

RTS News

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



Save the Dates!

RTS 2010 Family Conference For families living with Rubinstein-Taybi Syndrome

When? July 23, 24, & 25, 2010

Where? Radisson Cincinnati Riverfront
668 West 5th St.
Covington, KY 41011

More details coming soon!

Have Questions? Please Contact:

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RTS Reasons to Smile: The Myers' Family Dream Team

Juli and Donny Myers, and their two kids, Brandon (age 12) and Chris (age 10), live in an average, small town, called Belpre, OH. Juli says, with a big smile, "we're a little unique; Brandon has autism and RTS (Rubinstein-Taybi Syndrome), I am a domestic engineer, Donnie, a dispatcher for local police and fire squad, and Chris is the 'little big brother'." The Myers family motto is "we can do anything!"

Don't be fooled, this is no average family. Juli and Donny created an adapted baseball team called, I.C.E. It stands for *I Can Excel*, and their debut season, this Spring 2009, proved their point. The idea: Chris played ball since he was 5 years old, and they wished Brandon could play ball too. "We went to our local baseball league for support and they gave us the okay. Donnie created the name; it is meaningful and fun. The league offered support at each meeting too," stated Juli.

First, Juli and Donny needed ropes, beep balls, and many other supplies. Families and league members chipped in with adapting the players' needs and finding sponsors. "We decided on charging a flat family rate to play ball, so that siblings could join in the fun." The Myers' did not turn anyone away. There were 21 kids on the team, ages 5 to over 18 years old. They created a Buddy system, using siblings, other baseball teams, and parents. And, they held t-shirt fundraisers to cover costs of those who could not pay. The local baseball league and the families on Team I.C.E formed a great relationship from the beginning. Juli remarked, "the community support has been excellent." The Myers' are hoping for more community involvement next year as they 'ramp-up' advertising and awareness of this special ball team.

"The best thing is to look back at the kids who were able to play ball for the first time ever! And, some kids were really into it and now baseball is their favorite sport. Since the season has ended, I miss the smiles," says Juli. She is looking forward to building on what they've created, possibly



teaching baseball fundamentals, catching and running bases, and implementing practices into the 2010 season. Ultimately, Juli hopes that Team I.C.E realizes each player's potential to learn and enjoy the game.

In addition to organizing Team I.C.E. and their games, Juli shared her thoughts and feelings about RTS and her family.... *Living with RTS daily means regular day planning, sometimes having no control over what our day might look like. Other days are like any other family day. We struggle with communication, behaviors, and health issues. Baseball allowed us to show that although we're different, we still enjoy doing regular things. We want Brandon to be involved and get him out there, and 'adapt and overcome'. Chris has struggles as a sib too. But Team I.C.E. has allowed Chris to see other sibs and gain a unique knowledge about other families' differences. He enjoys planning future team ideas too! Chris stated recently to me, "I'm proud of Brandon today; he did a good job!"*

On school. . . *Brandon enjoys school, especially the bus-ride. Structure is really good for him. He was held back two years because the younger peers accept him and involve him more. We have had some good years with school and some bad. Unfortunately, this year has been a struggle. School is having more and more trouble understanding Brandon's abilities as he gets older. They seem to concentrate on the behavior not the possibilities he has. So we are looking into*

home schooling and having friends come over in the evening for socialization. As usual, it is a work in progress.

On AAC, Brandon's Communication Device . . . He has used a Vantage for 3 years at school, home and out in community. We still have to put it in front of him; he can tell us now when he doesn't feel good or what he wants. Otherwise, it would be very frustrating to communicate. Without his talker, as we call it, we would have never realized the understanding that Brandon has.

On Brandon's biggest challenges. . . He can be happy one moment and be aggressive the next. We are learning how to help him cope with these behaviors and feelings, and how to be comfortable. We are working with a neurologist and developmental specialists on this issue right now. We have tried some medication changes lately. Brandon was taking, Risperdal, which worked well for many years. But because we started seeing some walking issues, different tics, and sleep issues, the doctors recommended we take him off of it. We tried a new medicine but it produced some negative side effects. So, this is where we are now. We are seeing a new side of Brandon, and hope to keep it. Sleeping is still an issue but he is showing more happy moods. I would love to hear from anyone who could give us some suggestions on hitting, though. We have determined with the limited communication and social skills, Brandon cannot seem to express how he is glad to see you without coming to you and hitting your chest with both hands. We are working on this with some redirection techniques but they have not caught on yet.

When he is frustrated he also hits the same way. We are still in the beginning phase of no meds. Despite the hitting, he is a happier young man. We hope that we can continue to widen his world and allow him to grow into the best that he can be.

On Brandon's biggest successes . . . He is happy as a lark when he is making Lego roads and when he's in the water swimming.

The Myers' want Team I.C.E. to be recognized as a great team and a great group of kids. And, Juli says she wants people to know: "though we are a different family, our family is not controlled by RTS."

Simply put, the Myers' family is a dream team on and off the field!

For more on the I.C.E. Adapted Baseball Team in Belpre, Ohio, contact Juli Myers at belprebaseballmom@hotmail.com.



Brandon and brother, Chris, on the field of Team I.C.E.



Play ball!



RTS Regarding the Syndrome:

Augmentative or Alternative Communication Helps Some Students Learn in Schools

By Sandra M. Grether, Ph.D.



Working with Your School Team

Children with RTS may be in a variety of school settings. If they have only a few words or do not speak clearly, they may need to use augmentative and/or alternative communication (AAC) strategies to speak and learn. These strategies may include using signs, pictures, or a communication device. AAC **must** be listed on the student's Individual Education Plan (IEP) to be used. It **must** be supported by the IEP team with annual goals and objectives.

Students with RTS may need to use AAC to help them learn. The classroom teacher should consult with the speech-language pathologist (SLP) to decide what vocabulary may be needed and how it will be represented (e.g. symbols and/or digital pictures). Even children with RTS, who are verbal, may benefit from the structure that communication boards provide. If they are not clearly understood, a communication board may help them explain what they have tried to say.

Teachers may need to adjust how they ask questions. They need to make sure the student has appropriate vocabulary (at his level of understanding) to answer correctly. Sometimes, questions need just short or single word answers. Others may require longer sentences. Vocabulary sometimes needs to be very specific to answer correctly (e.g. when reading a book or studying about insects). Yes/no questions do not allow students to add more information. However, they may be used when there are no other ways to show what she knows.

Students are very social in the classroom. They need to share stories, ask questions, comment, and discuss different topics. It is important to include social messages as well on AAC systems.

Reading and Writing

Literacy is an important goal for all students with RTS. A child who can learn to read and write can communicate many more thoughts and ideas. It is important to work on moving from beginning readers and writers to more fluent readers and writers, dependent on the student's abilities. Research has shown that AAC strategies support learning to read and write with children with special needs.

Participation Plan

One way to implement AAC into the school setting for students with RTS is to use a Participation Plan. The Participation Plan is the team's map of the school day's activities. It is a collaborative action plan that focuses on what everybody must do to help the student with RTS participate to their greatest ability in the day's activities. This plan puts the IEP into action. It is integrated with the curriculum and allows students to be evaluated in natural settings such as the classroom. Participation plans specify:

- Team's expectations – the level of the student's participation
- Tools – what equipment and strategies are required
- Support strategies – who is responsible for what.

Participation Plan Example:

| Activity | IEP goals | Expectation of typical student | Expectation of _(name)_ | Low Tech Support | High Tech Support | Peer Support | Teacher/Resource Teacher or Aide Support | Parent support | SLP OT PT Support |
|---------------------|---|--|--|---|---|--|---|---|---|
| Hallway & Home-room | 1. Zach will greet the teacher, aide, and one school friend each morning 8 out of 10 opportunities. 2. Zach will tell peer about an activity each day 8 out of 10 opportunities. | Students initiate and respond to greetings with teachers and peers without prompting. Students share what they did at home. | Zach will initiate and respond to greetings with teachers and peers when prompted. Zach will share what he did at home. | Use his voice and gestures such as waving; show a picture card with what he did at home last night. | Use AAC device to say hello and ask how they are doing; use device to tell about last night event | Wait for Zach to say hello; respond to Zach's wave and ask him how he is doing; look at Zach's picture card and comment. | Assist with unpacking device if needed; prompt Zach to greet others; model greeting adults and students | Practice greeting at home; prepare picture card and message on AAC device; model greeting teacher and students when arrive at school. | Train teacher, aide, and peers on prompting, modeling, and waiting; monitor progress on goals and modify when needed. |
| Class | | | | | | | | | |

It is very important for students with RTS to be successful in the classroom. To do this, they may need to learn to juggle between many different modes of communication (voice, signs/gestures, verbal words/phrases, pictures, augmentative communication device). Most importantly, they need the right vocabulary, specific to the classroom activity. They also need to have the support of many individuals (e.g. teacher, family, therapists, aide, peers) to learn when and how to use it effectively.

What do I need to know about funding a communication device?

If your child needs an AAC device, it is important to choose a speech-language pathologist (SLP) for the evaluation who also knows about AAC funding. Each funding resource has very specific questions that must be answered in the evaluation report to be successful.

There are many resources that provide funding, including Private Medical Insurance, Medicaid, Schools, and many charitable organizations. A national resource that gives details about funding is <http://www.aacfundinghelp.com>. In addition, many of the major manufacturers also give general funding information as well as specifics about their own devices. DynaVox at <http://www.dynavoxtech.com> and Prentke Romich at <http://www.prentrom.com> are excellent resources.

Finally, we need to constantly raise the expectations for all who interact with students with RTS that they can be successful communicators!

Sandra M. Grether, PhD, CCC/SLP is the Coordinator of Speech Pathology for the Division of Developmental and Behavioral Pediatrics (DDBP) at Cincinnati Children's Hospital Medical Center, and Associate Professor of Clinical Pediatrics at the University of Cincinnati in the College of Allied Health Sciences, Department of Communication Sciences and Disorders.

RTS-OKI Around Town

Members of RTS-OKI walked for RTS at the Cincinnati Walks for Kids event sponsored by Cincinnati Children's Hospital Medical Center on October 10, 2009. It was a brisk, but fun, special day!



Pictured above: Jennifer Hans, parent; Amy Clawson, DDBP; Maria & Christopher Weitfle, parents; and their two children: Sophia and Elias.



**Rescheduled Fall meeting!
of the Rubinstein-Tabyi Family Support Group
for Ohio, Kentucky and Indiana:**

RTS-OKI Family Support Group Meeting

WHEN: Saturday, November 7, 2009

TIME: 11:30 am - 2:00 pm

WHERE: Arcadia Residential Suites

11180 Dowlin Dr

Cincinnati, OH

RSVP: Jennifer Hans at jbhans@bellsouth.net



Holiday Tip:

"During the holidays, take time to be glad you have a special person in your life; they will make you smile sometime that day."

*Regina Stoner, RTS-OKI member
Mom of Justin*

RTS Resources to Share

David Schor, MD, MPH

RTS Program Director

Division of Developmental and Behavioral Pediatrics
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Rubinstein Library

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MLC 4002, 3333 Burnet Ave.
Cincinnati, OH 45229
800-344-2462 ext. 4626, 513-636-4626
Email: barbara.johnson@cchmc.org

RTS-OKI Support Group

Bill Mann, Parent Leader

513-708-5611 or Email: bmenn@theppsgroup.com

RTS Email ListServ

Janet Estes, ListServ Manager

250-753-7795 or Email: janetestes@telus.net

RTS Parent Group USA

Lorrie Baxter, Coordinator

P.O. Box 146
Smith Center, KS 66967
Toll Free: 888-447-2989 or Email:
lbaxter@ruraltel.net

Rubinstein-Taybi Syndrome Website:

www.rubinstein-taybi.org

Special Friends Foundation Website:

www.specialfriends.org

Michelle Farrell, Director of Family Services

P.O. Box 313
Windham, NH 03087
Toll Free: 866-316-9029 or Email:
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.

Special Needs Resource Directory

Cincinnati Children's Hospital Medical Center
www.cincinnatichildrens.org/special-needs

NORD

National Organization for Rare Disorders, Inc.
55 Kenosia Avenue
P.O. Box 1968
Danbury, CT 06813-1968
www.rarediseases.org

Study for Adults with RTS

Purpose: To collect current information about the health concerns, developmental challenges, and other issues that are important for adults with RTS.

Who can do the study? Adults with RTS who are 18 years or older by January 1, 2010

Interested? Have questions? Need more information about the study?

Contact Cathy Stevens, MD at
cathy.stevens@erlangers.org or 423-778-6112