

Photo courtesy of Visit KC

Kansas City **NOAH**SM 2018



NOAHSM

NOAH's 17th National Conference
July 12 - 15, 2018
The Westin Kansas City Crown Center
One East Pershing Road, Kansas City, MO 64108
albinism.org/NOAHCon2018
#NOAHCon2018

Photo courtesy of Positive Exposure, Rick Guidotti



Details, Dates and Deadlines

Conference Fees

| | |
|-------------------------------------|---------------------------------------|
| Early Deadline 4/16/18 | Regular Deadline 5/14/18 |
|-------------------------------------|---------------------------------------|

Families/Individuals

| | |
|---------------------------------|-------|
| Children 5 yrs – Adults | |
| \$185 | \$240 |
| Young Children (6 mos. – 4 yrs) | |
| \$110 | \$135 |

Professionals

| | |
|-------|-------|
| \$300 | \$375 |
|-------|-------|

Registration includes:

- Thursday night reception
- Friday & Saturday lunches
- Saturday night reception
- Sunday farewell breakfast

Registrations after 5/14/18 on space-available basis only. Programs for attendees 17 and under have limited enrollment and are not available for walk-in registration.

CANCELLATION POLICY

Written refund requests are subject to a 9% processing fee and the following receipt deadlines:

By 5/14/18 – all fees

By 5/31/18 – 50%

After 5/31/18 – no refunds

**CONFERENCE
REGISTRATION:
[albinism.org/
NOAHCon2018](http://albinism.org/NOAHCon2018)**

**or phone
1-800-473-2310**



The Westin Kansas City at Crown Center

One East Pershing Road • Kansas City, Missouri 64108

Located in the heart of downtown, The Westin Kansas City at Crown Center is encompassed by Hallmark's Crown Center. This city within a city offers guests 85 acres of shops, restaurants, and theatres – all of which can be accessed from within the hotel.

Conference Rate Details

The discounted room rate of \$134/night + tax/fees (approx \$160) single/double occupancy; \$144/night + tax/fees triple occupancy (approx \$172); and \$154/night + tax/fees quad occupancy (approx \$184), *is only available to registered conference attendees.* After registration closes, NOAH will reconcile registered attendees against the group rooming list to confirm with the hotel those eligible to receive the discounted attendee rate – others will be charged the rack rate.

Adjoining Guest Rooms

If you require additional space, consider adjoining guest rooms (\$268/night + tax/fees). Contact laubrey@albinism.org to inquire about availability. *The configuration of adjoining rooms is such that a two-double-bed room attaches to a king room.*

Reservation Deadline

The cut-off date for reserving rooms in the group block is 5 PM CT, June 27, 2018.

Early Departure Fee

The hotel charges an early departure fee of \$75 to guests who check out prior to their checkout date.

Cancellation Policy

If you cancel by 6 PM hotel time two days prior to arrival, there will be no forfeiture amount. If you cancel after 6 PM hotel time two days prior to arrival, the forfeiture amount will be a one-night stay.

**HOTEL
RESERVATIONS:
[starwoodmeeting-
com/Book/
NOAHConference
2018](http://starwoodmeeting.com/Book/NOAHConference2018)
or phone
816-474-4400**



A special magic emerges when the albinism community comes together!

Our paths may not be exactly the same, but when we share our lives, we form bonds, and we become stronger. We “get it” because we’ve “been there.”

Come to Kansas City and be together with others in the albinism community, establish friendships, and learn about the latest albinism research.

Join us, because life really is better together!

Often described as a fun, festive family reunion, the national NOAH Conference presents the most comprehensive albinism education program anywhere and affords plenty of time to socialize and enjoy fellowship. Authorities in a variety of fields

present accurate information on living with albinism, raising a child with albinism and the latest albinism research.



Photo courtesy of Positive Exposure, Rick Guidotti

Free Friday Fun

Join us for two **free performances!**



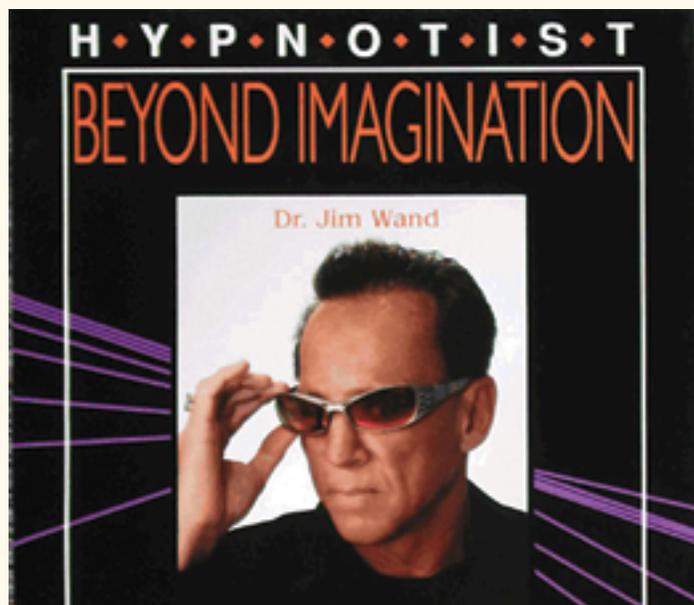
A Journey Beyond Imagination

Dr. Jim Wand

Friday, July 13, 7:30 – 9:00 PM, Free

For a unique entertainment experience come see Dr. Wand invite 20 volunteers from the audience to be hypnotized simultaneously and participate in tastefully done routines. The volunteers are never embarrassed and enjoy themselves immensely. Dr. Jim Wand is the founder and owner of Wand Enterprises. He has been involved in the field of hypnosis for over 30 years. Dr. Wand has a BS in Psychology, an MS in Counseling and a Doctorate in Philosophy. He is one of the only hypnotic entertainers in the world who has a doctorate in psychology. Dr. Wand is also considered an expert in the field of personal and group motivation.

Dr. Jim Wand's presentation is sponsored by the LaRue family.



Beautifully Broken Featuring Ashley J. Hicks

Friday, July 13, 9:00 PM, Free

Beautifully Broken explores one woman's desire to live a much bigger life than the one genetically handed to her. Ashley takes the audience along on her journey to acceptance of what makes her different. Through childhood memories, the portrayal of multiple people from her life, music, and movement, Ashley fully embraces all of the pieces that make her who she is.

Ashley J. Hicks is a Chicago based actor/writer/singer. She is an ensemble member of Eclipse Theatre Company and an ambassador for the Chicago Actor's Call to Action. She is the winner of the 2016 STL Fringe Fest Award for Beautifully Broken and has performed the show twice (so far) in Chicago. Recently, Ashley was seen in Megastasis (Eclipse Theater Co.), Shake, Teeth, Shake (20% Theatre) and Brita Water Filter's anti-bullying campaign with Steph Curry.

Conference Highlights



Photo courtesy of Positive Exposure, Rick Guidotti

Facts

Through keynote presentations and information sessions, you can increase your knowledge of albinism.

Keynote Presentation Research Updates

A panel of nationally recognized researchers share the latest scientific and medical information on identifying and understanding albinism. Learn about clinical trials and other albinism studies.

Educational Programs

Two full days are packed with a wide variety of information sessions and support forums. Here are just a few educational topics you will be able to explore:

- Genetics of Albinism
- What do People with Albinism See?
- Parenting a Child with Albinism

- Advocating for your Student
- Parenting without Pigment
- Resources for Adults with Albinism
- Workplace Topics
- Low Vision Driving Workshop and Educational Sessions
- Orientation & Mobility
- Assistive Technology
- Adaptive Recreational Opportunities
- Self Defense for Visually Impaired
- Much, much more

Fun

Exciting and enjoyable opportunities await kids of ALL ages.

Adult Pre-Conference Outings

Adults with albinism gather for pre-conference excursions. See page 11 for more about these optional activities.

Optional Activities

Choose from a number of tours to experience Kansas City. Get the scoop on page 10.

Children's Programs

From childcare for the little ones to engaging activities for older kids – caring, professional, trained staff and vetted volunteers provide a safe environment for kids to have fun!

Conference registration includes:

- Thursday evening opening reception
- Lunch Friday and Saturday
- Saturday evening dessert reception and dance party
- Sunday morning breakfast and closing session

Tentative Conference Schedule

Empowered to live life boldly:

“The infusion of self-confidence and self-acceptance and love that it gives me helps me feel empowered to go and live life boldly.”

“Leaving with the feeling of empowerment and confidence. It was a great reminder that our kids can do so much that we have to remember not to hold them back.”

1Touch

Self-defense workshop for people with low vision.

Multiple sessions on Friday and Saturday, Adults \$10, Children 10 and older \$5

1Touch Project is a not-for-profit organization that provides self-defense training specifically for people who are visually impaired. Participants in this 2-hour workshop will have the opportunity to practice hands on with their friends in non-threatening environment. A 1Touch self-defense workshop creates the environment of open discussion, question and answer time, and a chance to experience the effectiveness of the adapted techniques firsthand. Scenarios and role playing are big parts of the 1Touch training and are a lot of fun!

Thursday, July 12, 2018

Pre-conference Activities

These pre-conference activities require an additional fee and start early! If you register for these activities, be sure to make note of the start time when planning travel.

8:00 AM – 5:00 PM

Low Vision Driving Workshop

See page 8 for details

9:00 AM – 3:00 PM

Mothers' Workshop

see page 9 for details

1:00 PM – 3:00 PM

Adults with Albinism Outings

see page 11 for details

1:00 PM – 4:00 PM

Museum Outing

see page 10 for details

3:00 PM – 8:00 PM

Conference Check-in

After settling into your room, pick up your conference folder, name badge and pre-ordered merchandise.

Welcome

3:00 PM – 5:00 PM

Subgroup Meetings

Small groups with shared interests gather.

Worth the investment:

“Education... connections... family... we found it all at the NOAH conferences. Worth every penny!”

5:00 PM – 5:30 PM

First Timers' Session

Get some background information on NOAH and pick up some helpful tips to get the most from your conference experience.

6:00 PM – 7:15 PM

Kids' Conference

Orientation Session

Staff will explain procedures for drop-off, pick-up and emergency protocols, and give more information about the upcoming activities.

7:30 PM – 8:30 PM

Opening Session

The NOAH conference kicks off with an exciting program that you won't want to miss! Highlights include:

- traditional NOAH funny business
- leadership scholarship award
- and a surprise or two

8:30 PM – 9:30 PM

Reception

Light refreshments and snacks provide the perfect atmosphere to start making connections in the albinism community or to catch up with friends.

albinism.org/NOAHCon2018
#NOAHCon2018

Friday, July 13, 2018

8:00 AM – 8:45 AM

Subgroup Meetings

Small groups with shared interests gather.

9:00 AM – 3:15 PM

Preschool Program—8:00 AM check in and NOAH Kids' Programs—8:30 AM check in

Preschool Program and NOAH Kids' Programs

A preschool program and three separate programs for school-aged children give kids with albinism and their siblings the unique opportunity to interact with others like themselves in a safe environment designed to keep them engaged in fun activities while making friends. Lunch is provided for the kids separately from their parents / guardians.

9:00 AM – 3:10 PM

Educational Programs

Educational programming provides the opportunity to learn the most up to date information about living with albinism. Topics presented by experts in their fields will provide educational and community based sessions for people with albinism, family members, educators and professionals. Workshops, panel discussions and support forums will give each of us the opportunity to connect with the community and learn from one another.

3:30 PM – 4:30 PM

Extra Sessions

Special presentations address specific topics of interest to the albinism community.

3:30 PM – 4:30 PM

Out & About with Orientation & Mobility Skills

Out & About will provide family members and students the opportunity to get hands on experience with Orientation & Mobility techniques with specialist, Marjie Wood. Parents will accompany student during the workshop. Grab your hat, sunglasses, sunscreen, water and the low vision tools you use e.g. cane, monocular and join Marjie to learn safe ways for those with low vision to go out and about in KC.

3:30 PM – 4:30 PM

Subgroup Meetings –

Small groups with shared interests gather.

5:00 PM

Evening activities

See pages 10 and 12 for details.

Albinism Career Fair

Friday, 2:00 – 4:00 PM

This brand-new conference session will give attendees the chance to talk one on one with adults with albinism about their jobs. Young people with albinism can learn what it takes to work in their chosen field. Adults considering a new job can benefit too. And parents can check out the limitless employment opportunities for people with albinism.

Saturday, July 14, 2018

8:00 AM – 8:45 AM

Subgroup Meetings –

Small groups with shared interests gather.

9:00 AM – 3:15 PM

Preschool Program and NOAH Kids' Programs

Educational Program - Same as Friday, see Friday schedule.

3:30 PM – 4:30 PM

Extra Sessions – Special presentations address specific topics of interest to the community.



7:30 PM – 10:30 PM

Saturday Night Celebration

It's the albinism community's biggest party! Come relax and celebrate with friends new and old. We'll have a D.J. and sweets and treats. A cash bar will also be available. This is a wonderful way to begin to wrap up your NOAH conference experience.

Sunday, July 15, 2018

9:00 AM – 10:30 AM

Breakfast and Closing –

Sunday breakfast provides the setting for the conference wrap up. The closing session includes an awards presentation, a retrospective slideshow and announcements for the date and location of future NOAH events. There is also plenty of time to take pictures with your buddies and to say good-bye.

Pre-Conference Workshops

Two all-day pre-conference workshops are available. Plan to arrive in Kansas City by Wednesday, July 11th to participate. These activities require a separate fee.

Bioptic Driving or Not: A Multi-Disciplinary Approach

Thursday, July 12

8:00 AM – 5:00 PM

\$90 per person (includes lunch)

Register online only by June 14, 2018, at this special site: www.albinism.org/LVDriving

We are not able to accommodate on-site registrations

This workshop is intended for low vision individuals who are considering exploring the driving privilege. Obtaining a driver's license that requires the use of a bioptic lens system involves the cooperation and services of a multi-disciplinary team of professionals. Parents or spouses who might offer direct or indirect related services or emotional support are also encouraged to attend. Ample time will be allotted for addressing those questions or concerns that arise concerning low vision driving issues.



Photo courtesy of Lee Laughlin



Photo courtesy of Ali Adema

Topics & Presenters:

- The Clinical Low Vision Examination, Tom Porter, O.D.
- Bioptic Telescopes: "The Evaluation, Prescription and Fitting," Tom Porter, O.D.
- Pre-Driver Readiness, Chuck Huss, C.O.M.S., DRS
- Behind-The-Wheel Training and Testing, Mary Ellen Keith, COTA, CDRS
- How a Bioptic Bill Becomes Law: The Journey Of Consumer Advocacy in Changing Bioptic Driving Policy, Matt Bailey
- Uncovering the Hidden Population in Low Vision: A 5-Year Look at a Student-Parent Program on Driving with Low Vision and its Multiple Benefits, Cindy Bachofer, PhD, CLVT
- Reconsidering Driving as a Viable Option, Matt Bailey
- Getting in Charge of Getting Around: Accessing Transportation as a Non-Driver, Cindy Bachofer, PhD, CLVT
- Panel Discussion / Questions & Answers



Photo courtesy of Sheila Adamo

NOAH Mothers' Workshop

Thursday, 9:00 AM – 3:00 PM
\$50 per person (includes lunch and refreshments) *SPACE IS VERY LIMITED. Slots will be given to those who register first, so register early! Please note: childcare is NOT available, so please make other arrangements.*

Building Parent Connections is delighted to be partnering with NOAH to provide an opportunity for mothers of children with albinism to come together in a supportive environment to connect and empower each other as mothers and individuals. Through a combination of presentations and small group discussions, mothers will be provided the opportunity to put the outside world on hold and process the many emotions that come along with having a child with albinism. The workshop will discuss the common stages and emotions mothers experience while raising a child with albinism and provide strategies and tools for mothers and their families. Facilitated discussion

will create a fun and supportive environment where mothers with similar experiences will be able to learn and laugh with one another. Join us for an engaging day to start the conference off with new friends and an open heart and mind.

Sheila Adamo, LCSW, CADC is a Licensed Clinical Social Worker with an additional certification in Alcohol and Drug Abuse Counseling. She is the co-owner of Building Parent Connections which provides education, guidance and support to parents of children with special needs. She specializes in creating workshops, discussion groups, teleconferences and conference presentations that address the unique needs of parents of special needs children. Sheila and her husband are raising four children, one of which has albinism. Sheila has worked with many different populations in the mental health field. Her passion is working with parents of children with special needs to help them find the tools they need to be successful.



Photo courtesy of Positive Exposure, Rick Guiffanti

Dreams are possible:

"I had never in my life met someone with albinism. I had no idea what to expect for [my daughter]. I was told she would be legally blind but I had no idea what that meant. I met other moms who assured me that [she] really was going to be okay. I saw toddlers and kids with albinism playing in the lobby, and I realized she would be able to keep up with her brother and her friends. I saw teenagers with albinism, hanging out, joking, dating, and I realized she was going to find her own social circle. I met adults with albinism and I realized that all the things I dreamed for my child were still very much possible."

Kansas City Outings

NOAH conferences are packed with informational session and social opportunities. Here are some optional activities to see different parts of Kansas City while continuing your connection with the albinism community. *All optional outings require a separate fee.*

Museum Outing: Negro Leagues Baseball Museum / American Jazz Museum

Thursday, July 12,
1:00 – 4:00 PM
Kids (5 – 12) \$8,
Adults (13+) \$15

Busses will take you to the historic 18th and Vine District from the hotel. The price includes admission to both museums.

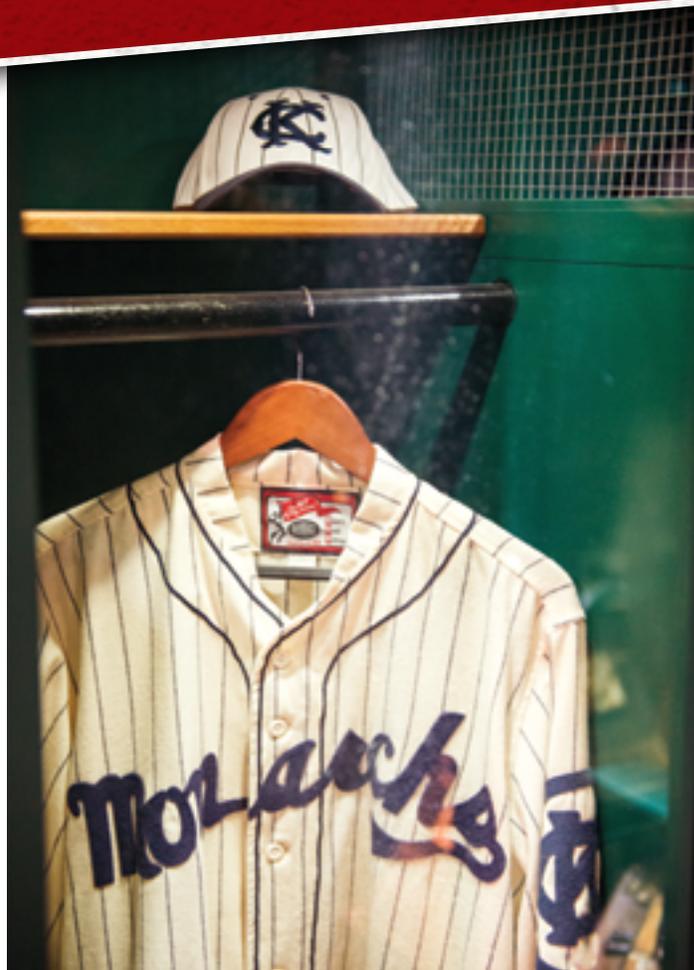


The Negro Leagues Baseball Museum was conceived as a museum to tell the complete story of Negro Leagues Baseball, from the average players to the superstars.

The American Jazz Museum showcases the sights and sounds of jazz through interactive exhibits and films, the Changing Gallery exhibit space, Horace M. Peterson III Visitors Center, Blue Room jazz club and Gem Theater.

You're not the only one:

“Living with albinism, you can feel like you're alone 99% of the time. At the NOAH conference people totally get you, understand what you're going through, and you discover you are not alone/strange/different.”



Shop and Dine on Your Own

Plaza Bus \$5 per person shuttle service
Friday, July 13, 5:00 – 10:00 PM

The Country Club Plaza is a district in Kansas City comprised of more than 150 shops and dozens of restaurants. Buses will run from the Westin Crown Center to a central location at the Plaza where you can spend an evening enjoying the company of new friends. A select number of reservations will be available for people to claim beginning at registration. Buses will board at the drop off location for the trip back to the hotel. This is a transportation-only event and does not include food or drink.

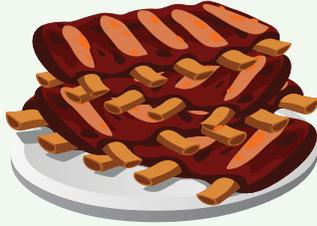
“You just can't miss the NOAH conference. You make a lot of new friends and get to see your old friends. You learn how to live with albinism.”

ADULTS NEED PLAY DATES TOO!

These two optional activities are meant for adults with albinism to enjoy fellowship. *If you opt for Thursday fun, please plan to arrive in Kansas City and be ready to rock and roll by midday on Thursday, July 12th.*

BBQ Tour

Thursday, July 12
1:00 – 3:00 PM
\$45 per person



Kansas City is known for BBQ and on this two-hour tour you will sample deliciously prepared meats and sides from two local favorites. Adults with albinism and their significant others will sample the flavor of KC BBQ. Join old friends or make new ones on this tasty tour. Buses board at our hotel for this tour punctuated with a one of a kind gastronomical experience.



Top Golf

Thursday, July 12,
12:30 – 3:30 PM, \$30 per person

No experience required for this one of a kind golfing experience. Participants will board buses at our hotel which will take them to Top Golf in Kansas City, Kansas. Once there, they will have two hours of time to play games centered around driving a golf ball. The driving bays are very well shaded and there is no need to see where your ball goes as the computers display where your ball landed on screens located in each bay. Food and drink are not included but are available for purchase. Teams of six can compete in a variety of games. If you don't have six people, this is a great opportunity to meet some new friends as we will pair you up.



Photos courtesy of Positive Exposure, Rick Guidotti

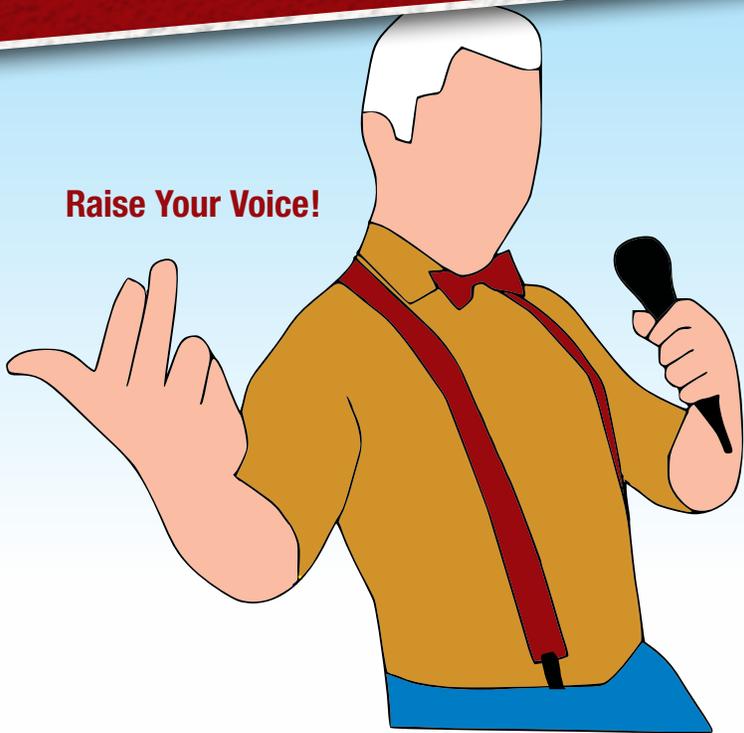
Brilliant and beautiful:

“Seeing so many adults with albinism – who were brilliant, beautiful, strong, capable, and confident living their dreams despite having low vision.”

Coming Together Through Song

ENCORE PERFORMANCE

Raise Your Voice!



Are you an adult with albinism who loves to sing? Do you sing in a choir or a band? Maybe you like to rock out in the shower? Or, maybe you just love music and would enjoy raising your voice with other PWA's in song? If the answer to any of these questions is "yes," we're looking for you! We are putting together an all adult PWA choir to perform the hit song "This Is Me" from the blockbuster movie, "The Greatest Showman." Led by vocalist and music director Marleena Barber, the PWA choir will come together in a series of sessions over the course of the conference to prepare for a performance at the closing session. Practice tracks and music will be available for download in early March. All levels of experiences welcome and all voice parts needed! Don't miss out on this unique opportunity!

Contact Marleena at marleenabarber@gmail.com for more information

Like coming home:

"It feels like coming home. You don't need to explain yourself. You're accepted and embraced by strangers who feel like family."



Photo courtesy of Nuvea Santos Cobb

"Thank You for the Music"

One-Woman (With Albinism) Cabaret Show
Featuring Marleena Barber

This performance is geared towards teens but all are welcome. Friday, July 13, 3:15 – 4:15 PM, Free

Marleena Barber is a performer, educator and disability advocate. She has performed in various musical theater productions and as a solo artist at festivals and concert venues throughout California. Her one-woman cabaret show, Thank You for the Music, tells the story about her life growing up with albinism and how music played a vital role in the journey to believing in herself. The show is an inspiring piece that reaches out to all ages, and encourages audiences, through a variety of different musical styles, to live their dreams despite any challenges they may face. The show was featured at the 2010 International VSA festival on arts and disability – produced by the Kennedy Center in Washington D.C. She has served as a keynote and motivational ambassador at various conferences across the country, including a performance on Capitol Hill for Congress as part of National Arts Advocacy Day. A former music teacher and choir director for the blind and visually impaired, Marleena strives to be a role model of independence and determination, demonstrating to her students, and her audiences, that with hard work dreams can come true. For more information about Marleena please visit: www.marleenabarber.com.

Kids' Conference

Conference Program for Your Kids

The Kids' Conference is a one-of-a-kind experience for school-aged children with albinism and their siblings. While the adults are engaged in the educational program, NOAH's kids enjoy the unique experience of being with others who share their condition. NOAH hopes that the children with albinism and their siblings will begin to feel the fellowship of the albinism community by creating an environment that allows kids to play and make lasting friendships while learning about albinism.

Children will be placed in one of four separate programs based on the grade they will be entering in the fall (see pages 15-17). Each program is designed to meet the interests and needs of that age group.

Photo courtesy of Positive Exposure, Rick Guidotti



IMPORTANT

NOAH will try to accommodate every child that registers for the conference in this program. However, due to constraints such as securing meeting space, reserving transportation, and other logistical considerations, NOAH may need to cap the number of children in the program to ensure proper staffing. It takes several weeks to plan activities, so last minute registrations pose significant problems. To ensure your child's spot in a program, please register early. Admission will be based on the date the registration and payment is received.



NOAH Apparel

We are pleased to offer several great merchandise options this year at

albinism.org/NOAH-Con2018

The **Bebops** Group

From six months to those entering kindergarten

The Bebops Group is childcare for children 6 months to 5 years of age. You will have peace of mind knowing your young ones are safe and having fun under the guidance of qualified, caring nannies. The program will provide a balance of quiet and active activities in a nurturing atmosphere.

The following is a list of planned activities:

- Free play
- Gross motor area
- Arts and crafts
- Quiet/rest time
- Story Time
- Music and Dance with Johnny and Adam
- Art with the Got Art Program
- Puppet show
- Under the Big Top
- Music with Robyn

Comfort and community:

“Parents will leave with comfortable feelings like ‘we can handle this.’ Children learn that ‘I’m not alone.’”

Photos courtesy of Positive Exposure, Rick Guidotti



Parents can relax and focus on the educational sessions and networking opportunities assured that their young children are in good hands.

NOAH is concerned about the safety and security of your child. Therefore the Bebops Group includes the following procedures:

- Matching security bracelets for parent and child
- CPR and First Aid certified team managers
- Licensed nurse on premise
- Vetting of all volunteers and staff

The power of observation:
“Parents can observe other children with albinism of all ages.”

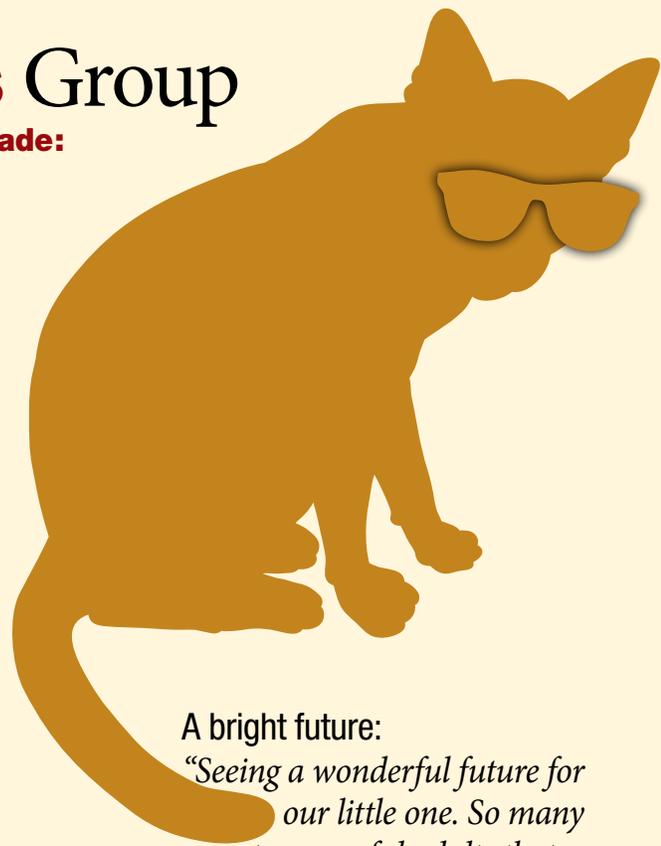
The **Kool Kats** Group

Entering 1st – 6th Grade:

The Kool Kats are made up of three tracks consisting of two grades each. Groups will be guided through a series of age-appropriate, fun and educational activities including art, science, physical activities, play time and albinism education.

The schedule includes:

- Kids Art Party from Got Arts Gallery
- Story Tellers from Kansas City Public Library
- Make NOAH stuffed Bears (younger grades)
- Mr. Stinky Feet Concert
- Drama program with Dennis Hurley
- Rhythm Band with Johnny & Adam
- Rockin' Reptiles
- Sun protection and skin care
- Drumming Safari
- Game Show
- Crafts & board games
- Puppet Show with Stone Lion Puppet Theatre
- Animal Wonders
- Street car ride & lunch out at Cosentino's Market (5th and 6th grade)

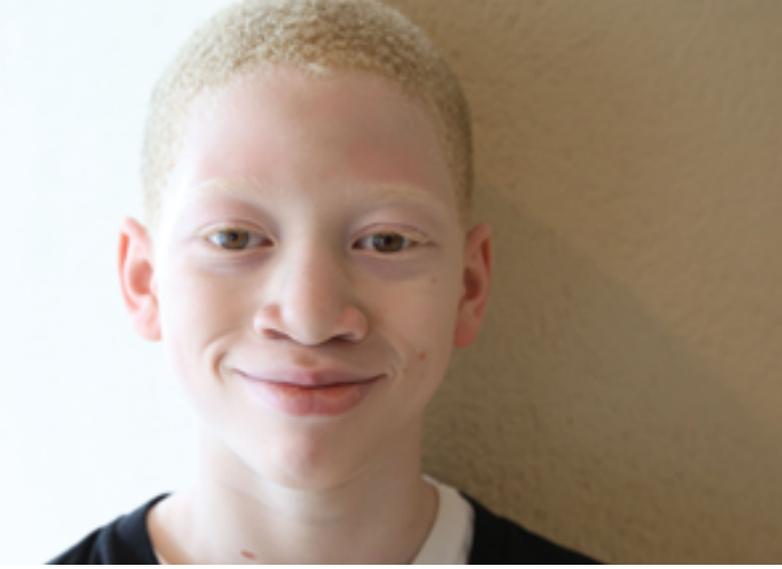


A bright future:

“Seeing a wonderful future for our little one. So many smart, successful adults that had very few aids or assistance. Knowing what our little one can accomplish with all the resources we can find for her.”

Photos courtesy of Positive Exposure, Rick Guidotti





The Jitterbugs

Entering Grades 7 - 9



The Jitterbugs and Big Band groups will have many opportunities for bonding with their peers in Kansas City. They will also have plenty of time to share the experiences they've had living with albinism during get to know you games and lunches off site. Here is what we have cooked up for NOAH tweens and teens.



Both the Jitterbugs and Big Band groups will have a blast at these two attractions:

Escape Room

Teams of teens will have one hour to work together to escape from a locked room by solving puzzles and finding codes.

The College Basketball Experience

There is no other place like this in America. It is definitely not a museum. It is a high-energy, highly-interactive place where casual and hard-core fans of any age can totally immerse themselves in the game of college basketball. Virtually every skill of the game has an activity station – rebounding, passing, three-point shooting, free throw shooting and more. For a change of pace, visitors can sit

Teen Room

Available each night of the conference, this safe and supervised space is designed to provide room for adolescents to play games, chat or just hang out.



Photos courtesy of Positive Exposure, Rick Guidotti



The Big Band

Entering Grades 10 - 12

down at the ESPN desk and call the highlights of actual NCAA basketball action.

The Jitterbug Group will also head to The Main Event.

The Main Event is an entertainment complex where kids will be able to play in the arcade, do a high ropes course, play shuffle board, play on simulators and have limitless access to laser tag.

The Big Band will visit Rockhurst University!

High school students will have an opportunity to talk with professionals at Rockhurst about support services that are available to them once they begin their collegiate career. The goal of the trip is to make sure that students with albinism have the confidence and knowledge to ask the right questions as they begin to think about where they want to go to college. The transition from high school to college can be very daunting, and we hope to provide our students with the tools that they need to make the best decision for their future. Even if the student is not interested in going to college at this point, they will still gain valuable insight about the process and will be ready for the challenge if they decide to pursue a degree in higher education.

NOAH's Teen Room is a rare opportunity for teens with albinism to socialize with others like them, those who get it. The fellowship and fun that fills the special space can lead to lifelong friendships.



Volunteer Opportunities



Photos courtesy of Positive Exposure, Rick Guidotti

It takes dozens of people with many different talents and countless hours of work to hold a national conference for over 1000 people. NOAH relies on volunteers to make it all happen. Please take a look at these volunteer opportunities and consider helping to create NOAH Magic!

If you have a little time to give, here are some great options.

- Session moderator
- Registration preparation
- Registration check in
- Silent auction and raffle

Here is what you can do if you have more time to give. Are you:

- A committed extended family member, doting aunt, cool cousin, proud grandma?
- An experienced daycare professional?
- An experienced teacher?
- An experienced early intervention specialist?
- An adult with albinism who loves to work with kids or teens?
- A parent who always volunteers to go on field trips?
- A college student studying education?

If so, please consider volunteering for one of the kids' programs. All volunteers working with children will be vetted and required to attend an orientation session on Thursday around 5 PM.

Crew Leaders

Kool Kats Group: Grades 1st – 6th
8:30 AM – 3:30 PM Friday and Saturday

Crew leaders chaperone groups of kids through a series of activities. An assistant will be assigned to crews made up of younger children. Using materials provided, leaders will facilitate short activities with their crews at the beginning and end of the each day.

Assistant Crew Leaders

Responsible teens and college students help manage groups of younger children through engaging activities. Assistant crew leaders will be paired with seasoned volunteer crew leaders.

Chaperones

Jitterbugs and Big Band Groups: Grades 7 – 12

A program of adventure and exploration of Kansas City, providing entertaining, engaging activities for teens and pre-teens, complete with a teen “hang out.” Volunteers are needed to chaperone field trips and to monitor the teen room. Planned activities will take place during the day Friday and Saturday. Teen room supervision is needed in the evening.

Tour Group Leaders

On Thursday afternoon and Friday evening, volunteers will direct those on optional trips and tours to transportation and make sure everyone gets where they need to be.

Contact NOAH at 1-800-473-2310. Go to albinism.org/conf-volunteer to sign up today.



NOAH 2018 Conference Personal Grant Program

NOAH has a limited budget for conference personal grants. The Personal Grant Program helps those who, without assistance, would not be able to afford to attend the conference. Applicants must contribute to the cost of attendance. The Personal Grant Program will not fund the full cost of attendance. Applicants are strongly encouraged to seek additional support as described in the Funding Sources Information Packet. Learn more at www.albinism.org/NOAHCon2018.

There are many ways to support the 2018 Conference!

Give to support your favorite part of the conference

**Honor a member of the NOAH
community with a tribute gift**

Make a gift toward a personal grant.

**Share NOAH's sponsorship package with someone who
would like to sponsor the conference**

**For more information, contact NOAH
at 1-800-473-2310 or conference@albinism.org.**

Help the albinism community be Better Together!

Registration fees **do not** cover the cost of the NOAH Conference. NOAH depends on support from generous donors to create an environment that transforms lives each time we bring the albinism community together. We need your support to make the NOAH Magic happen in Kansas City!

Your financial gifts support programs for infants, toddlers, school-aged children, tweens, teens and adults with albinism as well as programming for parents dealing with a new diagnosis, the challenges encountered during the educational process, and for all aspects of living with albinism.

NOAH also needs funding for personal grants. Personal grants are available to families and individuals who need a little extra support to be able to attend the conference and experience the NOAH Magic.



Photo courtesy of Positive Exposure, Rick Guidotti

Donate to the Conference

Easy as 1•2•3

**Make your tax
deductible
contribution today!**

1 Online at
albinism.org/donate

2 By Amex, Disc, MC, Visa
at 1-800-473-2310

3 By checks made payable to
NOAH and mailed to:

NOAH Conference Fund
P.O. Box 959
E. Hampstead, NH
03826-0959

NOAHSM National Organization for
Albinism and Hypopigmentation
PO Box 959, East Hampstead, NH 03826-0959 USA

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Kansas City NOAH 2018

Kansas City: Here We Come!

NOAHSM

NOAH's 17th National Conference
July 12 - 15, 2018
The Westin Kansas City Crown Center
albinism.org/NOAHCon2018
#NOAHCon2018



Photo courtesy of Visit KC