

# RTS News

A newsletter for families living with Rubinstein-Taybi Syndrome (RTS).

[www.cincinnatichildrens.org/rts](http://www.cincinnatichildrens.org/rts)

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*We can't wait to meet you!*

## **RTS 2010 Family Conference** **For Families living with Rubinstein-Taybi Syndrome**

**July 23 – 25, 2010**

**Covington, Kentucky**



<https://www.regonline.com/RTS2010FamilyConf>



## RTS 2010 Family Conference Update

### – *The Link We Share*

By Jennifer Black Hans &  
Christopher Weitfle, RTS-OKI Parents

*The Link We Share*, the theme for the RTS 2010 Family Conference, invokes many ideas. The genetic link, the link to the RTS community and the links we share in our own families and support networks. We are pleased to be your link, as parents, to the planning of the 2010 RTS Family Conference. The Conference will take place July 23, 24 and 25, 2010 at the Radisson Hotel Cincinnati Riverfront in historic Covington, Kentucky.

Together, the RTS Program in the Division of Developmental and Behavioral Pediatrics (DDBP) at Cincinnati Children's Hospital Medical Center teamed up with the RTS-OKI (Ohio, Kentucky, Indiana) Support Group to bring you this exciting weekend for the entire family!

We are thrilled to announce that registration for the Conference reached capacity in less than a week, which speaks to the desire families have expressed to gather together and connect! We will be welcoming **over 100 families** representing five (5) countries, including families from more than half of the USA. Families from our own area of Ohio, Kentucky and Indiana are well-represented—both as conference registrants and as volunteer “Ambassadors,” all of whom will be welcoming our visiting RTS families!

The 2010 RTS Family Conference will feature international speakers and timely topics to deliver an exciting, educational program that most represented the needs of families (based on survey results). The Conference will offer:

- **Dr. Raoul C.M. Hennekam as the keynote speaker**, a pediatric geneticist, who sees patients with RTS regularly and has published many genetics articles on RTS.

- **Stephanie Hunt**, the newly crowned Mrs. Michigan America 2010, whose platform is raising awareness for rare disorders, including RTS. Stephanie's son, Donnie, has RTS, and her advocacy on behalf of RTS families has been recognized on the floor of Congress.
- **FOR OUR CHILDREN**, the Conference will feature FREE childcare and activities, sibshops, family-friendly networking events, and information, support and inspiration for transition and success as adults living with RTS.

For the complete Schedule at a Glance, including all the featured speakers from DDBP, Community Advocates, and RTS USA parent resources, please go to the RTS 2010 Family Conference web site and check back often for updated information: [www.regonline.com/RTS2010FamilyConf](http://www.regonline.com/RTS2010FamilyConf)

We have been honored to be your representatives in planning this exciting Conference! This endeavor has been enhanced by the generous support and planning of key partners:

### *Thank You to . . .*

- The Dr. Jack H. Rubinstein Foundation for its generous financial support of the Conference.
- The Special Friends Foundation, for their support of RTS families attending the Conference.
- The Child Life Specialists at Cincinnati Children's Hospital, who will be providing professional, quality child care at no cost to RTS families attending the Conference.
- DDBP's Rubinstein Library and to the Family Resource Center at Cincinnati Children's Hospital, whose staff and resources are available to support RTS families.

- The ‘behind the scenes’ staff in DDBP, who have been the cornerstone of planning and support for both the RTS Program and the RTS 2010 Family Conference!
- Our fellow RTS 2010 Family Conference Planning Committee members. Particularly, thanks to Amy Clawson, DDBP’s Family Support Coordinator and our Conference coordinator!
- Dr. David Schor, who directs the RTS Program in DDBP, for chairing the Conference Planning Committee and providing guidance and support for its activities.
- The Radisson for providing the family-friendly conference facility and welcoming all the out of town RTS families.

RTS 2010 Conference Planning Committee members on a site visit at the Radisson Hotel Cincinnati Riverfront, Covington KY. Gearing up for July!



(left to right): Mary Jo Haviland, Radisson Director of Sales; Amy Clawson, RTS Conference Coordinator; Christopher Weiffle, RTS-OKI parent, Jennifer Hans, RTS-OKI parent, and (not shown) Karen Schulte, Family Resource Center Manager

While we are so pleased to be welcoming more than 100 families to the Conference this year, we realize that not all families will be joining us. Remember that *the links we share* reach beyond a certain time and place. We encourage you to reach out to RTS-OKI members, DDBP staff, and other vital links in the RTS community!

# NORTHERN **NK** KENTUCKY

THE SOUTHERN SIDE OF CINCINNATI

The Riverfront, where North meets South and the RTS 2010 Family Conference is centered in the heart of the most vibrant area in Greater Cincinnati.

[www.nkycvb.com](http://www.nkycvb.com)



## RTS Reasons to Smile:

### A Story of Independence ...Tina's in Charge!

*One sunny spring afternoon, Tina and a few close friends and family gathered for this interview. Even the sun outside could not outshine the bright, warm feeling in the room that day. Her smile and magnetic personality was captivating . . .*

Christina "Tina" Chiricosta grew up in Cincinnati, with a large, supportive family: two sisters, one brother, three nieces, and one nephew. She is very close with her sisters, Tracey and Terri, who both live locally. Tina loves her family and her independence. She lit up stating, "I live at Find Away, apartments for people with disabilities, through a program called LADD." (Living Arrangements for the Developmentally Disabled). Ruth Waldron is Tina's Direct Service Professional at LADD. "She helps me with money, go out places like grocery shopping. Ruth helps me a lot."

Tina has a full life and enjoys cooking and animals. "I have two parakeets, Petey and Hulk. One is quiet, and one is noisy." She also participates in "Out and About", an adult day program through Starfire Council of Greater Cincinnati. Out and About is a program that provides individuals with opportunities to volunteer and socialize in the community. They volunteer at the Red Cross, food pantries, and other local agencies, as well as go to the Aquarium, bowling, out to lunch with friends, have picnics, and more.

"I call her the volunteer queen," says her dad, Larry. Tina has an extensive volunteer history at various local hospitals. "I just like volunteering; working makes me nervous. I am doing things for other people, and that makes me feel good, she said. Tina is proud of herself and her work. In addition to her hospital work, Tina answers the phones at Starfire. In fact, she was recently honored at Starfire Council for reaching 40 volunteer service hours! Chris Bruewer, a coordinator at Starfire, looks forward to Tina's volunteering at Starfire, and she noted "I could not do it without her!"



**Tina and her dad, Larry**

Although Tina has RTS, she has not had the more serious medical complications that other people with RTS sometimes endure. Tina has actually experienced more typical yet very difficult challenges in her life. Her boyfriend died in 2007, she is a breast-cancer survivor since 2007, and her mom passed away 11 years ago. Tina admits she sometimes get depressed because she misses her mom. But, her sisters, their children, and her dad all help her any time she needs a family boost.

When asked about her disability, RTS, she simply says, "It's people with a slow learning style. Growing up, I didn't want to be in special education. When things went wrong in the house, I used to talk to myself. It's embarrassing now, but I used to cope better that way. My family didn't treat me any different during my childhood. I used to babysit too when I was a kid."

Tina wants to get involved in the local RTS-OKI (Ohio, Kentucky, Indiana) Family Support Group. She stated, "I want to learn more about it, and I want to talk to people who have it."

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“I want to advocate that people with RTS can live on their own! It was hard on my mom to let me go. But I wanted to be on my own. I was 28 years old when I left home; I have been here ever since.”

Tina (51) has been independent for 23 years. She uses Access Services, part of the Metro Bus Public Transportation System, to get around town and do most of her activities.

Tina would like to challenge people to “Try to think positive and keep perspective. And don’t think negative.” Ruth at LADD says, “RTS has not discouraged Tina. She stays busy and is working on staying physically active, just like everyone else. A typical, good week for Tina, is to have something on her calendar almost everyday of the week.”

Tina’s father, Larry recalls the early years... “When Tina was born, we knew something was wrong. Because we had a large, growing family, and Tina had several siblings, when Tina didn’t walk at the right time, we knew there was something up. Dr. Rubinstein, and other Children’s Hospital PhDs were studying the physical characteristics of RTS and various syndromes, and they did some tests. Tina was one of the first with the RTS diagnosis.” Larry states that Tina’s always had a way of touching people. “Once at the hospital, during an appointment, the doctors and nurses could not stop a little boy from screaming. He remembers how Tina went to the little boy and calmed him immediately – it was a magical moment.

Larry continued on Tina’s childhood: “Tina was always included in neighborhood activities. She was in special education, and we felt it was a good fit for her. We made sure not to treat her any different otherwise. She graduated from Cincinnati Public Schools with the goal to be independent. It was tough work and a long process. She rode the Metro bus, while I would follow and sometimes ride along.

We wanted her to be independent and get out and about. As time went on, we were less concerned. She has been a blessing.” Lovingly Larry added, “Tina’s become so independent over the years so the RTS has not been as big an issue.”

“Tina’s in Charge!” says Larry; “She’s a social butterfly, a caring person, and will do anything for anybody.”

For more information about LADD and/or Starfire’s services and programs, please visit [www.laddinc.org](http://www.laddinc.org) or [www.starfirecouncil.org](http://www.starfirecouncil.org).



**Tina and Chris (from Starfire)**



**Tina with friends: Steve, David, & Tim**

## **RTS Resources to Share: 10 Tips for a Successful School Year**

by Patricia Howey, Advocate & Speaker's Bureau Member for Wrightslaw

**Question:** *Help! School is starting. I want to make sure I have done my homework so this year is better than last year.*

**Answer:** You need to view your role as your child's "case manager." (Learn more about "The Parent as Project Manager" in Chapter 3 of *Wrightslaw: From Emotions to Advocacy*).

You need to be watchful, even when things appear to be going well.

Here are ten tips to help you get off to a good start at the beginning of the new school year.

### **1. Help Your Child Deal with Transitions.**

Is your child making the transition from preschool to kindergarten, from elementary to middle school, or from middle school to high school? Plan to take your child to visit the new school or classroom before the first day of school.

### **2. Reread your child's IEP.**

Do you understand what the school agreed to provide? Do your child's teachers understand what they are to provide?

Is your child's IEP SMART? (Specific, Measurable, Action words, Realistic, and Time-specific) (Review Chapter 12 about SMART IEPs from *Wrightslaw: From Emotions to Advocacy*).

### **3. Meet with your child's teacher(s) to discuss your child's special needs.**

Take a picture of your child to the meeting. Teachers are more likely to take a personal interest in your child and remember your child's special needs if s/he has seen a picture of your child.

### **4. Take extra copies of your child's IEP to the meeting with the teacher(s).**

Never assume that teachers have had time to read your child's IEP before school begins. Teachers have many things to do as they prepare for the first day of school. The teacher may not understand how important the IEP is to your child's success. Leave a copy of your child's IEP with each teacher.

### **5. Make a List of Important Things About Your Child .**

Make a list of the five most important things that the teacher(s) need to know about your child. Explain why these things are vital to your child's success. Leave a copy of the list with each teacher.

### **6. Prepare to Deal with Potential Problems Early.**

If your child is in general education classes, prepare for the teacher(s) who wants to see how your child "gets along" before making any changes in the way they run their classrooms.

Teachers often take this position because they want to give their students a fresh start. You may need to explain why your child may fail unless the teacher understands his/her unique needs and provides the necessary services, accommodations and supports.

### **7. Resolve Old Concerns and Issues.**

If you have concerns or issues that were not resolved during the last IEP meeting, request another IEP meeting immediately. Try to resolve these issues and concerns before your child begins to have problems this year.

**8. Get a New Assessment.** Consider getting your child's skills tested very early in the school year. Where are your child's skills on standardized educational achievement tests? Use these scores as baseline data. You can compare these scores with scores obtained at the end of the year to measure your child's progress. (See Chapter 8, Your Child's Evaluations, in *Wrightslaw: From Emotions to Advocacy*).

**9. Go to your school's Open House.** In addition to giving you another chance to meet with your child's teachers (and make a good impression), teachers often explain their classroom rules during Open House. When you attend, you have a chance to see if your child may have trouble understanding the teachers' rules. You will also be in a better position to explain these rules to your child.

**10. Get a bound notebook.** Use the notebook as a "contact log" to send messages to the teachers. Write a sentence or two to the teacher(s) every day. Do not make your child the bearer of messages about problems at school. Make an extra copy of your log often in case the notebook is lost.

*Printed with approval from: <http://www.wrightslaw.com/howey/10tips.sch.yr.htm>. About the author, Pat Howey: Pat is an advocate who has helped parents obtain special education services for their children with disabilities since 1986. For more information about Pat Howey, Wrightslaw, and books cited in this article, please visit: [www.wrightslaw.com](http://www.wrightslaw.com)*

## RTS-OKI Around Town

### RTS parent recognized for Leadership in Family-Centered Care at Cincinnati Children's Hospital

On April 20, 2010, several teams, parents, families, and staff gathered together for the 2009-2010 Family Recognition Reception. Jennifer Hans was one of the four finalists nominated for the Family Award.

Her nominee wrote, "Jennifer's candor and enthusiastic ideas toward a supportive RTS Program is a beacon of light for families and for DDBP."

Thank you for giving your time, sharing your experiences, and helping us make things better for patients and families!



### RTS-OKI Fall meeting! ...of the Rubinstein-Tabyi Family Support Group for Ohio, Kentucky and Indiana:

**RTS-OKI Family Support Group Meeting**  
**WHEN: Saturday, September 11, 2010**  
**TIME: 11:30 am - 2:00 pm**  
**WHERE: DDBP - 3430 Burnet Ave. Cincinnati, OH 45229**  
**RSVP to: Amy Clawson, [amy.clawson@cchmc.org](mailto:amy.clawson@cchmc.org)**  
**(Pizza & childcare provided with RSVP only)**



# RTS Resources to Share

## **David Schor, MD, MPH**

### **RTS Program Director**

Division of Developmental and Behavioral Pediatrics  
Cincinnati Children's Hospital Medical Center  
MLC 4002, 3333 Burnet Ave.  
Cincinnati, OH 45229  
800-344-2462 ext. 0541  
Email: [david.schor@cchmc.org](mailto:david.schor@cchmc.org)

## **Amy Clawson, Editor, RTS News**

### **Family Support Coordinator**

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Cincinnati, OH 45229  
800-344-2462 ext. 4723, 513-636-4723  
Email: [amy.clawson@cchmc.org](mailto:amy.clawson@cchmc.org)

## **Rubinstein Library**

Division of Developmental & Behavioral Pediatrics  
Cincinnati Children's Hospital Medical Center  
MLC 4002, 3333 Burnet Ave.  
Cincinnati, OH 45229  
800-344-2462 ext. 4626, 513-636-4626  
Email: [barbara.johnson@cchmc.org](mailto:barbara.johnson@cchmc.org)

## **RTS-OKI Support Group**

### **Bill Mann, Parent Leader**

513-708-5611 or Email: [bmann@theppsgroup.com](mailto:bmann@theppsgroup.com)

## **RTS Email ListServ**

### **Janet Estes, ListServ Manager**

250-753-7795 or Email: [janetestes@telus.net](mailto:janetestes@telus.net)

## **RTS Parent Group USA**

### **Lorrie Baxter, Coordinator**

P.O. Box 146  
Smith Center, KS 66967  
Toll Free: 888-447-2989  
Email: [lbaxter@ruraltel.net](mailto:lbaxter@ruraltel.net)

## **Rubinstein-Taybi Syndrome Website:**

[www.rubinstein-taybi.org](http://www.rubinstein-taybi.org)

## **Special Friends Foundation**

[www.specialfriends.org](http://www.specialfriends.org)

### **Michelle Farrell, Director of Family Services**

P.O. Box 313  
Windham, NH 03087  
Toll Free: 866-316-9029  
Email: [mfarrell@specialfriends.org](mailto:mfarrell@specialfriends.org)

## **Dr. Cathy A. Stevens**

Dept of Pediatrics  
T. C. Thompson Children's Hospital  
910 Blackford St.  
Chattanooga, TN 37403  
*To receive a copy of the blue booklet "Rubinstein-Taybi Syndrome A Book for Families", please contact Dr. Stevens at: (423) 778-6112.*

## **Family Resource Center**

Cincinnati Children's Hospital Medical Center  
[www.cincinnatichildrens.org/frc](http://www.cincinnatichildrens.org/frc)  
Email: [karen.schulte@cchmc.org](mailto:karen.schulte@cchmc.org)

## **NORD National Organization for Rare Disorders, Inc.**

55 Kenosia Avenue  
P.O. Box 1968  
Danbury, CT 06813-1968  
[www.rarediseases.org](http://www.rarediseases.org)

