

# "2004 CONVENTION UPDATE" JULY 8 - 11 • HURLEY, NEW YORK

(The following article was submitted by Anita Hutton)

## FOR THOSE OF YOU WHO HAVE NOT YET REPLIED - PLEASE REPLY TO ANITA IF YOU ARE ATTENDING

Following is the daily planner /list of events for the convention

The 7<sup>th</sup> Bi-Annual, Robinow Syndrome Convention is coming up quickly. I would like everyone to arrive on Thursday, July 8.

Accommodations can be made through: **The Ramada Inn**  
**Route 28 in Kingston, NY**  
**Phone: 845-339-3900**



Rooms are filling up fast, so be sure to make your reservation as soon as you know your schedule.

A block of rooms have been reserved. When calling, just mention you are with the Robinow Syndrome Convention.

### **THURSDAY:**

Everyone is invited to our residence before or after check-in for an informal dinner which will be provided by the ancient order of Hybernians (a local Irish Catholic group) Entertainment will include: a 4-piece band, the local fire department will bring a truck to hose down the kids. An ambulance for observation and a bouncy thing for the little ones. Fun Fun Fun!!!

### **FRIDAY:**

Breakfast buffet at the hotel. (which is all paid for). Then some of you will board the bus for New York City. (Arrival time 11:00 a.m.) We will first board a ferry to the **Statue of Liberty** and sight see. Once we return from there we can have lunch (pre-bagged lunches). Our bus will be guided. Other points of interest will



then be: **Ground Zero, Rockefeller Center, Central Park, Times Square, China-Town**, etc. We will plan to depart NYC approximately at 5:00 p.m. Stop for dinner (paid for) and arrive back to the Ramada Inn at approximately 8:00 p.m. for swimming until 11:00 p.m. For those **NOT** going to NYC, I am arranging a boat ride on the Rip Van Winkle cruisesline on the Hudson River. This ride takes approximately 2 hours. I will also fill you in on other things to do throughout the day.

**IMPORTANT!!!! If you are not going to NYC please still arrive on Thursday. I believe this is one of the most important days for getting to know each other. You are invited to arrive at our house anytime during the day. The atmosphere will be extremely relaxed. We are all here to have a GOOD TIME!!!!!!!**

### **SATURDAY:**

8:00 a.m. all be at St. John's Episcopal Church for breakfast. Following, Juliana will deliver her talk on Robinow and genetic research. Karla will have a chance to address everyone and we will have the opportunity to give her a standing ovation for all her efforts. We must all remember "if it weren't for Karla, this all would not have been possible!!!!"

Everyone (especially the new families) will also have time to participate in the question and answer period, or to ask Juliana specific questions. There will be

a magician for the kids and the older kids can help watch the younger ones so the adults can focus. I am trying to get a speaker on the topic of "bullying and self esteem" also. At the conclusion of the meeting, we will return to my house for lunch. I have the trolley donated for a tour of historic Kingston (we were the first capital of NY state before the British burned us down). For those of you who do not want the tour there will be alternatives. I just haven't figured that out yet - there is still time. (Ha Ha).

At 3:00 p.m. we will all proceed to the Hurley Rec. We have swimming, tennis, basketball, a playground, soup to nuts!!!! We have a band coming and I plan to have the bouncy thing moved there as well. Dinner will be catered. Party to end at around 10:00 p.m.

### **SUNDAY:**

Breakfast buffet at the Ramada Inn and our farewells. For those of you who are not leaving you are welcome to stay as long as you like. We belong to the Rec. so we can visit there. It's all up to you. Our home is your home. Just don't say until Christmas!!!! Only kidding!!!

Keep the E-mails coming. Once again for those of you who didn't reply about the bus I need to know ASAP.



Thanks I will see you soon!!!!!!

ANITA HUTTON  
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Phone: 845-331-2015

## **WELCOME HOME KYLA!!!**

Katherine J., (Missouri), attended the 2002 Convention held in Andover, MN alone to meet and learn from us all, while her baby daughter was still back home in the hospital. It has been a long, hard, road for both of them. BUT, now all of that has changed. Kyla is finally at home - where she belongs - surrounded by love! We wish you both the absolute **BEST** that life has to offer.

## **THE FOUNDATIONS FINANCIAL INFORMATION**

For those of you who are wondering where the fundraising money is, and what it is spent on, I will gladly send a copy of the financial statements to you. Please send a note requesting a copy. Include a "Self-Addressed, Stamped Envelope".

**TO HAVE YOUR PHOTO UPDATED, OR ADDED TO THE WEBSITE  
PLEASE SUBMIT TO THE FOUNDATION VIA SNAIL MAIL OR E-MAIL.**

# SMALL

## ABOUT ROBINOW SYNDROME

# STALK

We are a "Little" group of families reaching out for one another's support on dealing with this medical rarity and how it affects all of our lives.

ROBINOW SYNDROME FOUNDATION

SPRING 2004

## SILENT AUCTION

Anita Hutton & family organized our very first Silent Auction - Cocktail Party and Fundraiser which was held on Friday, April 30 from 7:00 p.m. - 10:00 p.m. at the Hillside Manor in Kingston, New York.



## FUNDRAISER

Donations from her local businesses, family, friends and neighbors were unbelievable. She had over 200 items and 144 people attended the evening event.

Some of the items donated were:

## RESULTS

### Gift Certificate's from:

- Lake Mohonk
- William's Lake
- Terrapin
- Roudigan's (2)
- The Hillside Manor
- Marinor's Harbor
- Bowery Dugout
- Gisiano's
- Amici
- La Mirage
- Rosita's
- Tony's Pizzeria
- Port Ewen Diner(2)
- Olive Garden
- Benny's Pizzeria(2)
- Friendly's Wash. Ave. (2)
- Friendly's anywhere
- Ground Round
- Applebee's (2)
- Hall of Fame
- Bowery Dugout-lunch
- Chic's
- Le Canard
- Hoffman House
- El Rodeo
- Lucas Ave. Pet Supply
- The flower nest
- Home Goods
- Ramada Inn - Pool Membership
- Holiday Inn - Pool Membership
- Fitness Unlimited - 3-Month Membership
- Fit Lady - 3-Month Membership
- Curves/Hurley - 1-Month Membership
- UPAC 4 Tickets - Babes in Toyland
- Teal - Fireworks Dinner Cruise (2)
- EAA CH 1359 - Plane Ride Over KGN (2)
- Sawkill Family Center - Passes
- Rosendale Theater - 10 Passes
- Belleayre Mountain - Lift Tickets
- Windham Frequent Savers - Pass
- Bradley Painting - 8x10 Room
- Ascot Park - Passes
- Green Acres - 18 Hole Pass for 2 w/cart(2)
- Green Acres - 9 Hole Pass (4)
- Snippers - Manicure and Pedicure
- Cutting Crew
- Perry Car Wash
- Hoffman Car Wash
- Ace Oil Furnace Cleaning
- Tinker Toys of Woodstock
- Montano's Shoe Store
- Ulster Savings - Bank Bonds (2)
- Barcone's
- Blockbuster video - Rental of Games (10)
- Style Fabrics
- Woodstock Wine and Liquor
- LaBella Pasta
- Adam Fairacre Farms
- Bread Alone
- Mother Earth
- Center for Photography - Season Pass
- Wood Family - Esopus Creek Print
- Herzogs - Leaf Blower
- Ameribag - Backpack
- Aarons - DVD Player
- Colony Liquor - Wine (6)
- Bruderhof - Children's Tricycle
- Kate Shapinsky - Picture
- Bruderhof - Handmade Pottery
- Doris Currier - Handpainted: Pitcher, Angel Plate, Morning Glory Plate, Pastel Flower Plate, Purple Iris Plate, 2 Iris Plate, Farmhouse Watercolor (Framed), Mountain Scene Watercolor (Framed)
- Patti Gibbons - Antique Paper Collage
- The Balogh's - Various Photo's (2)
- Jadine Hoefkler - Pencil Santa's
- Connie Pinkosz - Lithograph
- Marion Warnecke - Handmade Quilt
- Cindy Sherry - Handmade Scarf
- Dorothy Unger & Karla Kruger Handmade Doilies (2 sets of 4)
- Catskill Art Supply - Print
- JD Liquor - Basket of Cheer
- Summerset Winery - Basket
- Miron Liquor - Rack of Wine
- Marcuse - Picture Frame
- Schneiders Jewelers - Vase
- Whitworth Jewelers - Necklace
- Teapot Company - Vase
- Seasoned Nest - Plaque
- The Baloghs - Tiffany Lamp Kit
- Holly Sass - Picture
- Becky Veith - Children's Table
- Candlestick Store - Candle
- Clouds - Oil Lamp
- Tinker Street Toys - Wooden Horse
- Free Wheel Pottery - Earrings
- Jewelry Expressions - Earrings
- Pleasures - Earrings
- Hudson Valley Book Shop
- Golden Notebook - Books
- Burgevin Florist - Arngmnts.
- Tonner Doll Company - Dolls (2)
- Diane Esposito - Magic Attic Doll
- Carol Mahoney - Tupperware Basket
- Helping Hands Club: Garden Basket, Tea Time Basket, Pamper Basket, Harvest Basket
- Parent Teacher Store - Basket
- JoAnn's Fabrics - Basket
- Stephanie Messina - Basket
- The Hutton's - Basket
- Woodstock Chimes - Chimes
- Keven Ginty - Catskill Mountain Chimes
- Connie Pinkosz - Video Games
- Hammer Electronics - Pager
- Gerta's - Scalp Massage
- The Wood Family - CD Player
- Pawprints and Whiskers - Cup and Bowl
- Tails - Cat Bowl
- B Michaels Jensen - Car Stereo
- The Hutton's - Chess Game
- The Currier's - Wilson Golf Balls
- The Cigar Store - Antique Case w/Cigars
- The Stevanus Family - Spanish Program (CD)
- Woodstock Trading Post - Purse
- Annonymus - Full-Size School Violin
- Katherine DeLaRosa - Cutlery Set
- Pine Street Dental - Teeth Whitening
- The Currier's - Mustang Clock
- Emmerson Inn & Spa - (2 Nite Stay)
- Condo for a Week - in Naples, FL
- YMCA - 1-yr. Membership
- Wiltwyke Golf Club - Golf (4)
- Juliana Mazzeu - Handmade Brazilian Crafts
- Other groups donating their funds to us
- MANY OTHER CASH DONATIONS!!!

(Auction continued on page 3)

# MEDICAL FAQs

(The following articles were submitted by Kim Ortiz)

## TOPIC: CRANIOFACIAL

A Craniofacial Team may be considered as a medical assessment for those affected with Robinow Syndrome. Since Robinow Syndrome affects the craniofacial aspect of the patient, a team evaluation may something each family should consult for their child. The team examines all aspects of the head and face that could be affected by the syndrome, even in the mildest form. Something as simple as dental care may be more appropriate through a craniofacial team for the Robinow Syndrome patient. Dental and oral defects are common with the syndrome and may promote special treatment/surgical considerations that a craniofacial team is more able to handle.

### TEAM CARE: IMPORTANCE OF TEAM CARE

Children born with clefts or other craniofacial conditions often face multiple, complex health problems. Experience has shown that these complex issues can best be managed by an interdisciplinary team of specialists who work together, and with the family, to create and update the child's health care plan. Depending on the child's individual needs, these specialists may include:

**AUDIOLOGIST** (who assesses hearing);

**SURGEON** (such as a plastic surgeon, an oral/maxillofacial surgeon, craniofacial surgeon, or a neurosurgeon);

**PEDIATRIC DENTIST** or other dental specialist (such as a prosthodontist, who makes prosthetic devices for the mouth);

**ORTHODONTIST** (who straightens the teeth and aligns the jaws);

**GENETICIST** (who screens patients for craniofacial syndromes and helps parents and adult patients understand the chances of having more children with these conditions);

**NURSE** (who helps with feeding problems and provides ongoing supervision of the child's health);

**OTOLARYNGOLOGIST** (an "Ear, Nose and Throat" doctor, or "ENT");

**PEDIATRICIAN** (to monitor overall health and development);

**PSYCHOLOGIST** or other mental health specialist (to support the family and assess any adjustment problems);

**SPEECH-LANGUAGE PATHOLOGIST** (who assesses not only speech but also feeding problems);

and other necessary specialists who treat specific aspects of complex craniofacial anomalies.

When these specialists work together, and with the family, as an interdisciplinary team, treatment goals can be individualized for each child and parents and health care providers can make the best choices for treatment by consulting with each other. Since growth is a significant factor in the ultimate outcome of treatment, the child must be assessed thoroughly and regularly by the team until young adulthood.

If you are seeking a Craniofacial Team for your child you should consult with your pediatrician for a referral to a Children's Hospital or Craniofacial Clinic in your area. A list of Craniofacial teams can be obtained through the Robinow Syndrome Foundation.

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## TOPIC: OBSTRUCTIVE SLEEP APNEA

Obstructive sleep apnea (OSA) implies that breathing stops because of obstruction.

This is more common during sleep, because the muscles in the throat relax and the throat partially closes. Obstruction results in a drop in the blood oxygen. The obstruction is resolved when low blood oxygen causes the brain to arouse and the muscle tone in the throat to increase, relieving the obstruction.

As a result of OSA, children don't get enough oxygen, which may stress the heart and lungs, and may cause the child to have day-time behavior problems caused by their poor sleep. Babies and children are often evaluated that may have sleep apnea caused by Downs Syndrome, Achondroplasia, Asthma, Cerebral Palsy, Seizures or Facial Abnormalities such as small jaw, receding jaw, large tongue, cleft palate and/or deviated septum. Noticeable symptoms might include loud snoring, difficulty breathing, respiratory pauses and/or snorts, restless sleep, daytime irritability and occasional sleepiness. Remember: It is not normal for children to snore. Overnight studies are recommended for an accurate diagnosis of OSA.

Treatment may be surgical, such as tonsillectomy and/or adenoidectomy. Mechanical treatment with a CPAP (a mask worn at night which balloons the throat open with a small amount of positive pressure) is also very effective. The addition of oxygen is sometimes necessary. Weight loss, medications and other treatments are sometimes recommended.

Some children with Robinow Syndrome do experience episodes of sleep apnea. Parent's have reported that evaluations by sleep study showed various degrees of apnea. Some of these children showed behavioral problems during the day, aggressive, hyper or social behavior type problems in school. It can be easily mistaken for Attention Deficit Disorder (ADD/ADHD). While some children may have ADD or ADHD without sleep apnea it is best to consult with your child's pediatrician if you have any concerns. One tip from a craniofacial team is to put a tape recorder in the child's room after they have fallen asleep and do a recording of the breathing sounds. If periods of quiet are heard between breathing or most likely snoring, you may wish to ask the child's doctor for further evaluation.



## FEATURED FRIEND . . .

Hi, my name is Ryland Kremeier and I am 8 years old. I am homeschooled by my mom and ready to finish the 2nd grade. I live in a small town in Southwest Missouri near Branson. I live on a farm and I am raising chickens and ducks. I am helping my mom with a garage sale to help pay for our trip to NY this summer. I have helped my neighbors with jobs to earn my own spending money. I am looking forward to seeing everyone at the convention.

My best buddy "William" will be there and I am excited about that.

My favorite hobbies are: riding my bike and playing the piano. I can also do a really good handstand.

When I grow up I would like to have a job where I could help our military service people.

When I was a baby, the doctors told my mom that I have the recessive Robinow Syndrome. The one thing I hate about having Robinow Syndrome is when I have to go in for surgery and they put a mask on my face to make me go to sleep. I think that is real scary. If you asked me about one thing I like about Robinow Syndrome I would have to say "nothing".



## Silent Auction/Fundraiser Continued from page 1

To summarize, after paying off her incurred expenses to host the silent auction, and cover the costs of the upcoming convention, the Robinow Syndrome Foundation is pleased to announce that due to the overwhelming success of the auction, we may also be able to help defray some of the costs of the hotel room for those attending.

### FANTASTIC JOB & HATS OFF TO THE HUTTON FAMILY

YOUR EFFORTS WILL HELP OUT SO MANY!!!

*(The following article was submitted by Anita Hutton)*

*It was a night like no other! The room was packed, the musicians played beautifully, the food delicious and the items - unbelievable. 203 items in all, 144 people, just under \$10,000 raised. If we had one more item it would not have fit. My family, friends, neighbors and especially me were in awe. Everything could not have been more perfect. We had a r twork, sports memorabilia, Brazilian crafts, jewelry, tons of wine, over 75 gift certificates and much more!!!!!! All of this started back in September when the kids started school. I have been corresponding with a family called the Blakes. The story of their daughter Abbi has touched me so much, that they inspired me to go full-speed ahead and raise as much money as possible. My goals were to raise enough money to defray all cost (minus airfare) for everyone attending. Well, it appears as though I may have done this and more!!! I hope to be able to add a quite substantial amount towards the foundation as well. Without the help of my daughter Lauren I would not have made this event as eloquent as it was. She personally designed all 203 cards for displaying each item. At the age of 13 she spent well over 200+ hours creating these beautiful cards. They looked gorgeous! Sara spoke publicly to three service organizations and played her violin for them. She stood up and told all these people "What it is really like to have Robinow Syndrome." She brought tears to my eyes! Between the service groups and her newspaper my little girl has raised over \$1000 for our organization! Words cannot express the emotion this event brought. My community has been so supportive, my neighbors outstanding, my friends and family have expressed such love and compassion that I have been left speechless (for the first time in my life!)*

*Thank you to those of your that donated items and most of all for the kind e-mails!!!!!!*

**See you all in JULY!!!!!!**

ANITA

