative Writing Workshop**

**Emily Urquhart, PhD**

**FRIDAY and SATURDAY, July 12th and 13th  
12:45 PM – 1:45 PM  
Salon VI**

This two-part writing workshop is for everyone. No experience required! Through guided prompts and questions, you will create your own piece of writing from memory using all your senses, a method based on the teachings of Linda Barry. This is a pressure-free, fun, creative experience and there is no preparation necessary. Tools: Bring a pen and paper, but don't worry, there will be supplies on hand if you don't have these.

about your career! This informal discussion group serves as place for networking and engagement with a group of adult gals with albinism.

## **Red Carpet Ready**

Cassandra Mendez; Bianca McEvoy

Join us to learn and share ideas on how to be your most dazzling self with tips on hair care, skincare, and makeup for PWAs.

## **“Star Search” NOAH Fundraising and Fellowship**

Karen Bly; Emma Brinkley; Elizabeth Drury;  
Kayla Hamlin

Are you ready to “Be A Star” for NOAH? Whether you're new to NOAH or you've been with NOAH for the past 40 years, we're always searching for star-

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Photo courtesy of Angela Adamo

power when it comes to fundraising and community engagement. Join us for a fun, interactive session featuring the many ways you can help NOAH continue to shine!

**Supporting People with Albinism in Sport & Physical Activity**

Maria Lepore-Stevens, EdD, CAPE, COMS

Individuals with albinism often experience barriers to participation in physical education and sports. This presentation will provide attendees with the skills and knowledge to advocate for accommodations for themselves or their children. Participants will explore specialized adapted equipment, discuss specific language to request on IEPs, and learn about professionals they can work with to gain access to adapted physical activity. This presentation will also discuss the additional supports that individuals with HPS may need to be safe and successful in active environments.

**The Man Cave – PWA Guys Forum**

PWA guys, this one is for YOU! Join us for a lively chat about day-to-day living, tips and tricks for navigating your world, diving into the social scene, or share about your career! This informal discussion group serves as place for networking and engagement with a group of adult guys with albinism.

**The Power of Networking: Albinism Advocacy Around the World**

Olive Namutebi, Executive Director Albinism Umbrella

Born from an idea following NOAHCon 2014, this presentation discusses the birth of Albinism Umbrella, a NGO for persons with albinism in Uganda - Eastern Africa. This presentation emphasizes the need for knowledge sharing, building trust with stakeholders and a strategic focus to unite smaller local efforts across the African region.

**Understanding and Supporting the Psychosocial well-being of Children & Adolescents with Albinism from a Developmental Perspective**

Jocelyn Leworthy, MSc, Certified Child Life Specialist, RECE, CIMI

This session discusses psychosocial development throughout childhood and adolescence and describes how aspects of living with albinism, such as appearance, visual functioning, societal perceptions etc. can influence individuals throughout various ages and stages. These considerations will be examined in relation to areas related to self-identity, peer/intimate relationships, independence, self-

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esteem, and school/career life. Additionally, we will explore protective factors and practical strategies that adults can implement to support coping throughout life stages/experience that can promote the psychosocial well-being of children and youth living with albinism. There will be opportunities to engage in discussion, share perspectives, connect with others, and engage in interactive activities.

### **Unleashing the Adventurer Within**

Jerusha Day, Adventuress Ty

Adventure can be profoundly beneficial for both children and adults with albinism by offering a range of physical, psychological, and social advantages. Despite potential challenges related to visual impairments, individuals with albinism can thrive in adventurous activities, experiencing personal growth, empowerment, and enhanced well-being. These social connections offer emotional support, encouragement, and camaraderie, enriching lives and enhancing overall well-being.

### **Yoga**

Diana McCown

Rise and shine! Join us as we start the day with a group Yoga session. All experience levels welcome.

### **Young Adult Connections**

#### **“In Real Life” Meet-up**

Change out of your pajama pants, and get ready for some REAL LIFE fun with your young adult NOAH pals. Whether you’ve been networking with us on zoom or want to join others for the first time, we can’t wait to hang out IN PERSON!

*\*\*Note\*\** We will gather in Grand Ballroom E for about 15 minutes before moving on to another location to continue the fun.

#### **Young Adults with Albinism Forum**

Young Adult PWAs, this one is for YOU! Join us for a lively chat about day-to-day living, tips and tricks for navigating your world, and how to dive into the social scene or your a new job! This informal discussion group serves as place for networking and engagement among the 18–30 year-old crowd.

#### **Young Adult Orientation**

Consider this “Freshman Orientation” for 18 to 30(ish)adults who may be looking for session suggestions to get the most from their conference experience.



Photo courtesy of Rebecca Smith

# conference maps



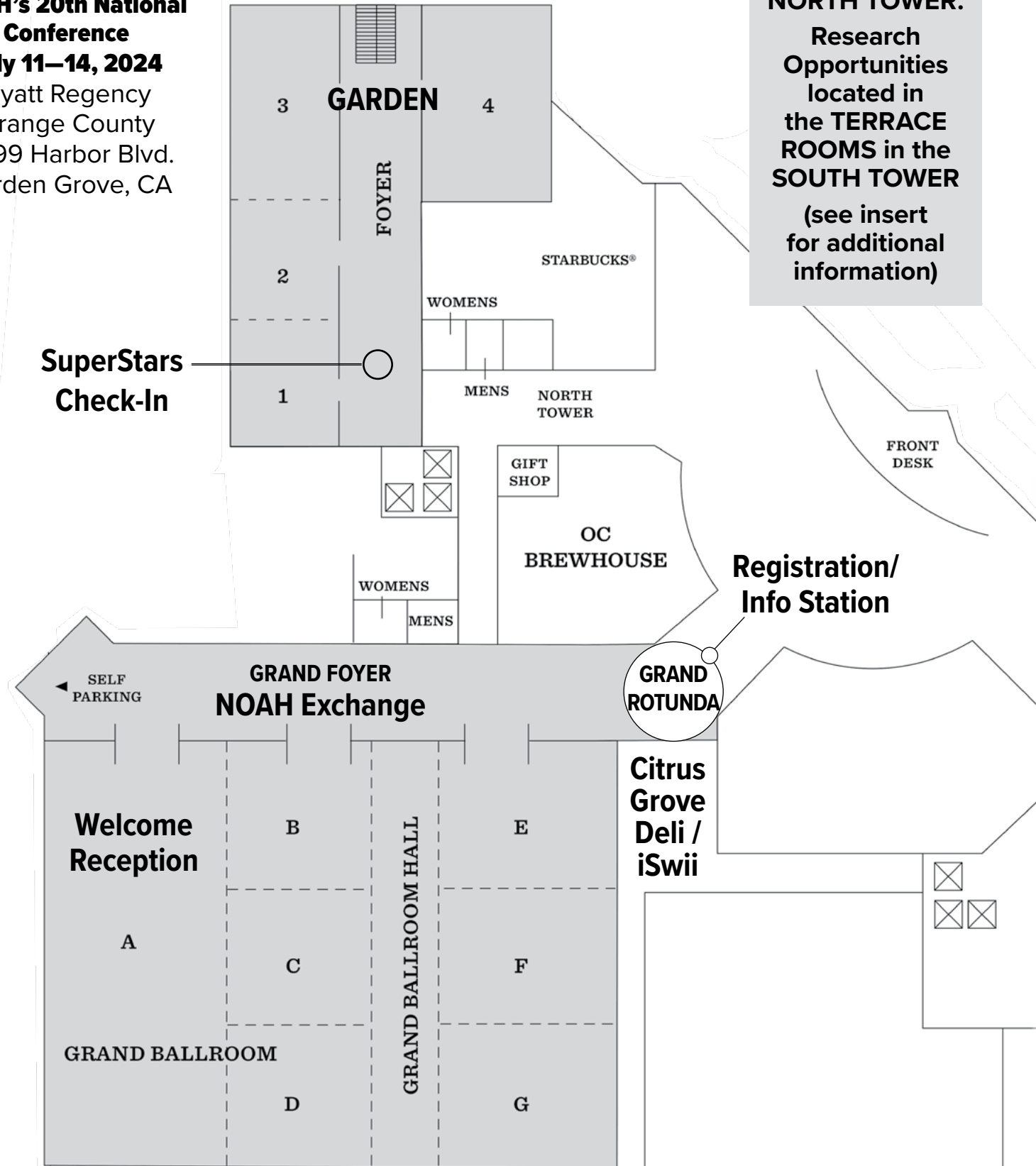
**NOAH's 20th National Conference**  
**July 11–14, 2024**  
 Hyatt Regency  
 Orange County  
 11999 Harbor Blvd.  
 Garden Grove, CA

## First Floor North Tower

NOAH Kids' Conference and NOAHCon Adult Education Programs are located in the NORTH TOWER.

Research Opportunities located in the TERRACE ROOMS in the SOUTH TOWER

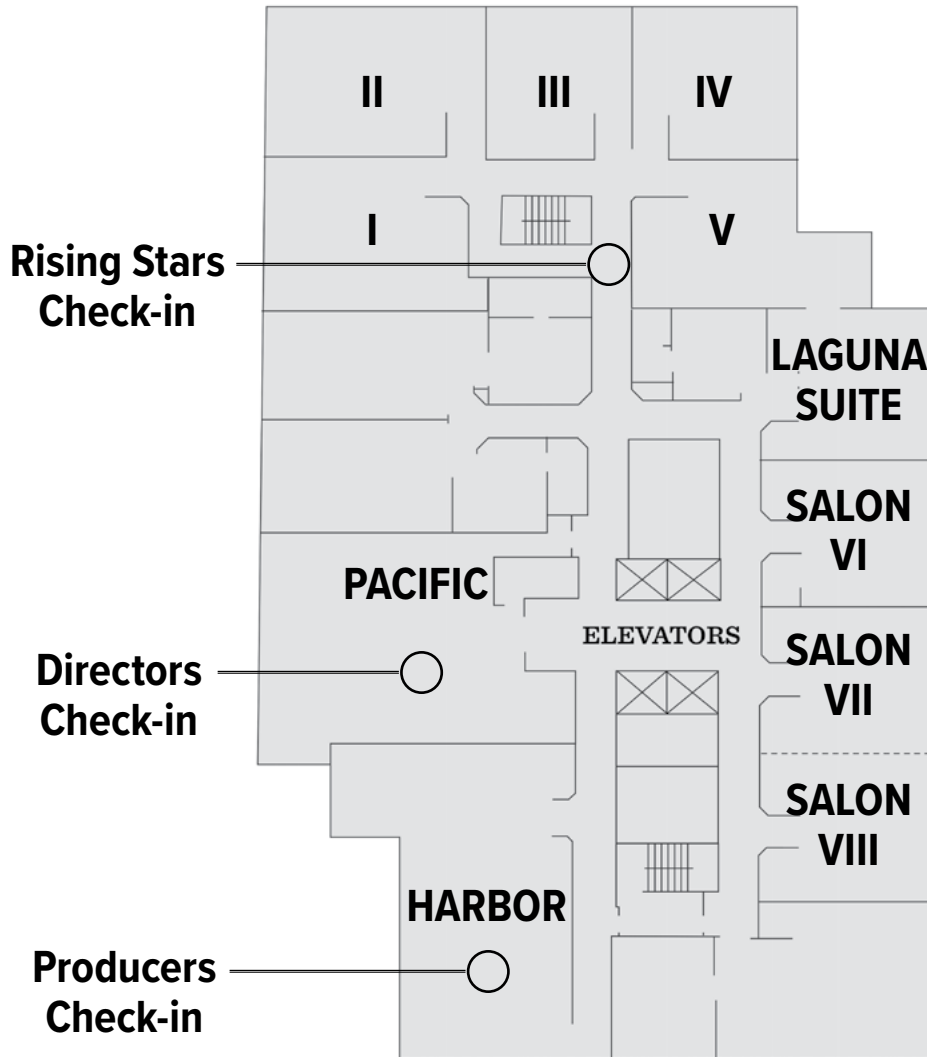
(see insert for additional information)



# conference maps

## SECOND FLOOR

North Tower



## So, How Was the Conference?

What did you think of NOAH's 2024 National Conference? Please complete your session and conference evaluations online at

[www.albinism.org/surveys](http://www.albinism.org/surveys)

NOAH greatly appreciates your response.



*There are so many ways YOU could*

*Be a* **STAR**  
*for* **NOAH**<sup>SM</sup>



**Build community and raise funds for NOAH by hosting a local in-person event!**



**Become a sponsor of Albinism InSight Magazine!**



**Support NOAH programs with an unrestricted gift!**



**Volunteer your time and talents to support NOAH!**



**Consider adding NOAH to your will.**



**Sponsor a NOAH event!! (NOAHCon, Family Camp, Adult Weekend and more!)**

**Now, more than ever, NOAH needs the support of community members like YOU to help us continue to shine. For more information, visit [albinism.org](http://albinism.org), or contact [info@albinism.org](mailto:info@albinism.org)**