

NOAH
National Organization
for Albinism & Hypopigmentation



South Texas Albinism Community
Information Packet

Important Contact Information:

NOAH:

The National Organization for Albinism and Hypopigmentation
PO Box 959, East Hampstead, NH 03826-0959
Phone: 800 473-2310 (US and Canada)
Phone: 603 887-2310
Fax: 800-648-2310
<http://www.albinism.org>

Host of South Texas Chapter:

Monica Blancas
stxnoahmom@yahoo.com
832-524-1581
<http://stx.albinism.org>

DARS:

Department of Assistive and Rehabilitative Services
4800 N. Lamar Blvd.
Austin, Texas 78756

DARS Disability Determination Services
P.O. Box 149198
Austin, TX 78714-9198

Email: DARS.Inquiries@dars.state.tx.us

1-800-628-5115 or TTY 1-866-581-9328

ECI: Early Childhood Intervention Services of Texas

1-800-628-5115

<http://www.dars.state.tx.us/ecis/index.shtml>

American Nystagmus Network

<http://www.nystagmus.org/entry.html>

Texas School for the Blind & Visually Impaired

1100 W. 45th St.
Austin, TX 78756
Switchboard: (512) 454-8631
Toll Free Recording Number: 1-800-872-5273
TDD (512) 206-9451
FAX Number: (512) 206-9450
<http://www.tsbvi.edu/>

Hermansky-Pudlak Syndrome (HPS)

HPS Network Incorporated
One South Road
Oyster Bay, New York 11771-1905

1 (800) 789-9HPS
1 (516) 922-4022

<http://www.hpsnetwork.org/>

The Hadley School for the Blind

http://www.hadley-school.org/2_d_FE.asp

The Light House of Houston

<http://www.houstonlighthouse.org/>
General Information: 713-284-8438
Education Programs: 713-284-8445
Volunteer Services: 713-284-8473



Helpful Resources

Dr. Richard Lewis

Baylor College Eye Clinic
7200B Cambridge St
Houston, TX 77030
713-798-6100

University of Houston Low Vision Clinic

The University of Houston
4901 Calhoun Road
Houston, Texas 77204
713-743-2005
713-743-0799
<http://www.opt.uh.edu/uei/services/lowvision/>

Helen Mintz-Hittner, M.D.

6410 Fannin St., Suite 920
Houston, TX 77030
Office: 713-704-2345
FAX: 713-790-1124
Cell: 713-828-2205

Texas Children's Hospital

Hematology (Dr. Lee-Kim): 832-822-4240
Genetics: 832-822-4293

Parent of a Child with Albinism:

Incredible website by a mother, and friend of mine, Marshawna.
This is a wonderful guide for new parents and wealth of information.

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



Sun Protection

Ingredients like zinc oxide, titanium dioxide or Parsol 1789 offer the best sun protection. The less ingredients the better (more can cause an uncomfortable reaction to the skin).

Recommended brands:

- Vanicream SPF 60
- Neutrogena SPF 55 or 70
- Neutrogena Sensitive Skin SPF 30
- Neutrogena Baby Pure & Free
- Total Block
- Blue Lizard
- Shiseido * Sun protection spray GREAT for scalps, crowns, & along parts in hair (only found at Dillard's Department stores)

***Mixing Bug Repellent (with Deet) on top of sunscreen can cause a bad reaction & is NOT recommended. A great Alternative is Bull Frog Mosquito Coast w/ SPF 30 DEET FREE (green bottle).

Tips from the Dermatologist:

- Sunscreen should be worn on sunny AND cloudy days and all year around
- Reapply during prolonged sun exposure or after swimming or heavy sweating
- Avoid sun exposure during 10AM and 4PM
- Wear a broad brimmed hat
- Wear sunglasses
- Wear sun protective clothing
- Protect skin from sun coming through windows at home and in your car
- Sit in the shade whenever possible

Great Web-sites:

UV Sun gear:	http://www.uvsungear.com/dar106.html
Solar Eclipse:	http://www.solareclipse.com/
Sun Togs:	http://www.sun-togs.com/page.home
Coolibar:	http://www.coolibar.com/
BabyBanz:	http://usa.babybanz.com/
One Step Ahead	http://www.onestepahead.com/home.jsp
Protect-A-Bub	http://protect-a-bubusa.com/index.shtml

Other helpful information about your skin:

Soap


- Dove for Sensitive Skin
- Cetaphil
- Oil of Olay
- Vanicream

Moisturizer

- Aquaphor ointment
- Vaseline ointment
- Vanicream
- Eucerin cream

Detergent

- Tide Free
- Cheer Free
- Cetaphil cream Detergent
- All Free
- Dreft (infant detergent)

 Rit Sun guard (add to laundry to add temporary sun protection to clothes) Usually found at fabric or craft stores in their fabric dept.

Photos of our events will be available at www.shutterfly.com . The Log In is stxnoahmom@yahoo.com and the password is aiden628. You can order pictures from our events and have them delivered to your house!