

NOAH Now!

Welcome to **NOAH Now!**, a new electronic newsletter to help NOAH stay in touch with the albinism community between issues of our quarterly member magazine, *Albinism InSight*. To join NOAH or renew your dues to ensure that you receive *Albinism InSight*, visit: <http://store.albinism.org>.

NOAH Activities Abound!



- Los Angeles Mini Conference
- **Go Cruisin' with NOAH!**
- **What's Happening in Your Area?**
- Scranton Mini Conference
- South Texas NOAH Day at the Zoo
- **North Texas Halloween Party**
- Cleveland Get Together
- **CRISIS: Tanzania and East Africa!**
- Albinism on National TV
- **2010 Bowl-a-thon**
- **NOAH's National Conference in D.C.**
- NOAH's CARE Project

Los Angeles Mini Conference

Deadline Extended, Register by Monday, 10/12

Join us Saturday, October 17th, at Childrens Hospital Los Angeles. This all-day event (8:30am to 4:00pm) provides valuable educational sessions for adults, and safe, age-appropriate activities for children.

Childrens Hospital Los Angeles
4661 Sunset Blvd.
Los Angeles, CA 9027

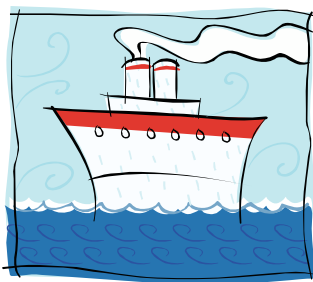
[http://www.albinism.org/
noahevents09.html](http://www.albinism.org/noahevents09.html)

Topics on the agenda include:

- Genetics of Albinism
- National Institutes of Health Protocol on Albinism
- Hermansky-Pudlak Syndrome
- Impact of Pigment on the Developing Visual System
- Latest Advances in Optical and Electronic Low-Vision Aids
- Albinism in the Movies & News
- Social Issues for Families and Children with Albinism
- IEPs and School Issues

Go Cruisin' with NOAH March 13-20, 2010!

Join your NOAH friends aboard the MSC Poesia March 13-20, 2010. Cruises International is offering a fun, 7-night island treasures & ancient temples cruise out of Fort Lauderdale, FL. Enjoy great savings with kids 17 and under cruising for FREE - only \$66.48 in taxes per child. This vacation doubles as a fundraising opportunity for NOAH - a potential to earn a cool



\$2,000 if friends of NOAH book just 10 cabins for this cruise. Cabins begin at a low \$419 per person double occupancy (plus port and tax charges), with third and fourth cabin occupants sailing for just \$149 per person (plus port and tax charges). Check out the cruise flyer http://www.albinism.org/publications/2009/pdf/cruise_info.pdf.

HURRY! Cabins must be booked by December 18th!

What's Happening in Your Area?

The enormous growth in local and regional NOAH activities recently is a tribute to the wonderful NOAH members who chose to step up and take the lead. With their initiative, NOAH helps spread the word and encourage people to get together and enjoy the fellowship of the albinism community. For more information about getting local activities organized in your area, [contact NOAH at info@albinism.org](mailto:info@albinism.org) or call 800.473.2310.



Scranton Mini Conference November 6th & 7th

The final stop on the 2009 NOAH mini conference whistle stop tour is in Scranton, Pennsylvania!

Comfort Suites & Marvelous Mugs
44 Montage Mountain Rd.
Scranton, PA 18507
Phone: 570.347.1551
www.comfortsuites.com/hotel/pa031
NOAH Lodging Rate of \$90/night plus tax
(includes breakfast)

Register Today!

The Scranton Mini Conference is the seventh in a series of regional events across North

Snow White's Ball!

We're kicking off the mini conference with a fun social event for all. Your registration includes attendance at Snow White's Ball. Come dressed as your favorite storybook character, and enjoy light refreshments, music, and conversation with friends old and new from 7:30-10:00pm.



Fun for Kids!

Children ages four and younger will enjoy age-appropriate, safe activities on site. School-aged children and teens will spend the morning at the nearby Everhart Museum at Nay Aug Park for a scavenger hunt! After lunchtime with parents, children will enjoy an afternoon swim under the supervision of a lifeguard in the hotel pool. What could be more fun than playing and having fun with friends old and new from the albinism community?

America in 2009. NOAH is committed to bringing the magical experience of an albinism community gathering to more locations this year; reaching out to those who might not be able to attend a NOAH conference. It's a jam-packed day featuring top experts in the field, meaningful panels and discussion groups, and the opportunity for kids to be kids amongst the albinism community. Be a part of the NOAH magic! Adult & teen member registration begins at just \$25.00, with children 12 & younger at just \$10.00. Conference registration includes educational presentations, discussion groups, children's activities, Friday night celebration, breakfast, lunch, and refreshments.



Registration materials are available at www.albinism.org/noahevents.html.

Register by Monday, October 19th.

South Texas NOAH Day at the Zoo



Saturday, October 17th
The Houston Zoo
1513 N Macgregor Dr.
Houston, TX 77030-1603
(713) 533-6500
www.houstonzoo.org

Lions, Tigers, and Bears....OH MY!



NOAH's South Texas Group invites you to spend the day with us at the Houston Zoo. There are many beautiful animals to see and learn about, and a wonderful children's area with a petting zoo and a splash park. There is a concession stand but feel free to pack a picnic dinner if you prefer. We hope to see you there!

Contact Monica at stxnoahmom@yahoo.com or call 800-473-2310.

North Texas Halloween Party Sunday, October 25th

October is here and Halloween is near! Let's get together for a party! Dress up, bring a favorite Halloween treat to share, and join in for some games and socializing. **Door prizes for best costumes!**



October 25th from 3-5pm
Lion's Club
Handley Meadowbrook Location
6013 Craig Street
Fort Worth, TX 76112
Please RSVP with Cyd at
NOAH.NTX@albinism.org

Cleveland Area Get Together Friday, October 30th

Join us Friday, October 30th from 6:00-8:30pm for our monthly Cleveland area get together. This month, we have a presentation on genetics scheduled with Carol Prowe. Come meet others from the albinism community and enjoy refreshment and fellowship! **Please RSVP with Venetta at 216.375.9351.**

Cleveland Sight Center
www.clevelandsightcenter.org
1909 E 101st St
Cleveland, OH 44106
(216) 791-8118
Accessible via the RTA

Meeting space provided by the Cleveland Sight Center

CRISIS: Tanzania and East Africa

People with albinism in East Africa are being mutilated and murdered for body parts. Although each week brings news of more bloodshed, courts in Tanzania have been very slow to prosecute these heinous crimes, citing a lack of funds. Since 2007, 53 children and adults with albinism have been slaughtered by people who believe that potions and charms made from the body parts of people with albinism can be used to ensure wealth and good fortune. Many others have been left to die, with arms and legs cut off.



TAKE ACTION!

While the attacks are occurring far away, we can use our power as citizens to ask Congress to sponsor a Joint Resolution condemning the slaughter of people with albinism and for the swift prosecution of their killers.

NOAH has prepared template letters to assist folks in this effort.

Visit <http://www.sas.albinism.org/take-action> to learn how you can make a difference!

Reaching out to the Children of Tanzania

NOAH and our partners have received a tremendous number of offers to help the children of Tanzania with essential sun-protective supplies such as hats, sunscreen, lip balm, and sun protective clothing. Together we are working to devise a strategy to allow the safe, cost-effective delivery of these life-saving items to Tanzania. We will report back to our members just as soon as we have a plan in place.

Albinism on National TV

October is shaping up to be a very busy month for albinism and TV! Following closely on the heels of the October 2nd [ABC News 20/20](#) Broadcast, Albinism will again be in the spotlight, this time on cable TV's [The Learning Channel \(TLC\)](#) on October 18th and 19th. While the atrocities in Tanzania have brought albinism into the spotlight, these programs provide an excellent opportunity to raise awareness about albinism at home and abroad.

TLC: My Shocking Story

NOAH has learned that a one-hour albinism documentary, "Albino Crisis", will air on The Learning Channel (TLC) program, My Shocking Story on Sunday, October 18th at 10:00pm ET and Monday, October 19th at 1:00am ET (**Please check local listings to confirm broadcast schedules in your area**).

NOAH Scientific Advisor and frequent conference presenter, Dr. Murray Brilliant, will be featured on this program. NOAH also expects footage to include interviews and conversation with NOAH members, both at home and at the awesome NOAH Family Summer Camp held last July in Mount Union, Pennsylvania! **Tune in!**

Albinism: Caught Between Dark and Light ABC News 20/20 Special

NOAH has received many phone calls and email messages about the recent ABC News 20/20 program on albinism. We thank everyone for the opinions, passion, and commitment to the albinism community. NOAH will continue to work to promote awareness and understanding of albinism, and the uniqueness of every member of our community.

The full episode is currently available for online viewing on the ABC News 20/20 website.

ABC News online store is also selling copies of the albinism program on DVD/VHS for \$29.95.

NOAH's 2010 Bowl-a-thon February 19th - 21st

Save the Date & Get Involved!

- Host an event
- Attend an event
- Help support NOAH programs and initiatives including
 - Conferences
 - Family camp
 - Outreach

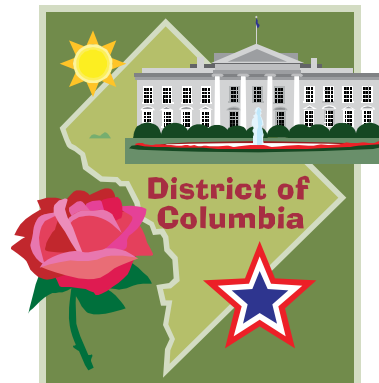
Visit www.albinism.org for updates and information as they become available.



National Conference in Washington, D.C.

July 15-18, 2010
Crystal Gateway Marriott
1700 Jefferson Davis Highway
Arlington, VA 22202
Ph. 1-703-920-3230
Lodging Rate: \$149/night

Save the date for NOAH's 13th National Conference in our nation's Capital, at the beautiful Crystal Gateway Marriott in the Crystal City section of Arlington, VA, just across the river from Washington, D.C., and located on a Metro stop accessible from the hotel lobby.



NOAH CARE PROJECT

CREATE ALBINISM RESOURCE FOR EDUCATION

NOAH has undertaken a new project entitled **CARE** (Create Albinism Resource for Education). The main objective of this project is to provide our parents of school aged children with resource information that will aid them in formulating their child's IEP.

Parents will be able to read through information gained from IEPs (grade level goals, assistive technology recommendations, Orientation & Mobility age objectives, and any social development objectives).

NOAH NEEDS YOUR HELP!!!!!!

NOAH is requesting that parents who wish to participate in the project submit copies of recent IEPs (**email to iep@albinism.org or mail to IEP, PO Box 959, E. Hampstead, NH 03826-0959**).

Please remove all personal information except for state and date of birth (names of parents, children, school's and school districts, addresses and telephone numbers).



Additional details will be released in *Albinism InSight*, and on our website at www.albinism.org as they become available. If you have questions about this project or would like additional information, please contact iep@albinism.org.

A WORD ABOUT THIS RESOURCE

NOAH wants to EMPHASIZE that all children with albinism have different visual acuities, different functional vision levels, and personal developmental needs. The purpose of CARE information is to inform parents of the "spectrum" of goals, technology, and educational methodologies implemented in our schools to aid children with albinism. After viewing the material provided by CARE, parents will have a broader knowledge background that will better assist them in establishing their child's individual and unique IEP.