

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>.



The Bowl-a-thon is COMING!

- Find the Bowl-a-thon Near You
- Uniting the Albinism Community
- Eyes on Tanzania
- Albinism on a World Stage
- 2010 McGowan Scholarship
- CCLVI Scholarship Opportunity
- Adventures in Darkness
- Rare Disease Day
- NOAH CARE Project

Bowl-a-thons are Popping Up All Over! Find an Event Near You or Plan Your Own!

ARIZONA

Monday, February 15, 2010

6:30 - 8:30 PM

TUCSON BOWLS

7020 E. 21st Street

Tucson, AZ

RSVP: Andrea at aarena02@yahoo.com!

ILLINOIS

TEAM ADAMO

Tivoli Lanes

938 Warren Ave

Downers Grove, IL

Saturday, February 20, 2010

1:00 - 3:30 pm

RSVP: Sheila at 630.420.6909 or sadamo@albinism.org

Get the latest team listings/information at <http://www.events.org/noah>

ILLINOIS (cont)

TEAM MCGOWAN

IC Bowling Alley
Immaculate Conception School
7263 W. Talcott Ave
Chicago, IL 60656

Saturday, March 6, 2010

7:00 - 11:00 pm

RSVP: Mike at 773.763.5571 or
president@albinism.org

PUB TRIVIA NIGHT

The Celtic Knot

Saturday February 20, 2010

7:00 pm

626 Church St,
Evanston, IL; CTA Purple
Line (Davis St.)

RSVP: Kelsey at
kthompson@albinism.org

KANSAS

KANSAS CITY BOWLS

Saturday, February 20, 2010

1:00 - 3:00 pm

College Lanes
10201 College Blvd
(69 & College)
Overland Park, KS
913-451-4799

RSVP: kc@albinism.org

LOUISIANA

OWEN'S BOWLING BUDDIES

Sunday, Feb 21, 2010

2:00 PM

Thunder Bowling Alley
Thibodaux, LA

RSVP: christinemb689@msn.com

MASSACHUSETTS

BOSTON AREA

Join Team Kelly

Saturday, February 20, 2010

1:00 - 4:00 pm

Lucky Strikes (Jillian's)

Ipswich St

Boston, MA

Please RSVP if you can join us, jodi.
kelly@verizon.net!

NORWOOD BOWL-A-THON

Join Team Bunker!

Saturday, February 20, 2010

1:00 pm

Norwood Sport Center
65 Cottage St East
Norwood, MA 02062
Pizza to follow at Papa
Ginos!

Please RSVP if you
can join us, [susan.
bunker@yahoo.com](mailto:susan.bunker@yahoo.com)!

MICHIGAN

THUNDERBIRD LANES

400 W Maple Road
Troy, MI 48084

<http://>

bowlthunderbird.com/

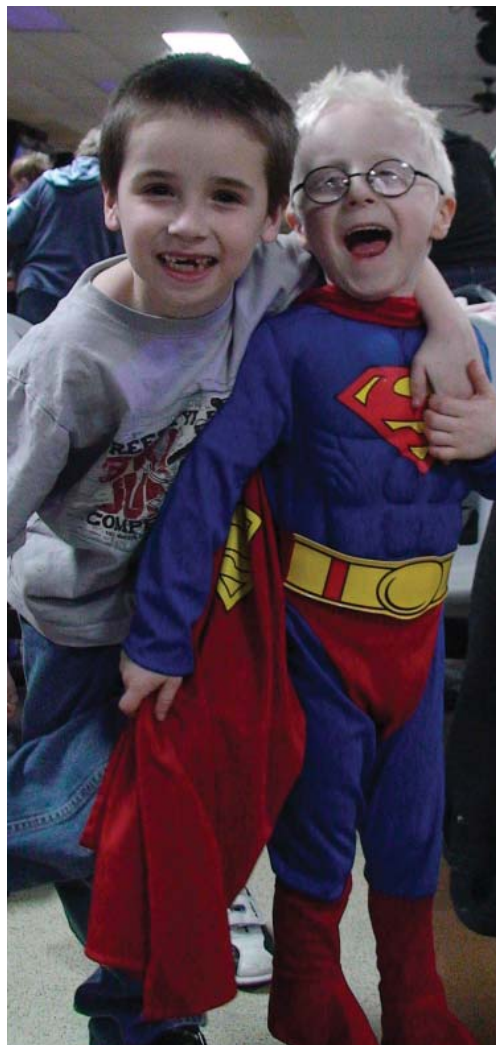
Saturday, February 20, 2010

1:30 - 3:30 pm

Cost \$10 per person
for 2 games, shoes,

pizza, pop. Additional donation to
NOAH requested but not necessary.

RSVP: kp15@chrysler.com by Feb 10



MINNESOTA

TWIN CITIES BOWL

Saturday, February 20, 2010

3:00pm

Southtown Lanes

Bloomington, MN

RSVP: Sue at 952-830-1515 or
gsmckinley@comcast.net!

NEW YORK

BROOKLYN BOWL

Saturday, February 20, 2010

12:30 - 3:00 pm

(bowling starts at 1:00 pm)

<http://www.brooklynbowl.com/>

81 Wythe Avenue and North 11
Street; L train to Bedford Avenue - 1st
stop in Brooklyn. Free street parking.

*Families welcome!

*50/50 Raffle and Fabulous Prizes!!!

*\$30 gets you 2 hours of bowling
(includes shoes) and a spread of
yummy sandwiches and snacks from

"Blue Ribbon". Additionally, a full
menu of food and drink are available.
(including six point beers - yum).

*RSVP by Feb 10th to Brooke at [info@
BrookeFox.com](mailto:info@BrookeFox.com)

LONG ISLAND BOWLS

Hosted by Carol and Daniel Carley

Saturday, March 6, 2010

12:00 - 2:00 pm

RVC Lanes

100 Maple Avenue

Rockville Centre NY 11570

\$20 a person. Includes bowling,
shoes and a little something to eat.

RSVP: to 516-766-2489 or [ccarley@
albinism.org](mailto:ccarley@albinism.org)

OHIO

CLEVELAND AREA BOWL-A-THON!

Sunday, February 21, 2010

1:00 pm

North Woods Lanes

10435 Valley View Road

Macedonia, Ohio 44056

330-659-4085

www.northwoodslanes.com

RSVP: Renee at drjtpiper@aol.com

PENNSYLVANIA

PHILADELPHIA AREA BOWL-A-THON!

Saturday, February 27, 2010

1:00 to 3:30 pm

Facenda Whitaker Lanes

2912 Swede Road

Norristown, PA 19401

(near King of Prussia, PA)

RSVP: Pam at 610-574-8905 or
pmcgonigle@albinism.org by Monday,
February 15th

SCRANTON JEOPARDY GAME DAY!

Sunday, March 7, 2010

2:00 to 4:00 pm

Marvelous Muggs

20 Montage Mountain Road

Scranton, PA 18507

www.marvelousmuggs.com

Games and sweet treats for ALL!

RSVP: mcampbell@albinism.org



SOUTH DAKOTA

ABERDEEN

Sunday, February 21, 2010

5:00 - 8:00 pm

Village Bowl

1314 8th Avenue Northwest

Aberdeen, SD 57401

<http://www.thevillagebowl.com/>

RSVP: Kelli Meister at 605-216-4382

or rkmeister@nvc.net

SIOUX FALLS AREA

Saturday, February 20, 2010

1:30 - 5:30 pm

Ten Pin Alley

I-90 to Exit 387

Hartford, SD 57033

Pizza, Pop, Bowling, Wii Bowling, and Raffles!

Childcare provided on site.

RSVP: Samantha Rinder at 759-6153

or SLR0831@AOL.COM

TENNESSEE

TEAM TENNESSEE

Saturday, February 13, 2010

6:00 pm

Strike N Spare at Hillwood Circus World

3710 Annex Ave

Nashville, TN 37209

<http://www.strikeandsparebowling.com>.

RSVP: akwright04@yahoo.com

TEXAS

HURST LANES

720 West Pipeline Road

Hurst, TX 76053

Saturday, February 20, 2010

2:00 - 4:00 pm

RSVP: noah.ntx@albinism.org

FRISCO - STRIKZ

8789 Lebanon Rd

Frisco, TX 75034

Sunday, February 21, 2010

4:00 - 6 pm

RSVP: gibsons@friscoisd.org

HOUSTON -ARMADILLO LANES

10055 Fuqua

Houston, TX 77089

Saturday, February 20, 2010

1:00 - 4:00 pm

RSVP: stxnoahmom@yahoo.com

ENNIS-ALL STAR BOWL

2302 West Ennis Ave

Ennis, TX 75119

Sunday, February 21, 2010

2:00 pm

RSVP: carolina-montoya@att.net

AUSTIN - HIGHLAND LANES

8909 Burnet Road

Austin, TX 78757

Saturday, February 20, 2010

1:00pm - 3:00 pm

RSVP: kathi.zuiga@comcast.net

SAN ANTONIO - UNIVERSITY BOWL

12332 IH-10 West at DeZavala

San Antonio, TX 78230

Sunday, February 28, 2010

2:00 - 4:00 pm

RSVP: aarena02@yahoo.com

NOAH



National Fundraiser

There's something for everyone at a NOAH Conference:

World's most comprehensive collection of educational sessions on albinism including:

- Research, science and medicine
- Living with Albinism
- Social Skills/Self-Esteem
- Low-Vision Driving
- Careers
- Parenting a child with albinism
- Educating a child with albinism
- Albinism and Society
- Discussion groups
- Organized social gatherings
- Networking opportunities
- School-aged kid's conference
- Pre-teen and Teen conference
- Professional child care for pre-schoolers

Benefits of Our Fabulous Conference City!

- Optional D.C. tour
- Hotel located 5 minutes from Regan National Airport
- Plan a vacation to see the many sights of Washington D.C.

NOAH 2010
WASHINGTON D.C.



UNITING
the **Albinism**
COMMUNITY

NOAH'S 13th National Conference
July 15-18, 2010
Crystal Gateway Marriott
1700 Jefferson Davis Highway
Arlington, VA 22202

**At NOAH Conferences, lives are touched, people are changed and there is a sense of renewal!
How will the conference affect you?**

Eyes on Tanzania Congressional Support Needed

At the urging of NOAH member Susan DuBois and others in the D.C. area, Representative Gerald E. Connolly (D-VA), pledged to introduce a House Resolution condemning the East African crisis. NOAH is asking members of the albinism community to consider calling their representative to and ask him/her to join Rep. Connolly as an original cosponsor for this House Resolution. We need at least 15 more cosponsors, 7 of whom need to come from the House

Committee on Foreign Affairs (<http://www.internationalrelations.house.gov/members.asp>) To locate contact information for your Representative, please visit: <https://writerep.house.gov/writerep/welcome.shtml>.

For talking points to help with your phone call, visit http://www.asante-mariamamu.org/Asante_Mariamamu/Help_Us_files/TalkingPointsforCongress.pdf . It is also important to follow up with a letter.

Albinism on a World Stage Voice of America

A nearly four and a half minute news report on albinism featuring NOAH members aired in 132 countries outside of the United States on The Voice of America (VOA) in December.

VOA, which first went on the air in 1942, is a multimedia international broadcasting service funded by the U.S. Government. VOA broadcasts news, information, educational, and cultural programming to an estimated

worldwide audience of 125 million people. This piece contains a concise description of albinism and covers the terrible killings of people with albinism in Tanzania.

Click here to view video:
<http://www.youtube.com/watch?v=e--Y6qXg8XA>

2010 Michael J. McGowan Leadership Scholarship Award

The Michael J. McGowan Leadership Scholarship Award was established in 2008 on behalf of the National Organization for Albinism and Hypopigmentation (NOAH) to recognize leadership and empower young people with albinism. NOAH will award one scholarship annually to a student with albinism enrolled in an undergraduate program at an institution of higher education. This award aims to enhance educational opportunities for students with albinism while celebrating outstanding leadership qualities

similar to those exhibited by NOAH's dedicated current and past leaders.

The 2010 scholarship award will be \$3,500. Download the application here: <http://www.albinism.org/publications/2010/McGowan%20Scholarship%20App%20-%202010.pdf>

See the 2010 McGowan Leadership Scholarship application for more information. Application materials for the 2010 McGowan Scholarship must be received by May 01, 2010.

CCLVI Scholarship Opportunity

NOAH has been made aware of the following scholarship opportunity from the Council of Citizens with Low Vision International (CCLVI). If you are interested, please contact the CCLVI directly, as NOAH is not affiliated with this program.

Announcing the Fred Scheigert Scholarship Program

This competitive scholarship awards three (3) students an individual prize of \$3000 annually. Applicants must be full-time college students with low vision, chosen from among those who

meet the visual acuity and academic guidelines.

Guidelines, Application and Certification of Low Vision forms and the on-line application are available at <http://www.cclvi.org/scholarship.htm>" The application must be completed online.

Completed applications and supporting documents must be received by March 1st. If you have any questions about the scholarship application guidelines, please call CCLVI at (800)733-2258.

Semi-finalists will be selected to participate in a telephone interview

with committee members. Winners will be notified in late spring. Winners are encouraged to attend our annual meeting, which is held in conjunction with the American Council of the Blind National Convention and generally takes place the first week in July.

Please note: The required CCLVI Certification of Low Vision form may be downloaded and completed between June and February preceding the March 1st deadline.

Adventures in Darkness

Delta Gamma Richard D. Shirk
Lectureship in Healthcare Ethics and
Values presents:

Tom Sullivan
"Adventures in Darkness"
Thursday, February 25, 2010
7pm - 8:15 pm
University of Houston

Cullen Performance Hall
4800 Calhoun Road
Houston, TX 77004

The lecture is free, open to the public,
and attire is casual.

Tom Sullivan's website and bio are at
<http://www.sullivanSpeaks.com/profile.asp>.

Rare Disease Day

NOAH will observe Rare Disease Day on February 28, along with the National Organization for Rare Disorders (NORD) and a coalition of more than 300 patient organizations, medical societies, government agencies and companies representing the rare disease community. The purpose is to focus attention on rare

diseases as a public health concern.



"People with rare diseases remain a medically underserved population around the world," said Peter L. Saltonstall, president and CEO of NORD. "Studies have shown that it typically takes many years to get an accurate diagnosis for a rare disease. Also, little or no research is being done on many of these

diseases, and more than 15 million Americans have rare diseases for which there is no treatment.”

Rare Disease Day started in Europe three years ago and now is spreading around the world. NORD is the sponsor in the U.S., and NOAH has joined the coalition organized by NORD to raise awareness of the needs of patients and families.

In the U.S., a disease is considered rare if it affects fewer than 200,000 Americans. According to the National Institutes of Health (NIH), there are nearly 7,000 such diseases affecting nearly 30 million Americans. That’s almost one in 10 people.

Patients and their families often feel isolated and forgotten. However, there are certain problems and challenges associated with having a rare disease that patients have in common, and Rare Disease Day is intended to focus attention on those needs.

Rare Disease Day activities in the U.S. will include a nationwide network of online videos, patient stories and blogs; newspaper, radio, and television reports; state and municipal proclamations; a Rare Disease Hall of Fame for researchers; and other activities designed to raise awareness of what it means to have a rare disease.

Rare Disease Day 2010 also will highlight the need for more

medical research and the unique partnership that exists between rare disease patients and researchers. Government entities that have signed on with NORD as “Rare Disease Day Partners” to help promote awareness of the day include the NIH Office of Rare Diseases Research, Food and Drug Administration (FDA) Office of Orphan Products Development, and Social Security Administration. “More than half of the people who have rare diseases are children,” Saltonstall said. “Parents often have difficulty finding a medical expert for their child or accessing other needed services. Also, many rare diseases have no approved treatment, and insurance may not cover treatments that aren’t approved.”

Rare Disease Day was launched by the European Rare Disease Organization, EURORDIS, in 2008. Last year, EURORDIS asked NORD to sponsor Rare Disease Day in the U.S. Rare Disease Day also is observed in other parts of the world, including Canada, Australia, China and—for the first time this year—Japan.

NORD was established in 1983 by patient leaders who helped get the Orphan Drug Act passed. It provides advocacy on behalf of the rare disease community; research grants and fellowships; educational services; and patient assistance programs.

www.rarediseaseday.us

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 Individualized Education Program (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 and 504 plans (**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 or 504 plan.