

# 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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THE LINK  
WE SHARE

Spring/Summer 2011

## RTS Reasons To Smile: Megan & Tucker, A Dynamic Duo

By Amy Clawson, Coordinator

*Recently, many of us celebrated Mother's Day with our families, recognizing all the moms in our lives. Although this story is primarily about Tucker Jackson, his happy life is due to the strength and courage of his amazing mom, Megan Jackson!*

Tucker Jackson and his mom, Megan, live in the small, rural town of Connersville, Indiana. "Yep, it's just me and Tucker," Megan happily said. Megan is a single parent who works full time at Connersville High School in the attendance office, and attends college in the evenings. She proudly says, "I'm in school fulltime this semester, and I graduate in June 2011 with a Bachelor's degree in Psychology! I have two other degrees – an Associate's in Liberal Arts and an Associate's in Sign Language Interpreting. I started school in 1999, with some breaks in between." Wow!

While Megan is busy at school, Tucker's great grandma helps out at home twice a week. Tucker's Grandma helps with other activities too. "My whole family is in town; that's why I moved back from Orlando, Florida, just over two years ago, in October 2008. Moving was scary but I knew it was best. We lived in Orlando, Florida by ourselves. When Tucker was born and was diagnosed with Rubinstein-Taybi Syndrome, I needed more support. So, we moved back to be with our family. I needed babysitters that I trusted with Tucker," she stated.

After their move, Tucker got settled in at public school. He is now 11 years old and in sixth grade at Maplewood Elementary School. Megan said, "Tucker is 100% non-verbal. He reads and writes at first grade level. He is mainstreamed ½ day and in a self-contained classroom ½ day. He loves school for the most part, but the bus is the highlight of his day! It's a small school, and they are willing to work with me, but sometimes we do have issues." Megan wishes Tucker had more



interactive coursework within the self-contained class. "The mainstream class is a typical 2<sup>nd</sup> grade classroom, in which he has a one-on-one aide. In the mainstream classroom Tucker does the daily calendar activities, science and writing centers and all "specials" classes like art, gym, and library. The self-contained class is a special needs class, with a 1:4 teacher/student ratio. Here, he works on reading, math, and spelling, basically all of his IEP goals."

"There are advantages and disadvantages of being in a small school (only 100 students). One advantage is how easily we can work on Tucker's independence goals. We simply call 'Miss Smith' to let her know when Tucker leaves the room (by himself) to drop off a note or to visit a teacher. A disadvantage of being in a small school district are that there fewer staff and fewer resources to help Tucker. I used to think that I wanted Tucker



included in regular classes all day, but now I believe he benefits from having both options.” Although Megan is comfortable with the school, the thought of an upcoming transition to junior high school worries her. She admits, “We are getting ready to go to junior high, and that is really scary.” Right now, all the kids know Tucker. And his school is so supportive. I’ve never been told ‘no’ when requesting a meeting; they are always willing to talk to me about his IEP, which means a lot to me. A con is that in Orlando, we had after school programs already available for Tucker to attend and this was no big deal. But here, we had to fight for an after school program for kids with special needs.”

“Tuck-Tuck”, as she fondly calls him, uses a *DynaVox* ([www.dynavoxtech.com](http://www.dynavoxtech.com)) communication device when he can. “He doesn’t use it often because it’s old and owned by school. Instead, he uses pointing gestures and picture symbols around the house. We use a little bit of everything to communicate,” Megan said confidently. “We are hoping to get him his own communication device later this year.”

Tucker has a wide range of hobbies. Megan continued, “He loves to watch roller coasters on *YouTube* ([www.youtube.com](http://www.youtube.com)). He also goes to Kings Island several times a summer to experience the real thing. He uses the “*Tag*” reading system by

*LeapFrog*. This is a little pen that helps children read books and earn rewards. Tucker’s favorite books are *Cat in the Hat* and *Green Eggs and Ham*. Tucker has a dog named Madison Avenue and cat named Sophie Lane. He just entered 4 H and will care for a rabbit and perform a rabbit show. Tucker rides horses too. A boy from the high school started teaching him how to ride. I never told him that Tucker had special needs. He just went with it believing that being non-verbal is not an issue. He taught Tucker how to clean stalls and feed horses too! Because of this cool bonding experience, Tucker is entering an exhibit at 4H by making a horse poster.”

Megan stays connected as much as possible to others who live with RTS. She attends the annual Midwest RTS Reunions in Wisconsin. “It’s nice because it is just social time, in a laid back, relaxed environment. They have movies and swimming in a party-type atmosphere. It’s very casual and comfortable for me,” she said. In addition, Megan often goes to the RTS-OKI (Ohio, Kentucky & Indiana) quarterly family meetings in Cincinnati. Megan has had to make big adjustments and work harder at networking with other families since her move to Indiana. She said, “Tucker is the only child with RTS living in our area of Indiana. In Orlando, there were contacts with RTS nearby when Tucker was 6 or 7 years old.” Megan also uses the RTS listserv to keep in touch with other parents. She scans it occasionally; when Tucker was younger, she used it every day.

“Having a child with Rubinstein-Taybi Syndrome feels like you have to explain everything all the time,” Megan said. I am asked frequently... *does he have Autism?* Because it’s a rare syndrome, if folks are curious, then I usually start with saying... *it affects a little bit of everything*. And, if they want to sit and listen, I’ll tell them more. I’d rather more people know about RTS than not.”

Megan has accepted Tucker as he is and encourages

others to do the same. She said, "I want Tucker to be himself; he is who he is with or without RTS. I ask therapists and doctors to treat him as a person, not just the 'what ifs' about RTS. He's Tucker and he needs care just like anyone else. It took a while to accept he doesn't talk, but I realized that's okay. When I can stop and look at the successes he has had, knowing he's different, I know it'll be okay," Megan shared. "Our vision for Tucker has changed over time. Tucker will probably be learning forever."

Megan has become a mentor to other parents. "When I talk with parents who are new to the diagnosis, I know that they are overwhelmed. The internet is scary. But, I tell them that over time it (life with RTS) works and you develop as a parent your own ways of coping. I try to encourage others to focus on the positive things their child does."

Megan stays very upbeat. She says, "It's easier for me to be strong and positive, maybe because he's my one and only."



Today, Tucker and Megan are working with their school to plan Tucker's arrival to junior high in the Fall.



### **RTS-OKI 2011 meeting schedule!**

...of the Rubinstein-Tabyi Syndrome Family Support Group for Ohio, Kentucky and Indiana (and nearby areas):

**Saturday, July 16, 2011**  
**Saturday, October 8, 2011**

TIME: 11:30 am - 2:00 pm  
LOCATION: 3430 Burnet Ave., 5<sup>th</sup> Floor, Cincinnati, OH 45229  
RSVP: Amy Clawson, [amy.clawson@cchmc.org](mailto:amy.clawson@cchmc.org) or 513-636-4723  
(Pizza & childcare provided with RSVP)

**Everyone is welcome!**

# RTS-OKI Events



*New friends...*



*Thank you to the volunteers!*



*Fun with music...*

## Ten aanzien van het syndroom: Derde RTS World Conference (Regarding the Syndrome: Third RTS World Conference)

By David Schor, MD, MPH

I was lucky to attend the Third RTS World Conference, held in the Netherlands, earlier this month. Over 100 families registered for the conference. It was organized to celebrate the 25th anniversary of the Dutch RTS Support Group. A small number of families from the United States attended. My impression was fewer people with RTS attended than we saw at our Cincinnati conference last July. Several families who attended our conference in July 2010 re-introduced themselves to me. Overall, I found much that was familiar: a lot of parent-to-parent sharing of experiences, problems/solutions, support--an upbeat mood--lots of smiles!

There were just enough cultural differences to keep me on my toes, like raw herring (tasted pretty good!). I was grateful that the official language for the conference was English. Listening to Dutch speech reminds me of driving down a bumpy road--did I mention that everyone talks very fast?

The conference program was similar to ours. On the first day, there were talks for the entire group to hear. The "breakout" sessions were held the next day. Dr. Raoul Hennekam's presence was also familiar. He gave a historical overview of RTS to open the formal conference. He also commented during other presentations.

Among the other presenters, I thought that Dr. Adam Shaw was of greatest interest. Dr. Shaw runs a clinic in London specific to patients with RTS. During his "health watch" program review, he summarized:

- *the characteristics of RTS and medical problems that may occur,*



- *the way these can be diagnosed, and*
- *some treatment options.*

He stressed that no particular medical problem occurs in every child with RTS. And many children with RTS have none of the major medical problems that can occur in others. My version of this health watch approach is to use the 2003 RTS medical guidelines of Wiley et al. and the 2010 review by Dr. Hennekam for the families I see in Cincinnati.

Dr. Dorien Peters discussed the genetics of RTS. Dr. Ina van Berckelaer-Onnes discussed autism and RTS. Dr. Jose Veen-Roelofs, a dietician, developed the "Happy Weight Dots" program with a psychologist. A panel of professionals from Denmark, South Africa, and the Netherlands shared their approaches for care of children with RTS.

The last part of the conference offered parents individual "clinics" with the presenters and other professionals. These 15--30 minute sessions were designed for parents to ask specific questions regarding their child. The clinicians involved in the clinics covered the areas of genetics, toys

for children with cognitive impairment, thumb reconstruction, keloid prevention and management, speech therapy, and dental issues.

Several times I was honored to be approached by a family who had a story to share or a concern to discuss. These settings generally led to an extended discussion far different from the usual clinical “encounters” I have at my regular job. These were totally parent-directed chats, with no need for me to document or to worry about running behind schedule. The most significant input often came from other families. Several times the participants--myself included--would respond to a comment with, “I hadn’t thought of that.”

Sadly, the conference was held about a week AFTER the tulips bloomed. So, instead of a blanket of colors at every turn, there were mostly empty fields. Holland was in the midst of a drought (despite being pretty much surrounded by water). I offered to do what I could to give some of our extra water to them. (I’m still working out how to do that.) I did manage to steal some time this trip to pass through the canals, ride public transportation, tour a couple of museums, and gaze at the city buildings. A friendly, energetic people, and a memorable experience for me.”

*David Schor, MD, MPH, is the RTS Program Director in the Division of Developmental and Behavioral Pediatrics (DDBP) at Cincinnati Children’s Hospital Medical Center. Dr. Schor is board certified in developmental and behavioral pediatrics following training in Cincinnati under Dr. Jack Rubinstein. He has degrees from the California Institute of Technology, Case Western Reserve University School of Medicine, and the University of Michigan School of Public Health.*

*To schedule an in-person clinical evaluation, please contact the DDBP RTS Program at 513-636-4723.*



**Tip:**

*Do you have your “umbrella”? An umbrella is not just for Spring showers! An umbrella of resources and supports can help throughout your child’s whole life...*

Often, connecting with others can help you find resources in your area and learn how to advocate for your child’s needs. These resources can be about funding all the extra needs. They can also help strengthen your family’s mental health.

Thanks to Erin Laffrey, LISW, Cincinnati Children’s Family Financial Advocate, and Cliff Copeland, LISW, the RTS-OKI families learned all about these resources in our region. We heard about Waivers, SSI, State Programs, Medicaid, and other resources available to families in Ohio, Kentucky & Indiana.

If you have a child with RTS, try to find the connections and resources in your area. These can help you, your child, and your whole family down the road. It’s like having an umbrella for extra coverage. It’s there when you need it.

For more information about resources in your area, contact someone on the Resources to Share list on Page 8. Or, contact your state’s department of developmental disabilities.

## *RTS Resources to Share*

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

#### **RTS Program Director**

Division of Developmental and Behavioral Pediatrics

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### **Rubinstein Library**

Division of Developmental & Behavioral Pediatrics

Cincinnati Children's Hospital Medical Center

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: [bmenn@theppsgroup.com](mailto:bmenn@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**

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

P.O. Box 313

Windham, NH 03087

Toll Free: 866-316-9029

Email: [mzfarrell@aol.com](mailto:mzfarrell@aol.com)

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

### **2003 RTS Conference Proceedings Website**

(aka "The Brown Book")

[www.rubinstein-taybisyndrome.info](http://www.rubinstein-taybisyndrome.info)

### ***Rubinstein-Taybi Syndrome: A Book for Families***

(aka "the Blue Booklet")

#### **Cathy A. Stevens, MD**

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910 Blackford St.

Chattanooga, TN 37403

(423) 778-6112 or [cathy.stevens@erlang.com](mailto:cathy.stevens@erlang.com)

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

(NORD)

55 Kenosia Avenue

P.O. Box 1968

Danbury, CT 06813-1968

Website: [www.rarediseases.org](http://www.rarediseases.org)

### **The Arc**

For People with Intellectual & Developmental Disabilities

1660 L Street, NW, Suite 301

Washington, DC 20036

(800) 433-5255

Website: [www.thearc.org](http://www.thearc.org)

### **Administration on Developmental Disabilities (ADD)**

Office of the Commissioner

U.S. Department of Health and Human Services

370 L'Enfant Promenade, S.W.

Washington, D.C. 20447

Phone number: 202.690.6590

Website: [www.acf.hhs.gov/programs/add](http://www.acf.hhs.gov/programs/add)

*Coming soon... new updates to the Rubinstein-Taybi Syndrome website!  
Stay tuned!*